

# Sensitive Demographic Data: How to Keep Your People Safe

**Presented by:**

Abby Miller (she/they), Chief Innovation Officer, Housing Collective

Kim Keaton (she/her), Board President, NHSDC + Director Data/Analytics, CSH

Alexandra Cantrell, NHSDC Board Member



nhsd@

National Human Services Data Consortium



## AGENDA

---

- Explore the shifting legal threats and risks of harm for vulnerable communities, including State and Federal government suppression and expansion of targeted groups' rights
- Understand the legal frameworks guiding stewardship of vulnerable people's data and care records
- Consider use and disclosure policies that enhance protections
- Responding to requests for information
- HMIS system administrator role
- How are you addressing these topics in your community?



HEALTHCARE

## Parents of trans children 'feel betrayed' by Vanderbilt hospital

Medical center releases medical records, including those of transgender minors, to Tennessee Attorney General

BY: **SAM STOCKARD AND ANITA WADHWANI** - JUNE 21, 2023 6:00 AM



## Va. AG office denies LGBTQ student records subpoena in Loudoun Co. grand jury investigation

Ivy Lyons | [ilyons@wtop.com](mailto:ilyons@wtop.com)  
May 9, 2022, 12:16 AM



## Pediatricians battling Florida House's subpoena over trans care standards

Health News Florida | By **Dara Kam** - News Service of Florida  
Published May 24, 2023 at 7:00 AM EDT



## State asks for medical records of transgender youth in court case

Plaintiffs are challenging the motion, saying those records are confidential and could lead to criminal charges under the new law.

By **JACOB HOLMES** • Published on January 9, 2023 at 8:08 am CST



HEALTH

## HIPAA won't protect you if prosecutors want your reproductive health records



By **Eric Boodman**, **Tara Bannow**, **Bob Herman** and **Casey Ross** June 24, 2022

[Reprints](#)



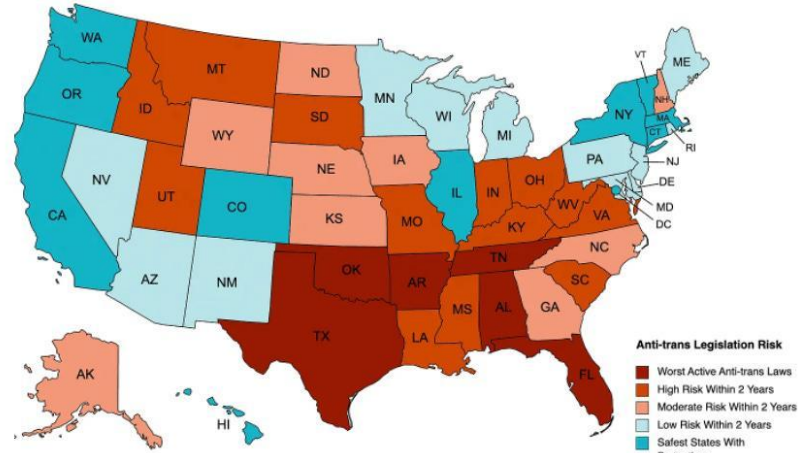
## Human Rights Trends in Federal and State Government as of July 2023

	Heavily Red States	Heavily Blue States	Federal Executive Branch	Federal Supreme Court
<b>LGBTQ+ people</b>	Rights suppression	Rights expansion	Rights expansion	Mixed bag
<b>Trans people (specifically)</b>	Rights suppression	Rights expansion	Rights expansion	Mixed bag
<b>Undocumented people</b>	Rights suppression	Rights expansion	Mixed bag	Mixed bag
<b>Pregnant people</b>	Rights suppression	Rights expansion	Rights expansion	Rights suppression

