

Case Study: Managing Pediatric Health Information in a Patient Portal

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The healthcare industry has made, and will continue to make, immense advancements with technology and therefore impact the practice of medicine. Consumer-centric healthcare and the way in which providers communicate with patients go hand-in-hand with the use of technology. One concentrated area of consumer healthcare is the use of patient portals and individual access to protected health information (PHI). There is an increasing need for best practices that ensure the overall privacy and security of the PHI within these patient portals is maintained, especially for the pediatric (minor) population.

Many factors must be considered to manage minors' health information in patient portals. First and foremost, an organization must have a strong understanding of state and federal privacy laws and regulations in order to implement policies and procedures that grant individuals appropriate access to PHI. Today there are many complex family relationships: blended families, extended families, grandparents with guardianship, foster parents, and same sex parents, to name a few. So it is critical that organizations have a process and mechanism in place for granting the appropriate individuals access to a minor's health information via the patient portal.

At Vanderbilt University Medical Center (VUMC), health information management (HIM) professionals play a gate keeping role in managing the patient portal. VUMC is an academic medical center spanning 72 counties throughout the state of Tennessee, and is made up of six hospital systems and 32 hospital locations. As of December 2013, VUMC had approximately 17,722 registered pediatric accounts. The HIM staff at VUMC work very closely with the office general counsel (OGC) and the privacy officer to ensure pediatric PHI is confidential and secure through the portal.

Granting Portal Access to Patients

When establishing a patient portal an organization will need to establish its own internal best practices for compliance. VUMC's processes for granting access are outlined below:

- A paper application for each minor child between the ages of 0-17 must be completed onsite at the clinic by each parent requesting access. The application must be signed in front of VUMC personnel and the parent and/or legal guardian must show proof of identification (i.e., driver's license).
- Rules for various parent/legal guardianship—all applications and accompanying legal documentation is verified by HIM personnel and then sent on to the OGC for final approval:
 - Natural or adoptive parent—Given access without a court order or legal documentation proving legal custody. Exception: International adoptions must be sent to the OGC for approval due to additional legal requirements.
 - Legal guardian—A valid court order or other legal documentation must be presented for proof of custody. A legal guardian can be a grandparent, a foster parent, a stepparent, or the child could be in state custody.
 - Stepparent—Given access if proper documentation proves legal custody and/or other status such as power of attorney (POA). A POA would be used in specific cases (i.e., a stepparent wants to have access to the child's account and the natural parent is in the military and deployed).
- Once approved by the OGC, the application is processed.
 - In certain situations, the OGC will require that additional documentation is submitted before an application can be approved. For example, if a court order is not signed by the judge, the OGC will ask for further documentation to prove the order is still in place. In addition, the OGC may ask for follow-up in one year to ensure the document is still valid.

- Upon OGC approval, the minor's PHI will be linked to the parent/legal guardian's information on the application and the parent/legal guardian will receive an e-mail notification that the account is available for access and viewing.

Each adult who has access to the patient portal must register for their own account. If the parent is not a patient at the medical center, they must still register for an account if they want access to their child's portal account. They will register for a non-patient account. When the non-patient parent registers, he or she will create a username and a password for his or her account.

Each parent, both father and mother, may have an account that accesses the minor child's portal account. Each parent may also delegate legal access to one other person (i.e., a stepparent or grandparent), so it is possible for a total of four people to have access to a minor child's account. VUMC has the right to disable any parent account in the case of a suspected abuse or neglect case that is reported to HIM personnel by a social worker or other qualified staff.

State Law Also Dictates Minors' Rights

Each state governs the rights of adolescents and their health information. Each state also has their own definition of a minor and what is considered age of majority, so it is imperative to know state laws. In the state of Tennessee a child at age 13 has certain rights. VUMC has a separate application for teen pediatric patients between 13 and 17 years old. About a month before a child turns 13, an e-mail notification is automatically sent to the parent informing them that the account will expire on the child's 13th birthday.

At this point the parent is given information on the portal application process for ages 13 to 17 and how access can continue. The pediatric teen patient who is 13-17 years old must sign the application as well as the parent and/or legal guardian. In this instance if the teen does not sign the application the parents cannot have portal access. On the other hand, the teen cannot have portal access if they do not sign the application giving the parents portal access. The only way a teen can register for their own account online is by having the application signed by both the teen and a parent. Since the teen will have a separate account, the teen has a secure way to message their provider and be actively involved in their healthcare and health maintenance.

It should be noted that VUMC does not allow teen parents to have access to their minor child's accounts as they are considered a teen under age 18 and cannot have an account of their own without a parent. The teen parent will not have portal access to their own child's account until the teen turns 18 years old.

Portal Access Rights Evolving

Policies and procedures continue to evolve and change as the functionality of the portal changes. Organizations must not only consider complex family relationships, but also what kind of information will be available for pediatric accounts versus adult accounts. For example, radiology results are not available for pediatric accounts at VUMC. Each individual facility must also determine how often a teen account should be renewed for access.

This is a great arena for HIM professionals to be involved in. HIM professionals have a strong knowledge base in health data management, information technology and systems, privacy and security standards, and legal and regulatory standards. This knowledge base is necessary to help support and build policies and procedures for successful patient portal use.

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