Stanford
MEDICINE
School of Medicine
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Where's the data going? An example of adolescent data management

Meet Andres

Andres is a 16-year-old boy with type 1 diabetes mellitus. He attends a check-up with his primary care doctor, Dr. Grande, and his endocrinologist, Dr. Shah. Andres' mom, Veronica, encourages him to manage his blood sugar levels and diet independently, but she needs access to medication refill updates and treatment plans. At the same time, Andres is navigating personal aspects of his life—such as being in a same-sex relationship—which he wishes to keep confidential from his parents, as allowed under his state's laws.

The challenge

Adolescent healthcare often **requires balancing confidentiality** with **caregiver involvement**. Andres' case illustrates challenges in this area:

- Confidentiality: How can Andres' healthcare team document and share sensitive information securely?

- Autonomy: How can Andres' rights to privacy be upheld while still providing Veronica access to information essential for supporting his health?

- Technology limitations: Current EHR systems and digital health tools often lack the functionality to segment and protect adolescent-specific confidential data from general health records.

The reality

In the US, each state has different laws governing adolescent confidentiality.

- **Data classification:** EHR vendors and digital health applications do not yet have sufficient capabilities to segregate protected data from the rest of the health record to ensure there isn't an accidental disclosure. If you are sharing a medication list, for example, how can an antibiotic given for pneumonia be classified differently than the *same drug* when used to treat chlamydia?

- **Accidental disclosure:** Sharing consolidated health records with caregivers often inadvertently includes confidential information.

- **Lack of adolescent-centered features**: Most platforms do not provide adolescents and caregivers with distinct user profiles or permissions.

A better way

Innovative approaches to adolescent data management are crucial to address these gaps. Potential solutions include:

- Segmented data**:** Enable segregating sensitive data categories, such as medications, labs, diagnoses, and notes.
- Distinct user profiles**:** Create distinct profiles for adolescents and caregivers with customizable permissions.
- User-centered design: Support features that empower adolescents as they transition to independent healthcare management.

Key considerations for success

- ✔ Familiarize healthcare teams with state-specific adolescent confidentiality laws.
- ✔ Develop systems to classify and sequester confidential data—e.g., sexual health, mental health—separately from general health data.
- ✔ Allow adolescents and caregivers to work with healthcare providers to determine what data is shared.
- ✔ Introduce tools that help adolescents gradually take control of their health decisions while involving caregivers appropriately.
- ✔ Collaborate with adolescents and caregivers to develop a clear transition plan toward independent health management.
- ✔ Ensure caregiver and adolescent contact information is up-to-date for proxy account setup.
- ✔ Provide mechanisms to reclassify data as confidential or shared when needed.