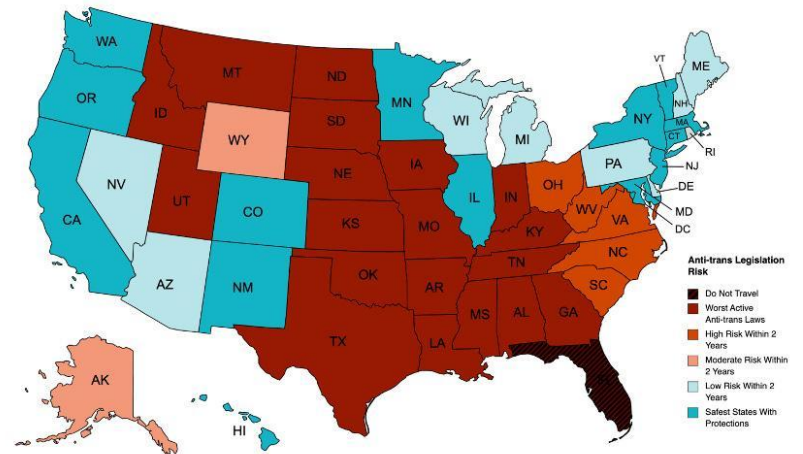


## Anti-Trans Legislation Tracker

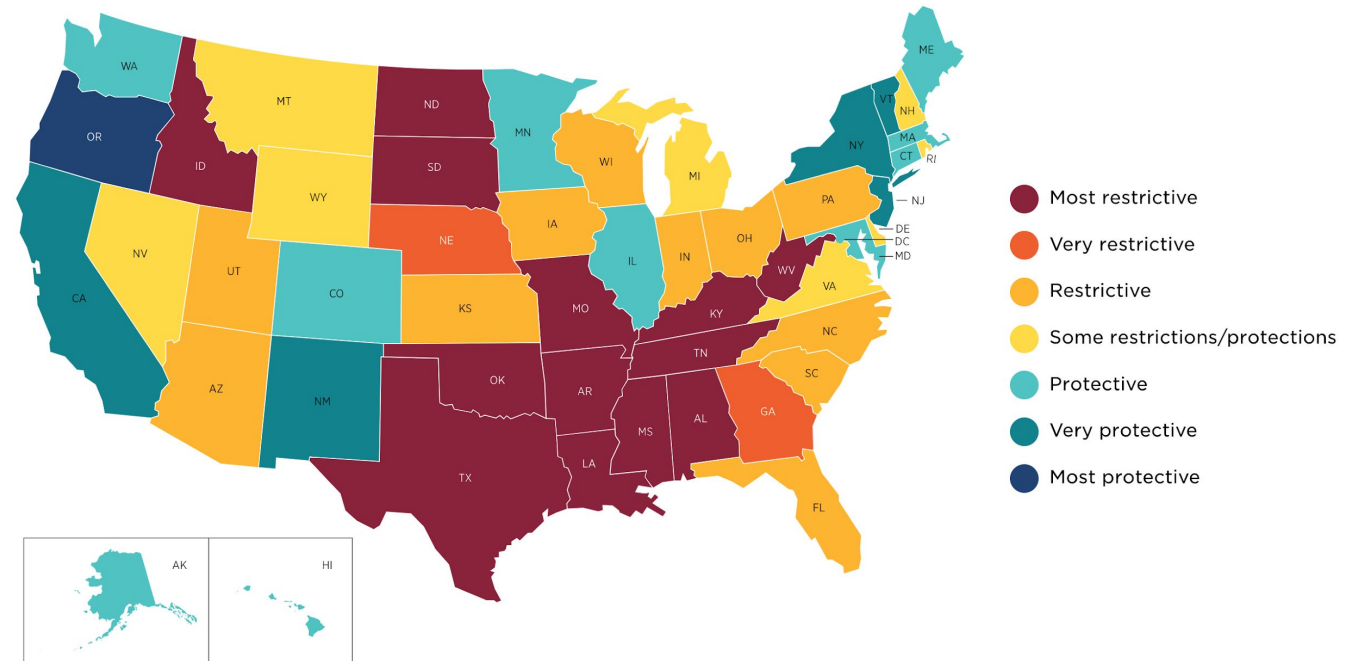
December 2022



June 2023



