Seen Safely: Protecting Adolescent Health Information in a Shifting Data Landscape

Adolescent Health & Well-Being

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Editor's Note: This post is part of our Blind Spots series, exploring how current and potential future policy changes will affect children, families, and communities, and what can be done to mitigate harm.

When a young person shares something sensitive with their clinician, whether that is their gender identity, a mental health concern, substance use, or their sexual activity, they are doing something that requires real trust. They need to believe that what they say in that room stays there.

But in an era of patient portals, automated billing summaries, and electronic health information exchanges, the line between “shared with my clinician” and “visible to my parents” is increasingly hard to see.

At the same moment, the federal data infrastructure that has helped make LGBTQ+ youth visible to health systems and policymakers is quietly contracting. The two pressures of inadequate protection within clinical systems and shrinking visibility in national data do not exist in isolation. Together, they shape whether young people feel safe enough to seek care and be open and engaging when they get there.

In the first year of the current administration, approximately 360 federal data collections removed at least one measure of sexual orientation or gender identity (SOGI), most through administrative processes without public comment. These changes narrow our collective ability to monitor health disparities and create data-driven interventions for LGBTQ+ youth. Meanwhile, clinical systems are growing more complex and more porous, lacking trustworthy confidentiality unless deliberate protections are built in.

These changes are of interest to us as researchers who investigate ways to leverage health information technology to advance the health and well-being of LGBTQ+ youth and their families. In this post, we describe the importance of confidentiality in health information technology, opportunities to strengthen the systems for adolescents and young adults (AYA) and why the current policy moment makes this work urgent.

What Adolescents Tell Us: Evidence from Children's Hospital of Philadelphia (CHOP)

Even before recent changes heightened data-sharing concerns for LGBTQ+ youth, privacy and confidentiality were already their top priorities. In a qualitative study conducted at CHOP examining SOGI data collection in health care settings, privacy and confidentiality were of the main concerns among the 29 AYA interviewed. Participants wanted meaningful control over who could access their health information. Some youth in the study described how parental or caregiver access to their sensitive health?records carried real risk of unwanted disclosure, particularly for those whose families may not have been aware of or supportive of their identities. They understood the tradeoff between disclosure and tailored care, yet fears of judgment and discrimination remained persistent barriers.

Participants were open to electronic surveys for initial SOGI collection but clear that no digital tool could substitute for a trusted clinician relationship. They valued autonomy and endorsed technology that would give them control over how and where their data were stored and shared. Most pointedly, they described the broader sociopolitical climate as directly shaping their willingness to disclose. What happens in federal policy is not invisible to AYA, as it can change their calculus about being open with their clinicians.

Adolescents are not asking to disappear from health data systems. They are asking to be seen safely.

What Creates an Enabling Environment?

Translating what AYAs tell us into systems that actually protect them requires attending to three interconnected domains.

State policy sets the floor.

While the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule establishes a federal baseline, minor consent laws and confidentiality protections vary significantly from state to state, directly shaping what electronic health records (EHRs) can do to protect AYA information. As the federal data environment shifts and uncertainty grows, state minor consent and confidentiality laws are increasingly the critical line of defense for AYA seeking sensitive care. Health system leaders should know their state's policy environment and advocate for legal clarity that enables, rather than constrains, confidentiality protections within digital systems.

EHR design and institutional governance shape adolescent trust.

Design choices within health information systems are never neutral. Whether a sensitive note appears in a caregiver's portal, a confidential prescription surfaces in a billing summary, or a SOGI data element persists across health information exchanges, each reflects a choice about whose interests are prioritized. Institutional responsibility for these choices cannot rest on individual clinicians alone. Health systems need interdisciplinary governance, adolescent-specific EHR audits, and provider education that explains how information actually flows through the system.

Youth and caregiver engagement is not optional: it is the work.

When young people are partners in designing the systems that affect them, the result is infrastructure that is more trustworthy and more durable. CHOP’s?recent work?on integrating chosen names into patient identification offers a concrete example of what this looks like. When CHOP’s Family and Youth Advisory Councils were brought into the process alongside healthcare workers, what emerged was not just feedback but a clear finding: not using chosen names in clinical settings causes real emotional harm to transgender and gender-diverse youth, and families consistently advocated for chosen names to appear prominently as the primary identifier. That input directly shaped the work. CHOP consolidated five separate identification policies into one unified guideline that explicitly permits chosen names alongside legal names. New wristband prototypes with chosen names front and center have been designed, and usability testing is currently underway. Perhaps most importantly, the process confirmed what youth and families already knew: keeping patients safe and affirming their identities are not competing goals, they work together, and young people are exactly the right people to show health systems how.

Confidentiality Is a Patient Safety Issue Where Everyone Has a Role

When AYA cannot trust that sensitive information will stay private, they may delay or avoid seeking the care they need. That avoidance is not a personal failing, it is a predictable and preventable system failure.

Protecting adolescent health information requires coordinated action across roles. A newly published position statement from the Society for Adolescent Health and Medicine (SAHM), frames EHR confidentiality as a prerequisite for high-quality, equitable care. It calls on institutions, providers, and EHR vendors to address AYA confidentiality in policy and practice, use existing EHR tools to protect sensitive information, and advocate for better vendor-level functionality. These recommendations matter especially now: as federal SOGI data collection contracts and clinical systems grow more complex, coordinated institutional action is what builds the local infrastructure capable of protecting AYA and keeping them visible where national frameworks fall short.

Health systems:

- Treat adolescent confidentiality as a patient safety priority, not an administrative preference.
- Review EHR tools and updates through an adolescent lens with youth input, and pair sensitive screening with clear, developmentally appropriate explanations of how information is shared.

Policymakers:

- Preserve and strengthen minor consent protections.
- Avoid changes that undermine safe data segmentation in clinical systems.
- Fund research that centers youth perspectives and examines the relationship between data policy and care-seeking behavior.

EHR vendors:

- Build default adolescent data segmentation tools that prioritize protection.
- Develop configurable proxy access that accommodates state-level legal variability.
- Engage adolescent medicine specialists directly in product development.

Clinicians:

- Explain to patients how their information moves through the EHR and portal.
- Document intentionally, using confidential note types where they exist, and advocate within your institution for better workflows and vendor accountability.

Protecting Privacy Is About Fostering Inclusion, Not Hiding Youth

Visibility matters. When health systems can reliably collect and use sensitive information like SOGI data, they can monitor disparities, tailor care and hold themselves accountable. But visibility without protection is not a feature; it is a harm. And protection without visibility risks erasing the populations most in need of targeted care from the systems meant to serve them.

The goal is systems that allow young people to be seen safely, where sharing information with a clinician does not mean losing control of it, and where health information technology is built around the dignity and developmental realities of its patients. The policy frameworks, clinical evidence and implementation tools to build those systems already exist. What is needed now is the institutional will to use them, particularly at a moment when the stakes for LGBTQ+ youth could not be higher.

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