## Abortion Access Restriction Tracker



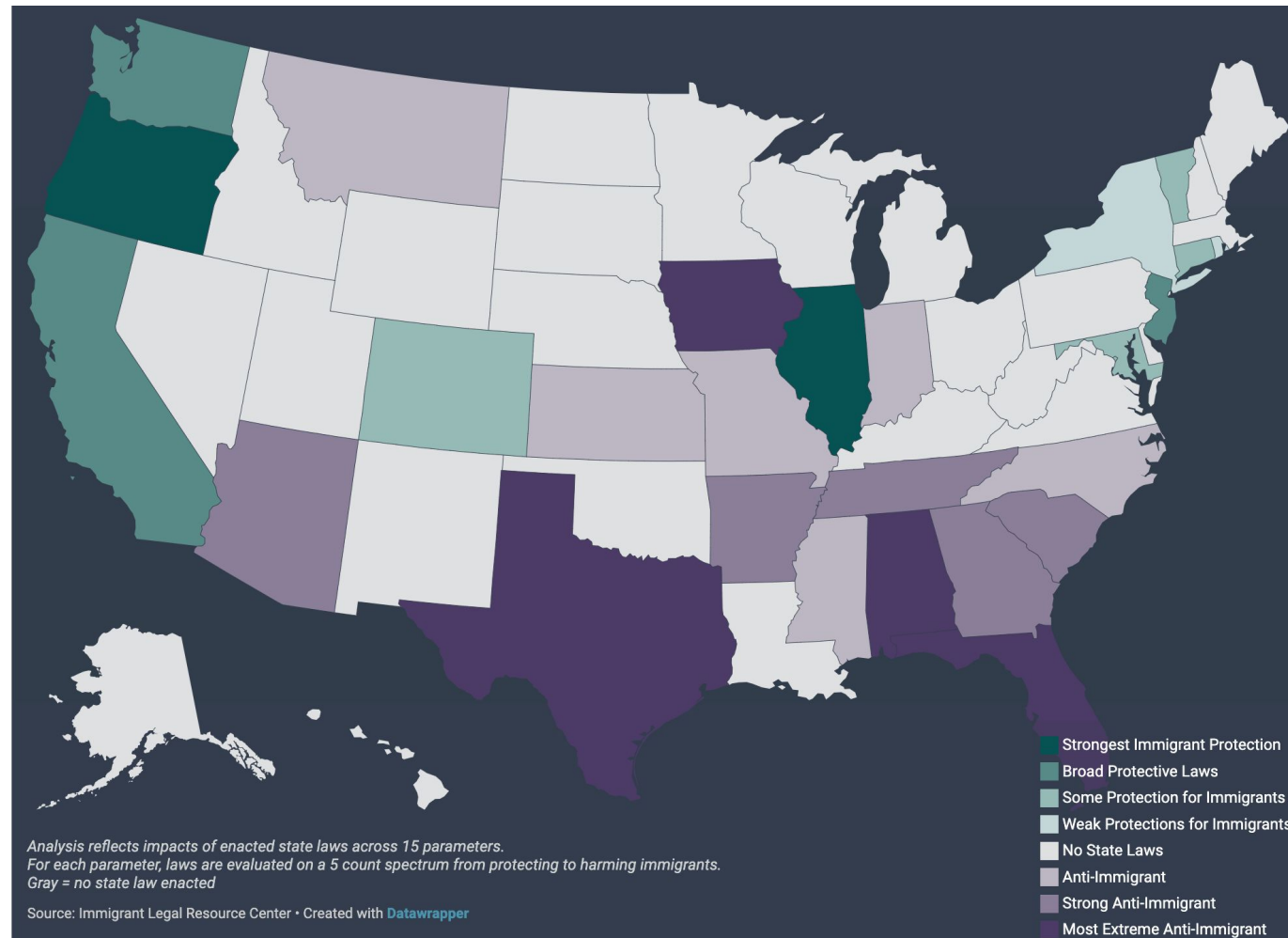
[View the Guttmacher Institute's Interactive Map](#)

[Visit Erin In the Morning](#)





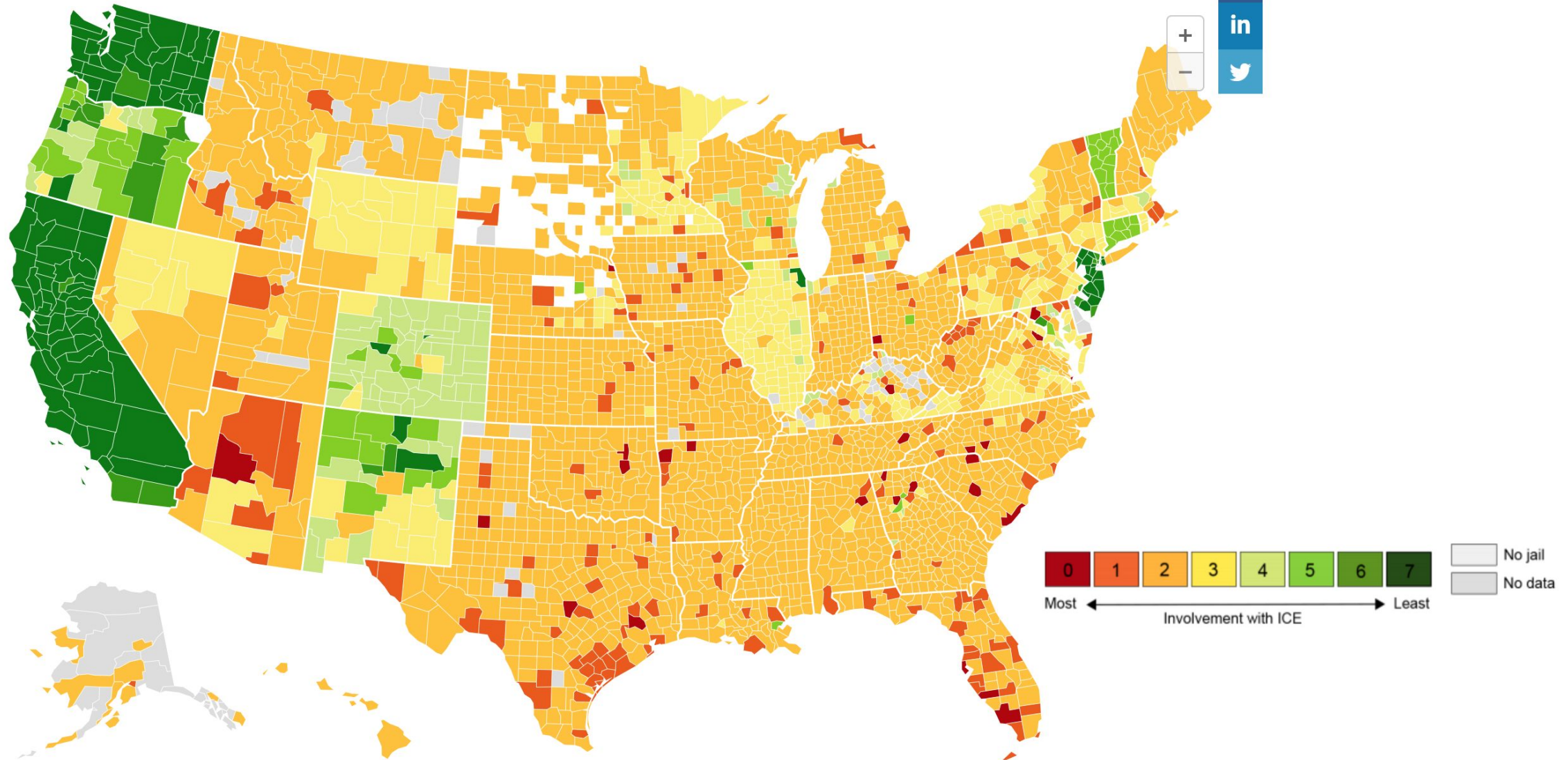
## Immigration Enforcement Tracker



[See Immigrant Legal Resource Center Interactive Map](#)



## Local Policies on Assistance in Immigration Enforcement



For permission to use the map, contact [media@ilrc.org](mailto:media@ilrc.org).

Source: ILRC • Created with [Datawrapper](#)

[See Immigrant Legal Resource Center Interactive Map](#)



## FORUM

# The Abortion Interoperability Trap

18 OCT 2022

[Carleen M. Zubrzycki](#)

**ABSTRACT.** Legislatures in blue states are trying to shield patients' medical records from being used against them in antiabortion litigation and persecutions. The problem is, as medical records increasingly follow the patient, those records are likely to end up in the hands of actors who are not subject to safe-haven laws and who can easily be required to hand over the records to law enforcement or private litigants. Legislatures, policymakers, and private actors should all take steps to close the loopholes that allow this.

## HEALTH

# HIPAA won't protect you if prosecutors want your reproductive health records



By [Eric Boodman](#) , [Tara Bannow](#) , [Bob Herman](#)  and

[Casey Ross](#)  June 24, 2022

[Reprints](#)

[Read journal article](#)

[Read article](#)





## Va. AG office denies LGBTQ student records subpoena in Loudoun Co. grand jury investigation

Ivy Lyons | [ilyons@wtop.com](mailto:ilyons@wtop.com)

May 9, 2022, 12:16 AM



[Read article](#)

*“Certain sensitive documents cannot be pulled from a student’s file after they have been subpoenaed. Legal representatives have indicated that the process to file injunctions to protect student records have to be made against individual records, which results in costly efforts to keep sensitive student information private.”*



*“There’s nothing hysterical about worrying about what might be done with this data in a state like Tennessee.”*

HEALTHCARE

## Parents of trans children ‘feel betrayed’ by Vanderbilt hospital

Medical center releases medical records, including those of transgender minors, to Tennessee Attorney General

BY: SAM STOCKARD AND ANITA WADHWANI - JUNE 21, 2023 6:00 AM



[Read article](#)

*“A spokesperson for Vanderbilt declined to respond to questions about what specific legal mechanism the attorney general used to obtain the records — such as a subpoena, a civil investigative demand or something else — or whether hospital officials undertook any steps to legally withhold the information.”*

*“Texas Children’s Hospital illegally released records involving children and gender-affirming care to a person unaffiliated with the hospital. The Manhattan Institute, a conservative think tank, then published the medical records, according to reports.”*



*The crux of the law makes it a felony for doctors to prescribe, or anyone, to provide puberty blockers and cross-sex hormones to children. The law also bans gender affirming surgeries on children, which have never been performed in the state. U.S. District Judge Liles C. Burke enjoined the law days after it took effect, noting that the plaintiffs are likely to win the case on the merits when it is argued in full.*

## State asks for medical records of transgender youth in court case

Plaintiffs are challenging the motion, saying those records are confidential and could lead to criminal charges under the new law.

By **JACOB HOLMES** • Published on January 9, 2023 at 8:08 am CST



[Read article](#)



## Pediatricians battling Florida House's subpoena over trans care standards

Health News Florida | By **Dara Kam - News Service of Florida**

Published May 24, 2023 at 7:00 AM EDT



[Read article](#)

*Compliance with the subpoena issued to the group would result in “disclosure of the position of individual members with respect to a controversial political issue,” which “not only violates the First Amendment rights of those individuals but can reasonably be expected to discourage future membership in the association.”*





## Texas high court OKs investigations into parents of transgender kids

*While the Texas Department of Family and Protective Services may resume investigating parents who provide gender-affirming care for child abuse, the court stressed the agency is not legally required to follow Governor Greg Abbott's directive telling it to do so.*

[KIRK MCDANIEL](#) / May 13, 2022



[Read article](#)

*“Texas law...imposes a duty on DFPS to investigate the parents of a child who is subjected to these abusive gender-transitioning procedures, and on other state agencies to investigate licensed facilities where such procedures may occur.”*

Directive signed by TX Gov. Greg Abbott



## What risk of harm do vulnerable groups face in your state and community(s)?

---

- Criminalization of medical care for pregnancy terminations
- Criminalization of gender affirming medical care
- Criminalization of public restroom usage
- Cooperation with Immigration and Customs Enforcement
- Local book bans
- Local drag bans
- Uptick in physical or verbal attacks

*“We don’t know what’s going to play out in appeal or if states will find other kinds of laws they can get through to courts,” Wiener said in an interview before the bill’s passage. “It would be absolutely negligence for us to say we’re not going to do anything until one of these laws gets upheld and someone gets put in prison.”*

[Read article](#)

*“While attacks on the transgender community are not new, we are experiencing alarmingly blatant attempts to use legislation, policy and political rhetoric to restrict or eliminate the autonomy, freedom and existence of transgender people across the country”*

Equality California, Sept 2022



***We know this seems like a lot, but there are things you can do to keep people safe!***







## LAWS, GUIDES & STANDARDS PROTECTING PII

### Which apply to you?

- National Institute of Standards and Technology (NIST) [Guide to Protecting the Confidentiality of Personally Identifiable information](#) (Special Pub 800-122)
- [2004 HMIS Data and Technical Standards Notice](#)
- [Section 5 of Federal Trade Commission Act](#)
- [Health Insurance Portability and Accountability Act \(HIPAA\)](#)
- 42 CFR 2.13 [Confidentiality of Substance Use Disorder patient Records](#)
- [Family Educational Rights and Privacy Act \(FERPA\)](#)
- [Violence Against Women Act \(VAWA\)](#)
- [Victims of Crime Act \(VOCA\)](#)
- [Family Violence Prevention and Services Act \(FVPSA\)](#)
- [Victims of Trafficking and Violence Protection Act \(VTVPA\)](#)
- Applicable State Laws

### State Laws on Vital Records

Apr 5, 2023 | Resources, State Policy



[Visit this site](#) to learn more about current state laws pertaining to access to vital records for children and youth experiencing homelessness





## CONFIDENTIALITY AND PRIVACY IN PRACTICE

---

### *USE CONSIDERATIONS*

- Appropriate uses: name, gender, and pronoun usage
  - Training everyone on data collection practices
  - Teaching provider staff about how to fulfill their responsibility to keep PII private and secure
- Inappropriate uses: sharing a trans client's legal name and/or sex assigned at birth without reason
  - Take care to follow the client's decisions about their data and not to inadvertently disclose information that is intended to be kept private or that is protected from disclosure (such as confidential medical information).



## COLLECTION, USE & DISCLOSURE POLICIES

---

Programs should develop policies and procedures that address the following:

- Avoid unauthorized disclosure of immigration, pregnancy, or transgender status information regarding a client or family member of a client
- Provide notification of individual and family's privacy rights upon admittance to the program
- Refer all requests for information about individual clients or their family members to a designated program administrator (working in consultation with legal counsel, where possible)
- Address non-disclosure of information for individuals participating in programs that may disproportionately serve undocumented individuals or families
- Collection of immigration, pregnancy, and transgender status information, using “minimally necessary” standard
- Response to requests from clients to remove immigration, pregnancy, or transgender status information from records
- Non-disclosure of juvenile client names or identities without a court order to disclose

Recommendations from [Becerra \(2018\). Promoting Safe and Secure Shelters for All: Guidance and Model Policies to Assist California Shelters in Responding to Immigration Enforcement.](#)



## PRACTICING TRULY INFORMED CONSENT

---

- All clients get a hard copy of the privacy notice upon arrival:
  - Describes the types of records maintained by the agency;
  - Describes retention and destruction of personal information; and
  - Describes the circumstances under which the agency might disclose personal information about agency clients to outside entities (who, why, and how long the information may be retained by outside entity).
- Are you informing of risks associated with a targeted data breach?
- Are you informing of risks associated with government units accessing PII?
- Are you informing of risks associated with targeted legal tactics?
  - Rights suppression via legal methods, e.g., subpoenas, court orders



## RESPONDING TO REQUESTS FOR INFORMATION

---

- **Court Order:** If an immigration enforcement officer arrives with a court order, a designated administrator or the shelter's legal counsel should review the order, and then respond accordingly
- **Federal Judicial Subpoenas:** Asks for the production of documents or other evidence, identifies a federal court and the name of the judge or judicial magistrate issuing the subpoena, and may require attendance at a specific time and location and the production of prescribed records
  - A program generally does not need to immediately comply, but may challenge it before a federal judge in a U.S. District Court. Staff should immediately contact a designated administrator or legal counsel upon receipt of a federal judicial subpoena
- **Administrative Subpoenas:** Requests production of documents or other evidence, and (in the immigration enforcement context) is issued by an immigration enforcement officer
  - A program generally does not need to immediately comply. If an immigration enforcement officer arrives with a pre-designated administrative subpoena, the shelter may decline to produce the information sought and may choose to challenge the administrative subpoena before a judge. Staff should immediately contact a designated administrator or legal counsel upon receipt of a subpoena.
- **Freedom of Information Act (FOIA) Request:** Requests records from federal government and excludes Personally Identifiable Information (PII)





## SUBPOENAS

AO 88B (Rev. 02/14) Subpoena to Produce Documents, Information, or Objects or to Permit Inspection of Premises in a Civil Action

UNITED STATES DISTRICT COURT  
for the

Plaintiff )  
v. ) Civil Action No. )  
Defendant )

**SUBPOENA TO PRODUCE DOCUMENTS, INFORMATION, OR OBJECTS  
OR TO PERMIT INSPECTION OF PREMISES IN A CIVIL ACTION**

To: \_\_\_\_\_  
(Name of person to whom this subpoena is directed)

**Production:** YOU ARE COMMANDED to produce at the time, date, and place set forth below the following documents, electronically stored information, or objects, and to permit inspection, copying, testing, or sampling of the material:

Place: \_\_\_\_\_ Date and Time: \_\_\_\_\_

**Inspection of Premises:** YOU ARE COMMANDED to permit entry onto the designated premises, land, or other property possessed or controlled by you at the time, date, and location set forth below, so that the requesting party may inspect, measure, survey, photograph, test, or sample the property or any designated object or operation on it.

Place: \_\_\_\_\_ Date and Time: \_\_\_\_\_

The following provisions of Fed. R. Civ. P. 45 are attached – Rule 45(c), relating to the place of compliance; Rule 45(d), relating to your production as a person subject to a subpoena; and Rule 45(e) and (g), relating to your duty to respond to this subpoena and the potential consequences of not doing so.

Date: \_\_\_\_\_  
CLERK OF COURT OR  
Signature of Clerk or Deputy Clerk Attorney's signature

The name, address, e-mail address, and telephone number of the attorney representing (name of party) \_\_\_\_\_, who issues or requests this subpoena, are: \_\_\_\_\_

**Notice to the person who issues or requests this subpoena**  
If this subpoena commands the production of documents, electronically stored information, or tangible things or the inspection of premises before trial, a notice and a copy of the subpoena must be served on each party in this case before it is served on the person to whom it is directed. Fed. R. Civ. P. 45(a)(4).

Federal Judicial Subpoena

1. To (Name, Address, City, State, Zip Code) DEPARTMENT OF HOMELAND SECURITY  
**IMMIGRATION ENFORCEMENT  
SUBPOENA  
to Appear and/or Produce Records**  
8 U.S.C. § 1225(g), 8 C.F.R. § 287.4

Subpoena Number \_\_\_\_\_

2. In Reference To \_\_\_\_\_  
(Title of Proceeding) (File Number, if Applicable)

By the service of this subpoena upon you, **YOU ARE HEREBY SUMMONED AND REQUIRED TO:**

(A)  **APPEAR** before the U.S. Customs and Border Protection (CBP), U.S. Immigration and Customs Enforcement (ICE), or U.S. Citizenship and Immigration Services (USCIS) Official named in Block 3 at the place, date, and time specified, to testify and give information relating to the matter indicated in Block 2.


(B)  **PRODUCE** the records (books, papers, or other documents) indicated in Block 4, to the CBP, ICE, or USCIS Official named in Block 3 at the place, date, and time specified.

Your testimony and/or production of the indicated records is required in connection with an investigation or inquiry relating to the enforcement of U.S. immigration laws. Failure to comply with this subpoena may subject you to an order of contempt by a federal District Court, as provided by 8 U.S.C. § 1225(d)(4)(B).

3. (A) CBP, ICE or USCIS Official before whom you are required to appear (B) Date  
Name \_\_\_\_\_  
Title \_\_\_\_\_  
Address \_\_\_\_\_ (C) Time  a.m.  p.m.  
Telephone Number \_\_\_\_\_

4. Records required to be produced for inspection \_\_\_\_\_

5. Authorized Official  
\_\_\_\_\_  
(Signature)  
\_\_\_\_\_  
(Printed Name)  
\_\_\_\_\_  
(Title)  
\_\_\_\_\_  
(Date)

  
If you have any questions regarding this subpoena, contact the CBP, ICE, or USCIS Official identified in Block 3.

DHS Form I-138 (6/09)

Immigration Enforcement Subpoena



## INVOLVING CLIENTS IN DISCLOSURE REQUESTS

---

- If and when information requests are made by any authorities, provide clients with appropriate notice
- Document any verbal or written request for information by authorities
- Report requests for information to a designated administrator (working in consultation with legal counsel, where possible)
- If possible, provide documents regarding the request for information to the client
- If the individual is not English proficient, provide the documents in the client's primary language



## POLICIES TO REDUCE THIRD-PARTY MISUSE

---

- Protecting against third-party misuse after an appropriate disclosure
- Revisiting contracts and holding contractors responsible for breaches of contract
- Know who you're working with: [Who's Behind ICE?](#)



## WORKING WITH YOUR HMIS SYSTEM ADMIN

---

Reminder: [HMIS System Admin Checklist](#)

- Project management
- **System administration**
- Training
- Helpdesk support
- Data analysis and reporting
- Communications

System administration role includes set up and monitoring of HMIS security and privacy. Talk to your HMIS sys admin about any changes you want to the CoC's established policies and procedures. **It's their responsibility to establish and implement a system privacy and security plan, and to ensure that HMIS software is set up to configured correctly to ensure compliance with CoC established privacy policies and procedures**





## DUE DILIGENCE AS HMIS SYSTEM ADMINISTRATOR

---

- ✓ Stay abreast of HUD HMIS policies, guidelines, and considerations
  - [Sign up for HMIS Lead and System Administrator Forum](#)
  - [HMIS Privacy and Security information on HUDEXchange](#)
- ✓ Update your use and disclosure policies to account for risks of serious harm
- ✓ Update your privacy notice to reflect current state and community circumstances
  - [Great example from Boston Healthcare for the Homeless Program](#)
  - [Use HUD's HMIS Privacy Notice Development Template](#)
- ✓ Update your Release of Information
- ✓ Develop interactive trainings for intake staff to practice informing clients and seeking consent
- ✓ Create an inclusive workplace where people with different life experiences and cultural backgrounds feel safe and take seriously the responsibility to steward others' sensitive data
- ✓ Get to know the ACLU



## NUANCES ON “OPEN” AND “CLOSED”

---

- **Open HMIS Systems** - An “open” HMIS allows for clients’ HMIS identification, assessment, and service transaction information to be shared between HMIS participating providers and their HMIS end users, provided that they have signed an “open” HMIS memorandum of understanding and end user agreement, respectively; and that clients have signed an “open” HMIS Release of Information (ROI).
- **Closed Systems and Closed Client Records** - All HMIS systems are closed for some populations (DV, youth). If you are practicing informed consent you may have more people not signing the ROI that allows for open sharing between providers. Work with your HMIS System Admin to ensure that all CES entry sites and workers are trained on the method for ensuring that a client record is closed.



## WHAT ELSE? WHAT NEXT?

---

- We want to hear from you!
- What are some best practices your CoC is doing to keep people and their data safe?
- What should we (human services data community) be thinking about more?

