



Privacy, Please: Health Consent Laws for Minors in the Information Age

Introduction

In many states, minors can get abortions, treatment for sexually transmitted diseases, or mental health services without their parents' knowledge or consent. In the era of electronic health information exchange, however, maintaining this confidentiality is a vexing challenge. Information about minors is subject to myriad laws that require health care providers to treat it differently than health information about adults.¹

This issue brief provides an overview of the laws governing disclosure of minors' health information and spotlights the challenges that these laws pose to comprehensive electronic health information exchange.

Laws Governing Disclosure of Minors' Health Information

The rules governing disclosure of minors' health information are outlined in a patchwork of state and federal laws. To understand them, it is important to know whether and how minors may consent on their own to receive various types of health care services. The reason is this: If a minor is legally able to provide consent to receive a health care service, then the minor — not the minor's parent or guardian — generally has the right of access to, and may provide consent for, the disclosure of information about the services.²

Typically, for a minor to receive health care services, someone with the appropriate legal authority must provide consent. Until a minor reaches the age of majority (usually 18) and attains adult status, consent is usually provided by the

minor's parent or guardian. However, there are a number of circumstances under which a minor may consent to care before turning 18.

State Law

Many states have laws that outline the specific circumstances under which minors may consent to receive health care services. These laws generally fall into two categories: (1) those that allow consent based on the status of the minor (e.g., married or emancipated) and (2) those that allow consent based on the type of health care service the minor is seeking (e.g., reproductive or mental health care).

In California, for example, emancipated minors and minors living separate and apart from their parents may consent to their own medical care.^{3,4} In addition, minors of various ages may consent to the following services:

- Abortion⁵
- Treatment for drug- and alcohol-related problems⁶
- HIV/AIDS testing and treatment⁷
- Diagnosis or treatment of certain infectious, contagious, or communicable diseases, including sexually transmitted diseases⁸
- Mental health treatment and counseling⁹
- Treatment or prevention of pregnancy, including family planning and contraception¹⁰
- Rape treatment¹¹
- Sexual assault treatment¹²

Table 1 highlights some of the circumstances under which minors may consent to receive health care services under various states' laws.

In the absence of specific statutory provisions, state courts generally follow the “mature minor rule.” Under this doctrine, courts consider whether the minor has the capacity to consent to and appreciate the risks and consequences of the medical treatment involved.¹³

Federal Law

There are also a number of federal laws that spell out specific circumstances under which minors may consent to receive health care services.

Title X of the Public Health Service Act, for example, authorizes federal grants to health care providers for the provision of family planning and related preventive health services, including contraceptive services, to all in need, including adolescents.¹⁴ These services must be provided on a confidential basis. The regulations governing the

Table 1. Examples of Health Care Services and the Circumstances Under Which Minors May Consent to Receive Them Under State Laws

Contraceptive Services	<ul style="list-style-type: none"> • Twenty-six states and Washington, DC, allow all minors (ages 12 and older) to consent to contraceptive services. • Twenty states allow only certain categories of minors to consent to contraceptive services. • Four states have no relevant policy or case law.
Sexually Transmitted Infection Services	<ul style="list-style-type: none"> • All states and Washington, DC, allow all minors to consent to sexually transmitted infection (STI) services. • Eighteen of these states allow, but do not require, a physician to inform a minor’s parents that the minor is seeking or receiving STI services when the doctor deems it to be in the minor’s best interest.
Prenatal Care	<ul style="list-style-type: none"> • Thirty-two states and Washington, DC, explicitly allow all minors to consent to prenatal care. • Another state allows a minor to consent to prenatal care during the first trimester and requires parental consent for most care during the second and third trimesters. • Thirteen of these states allow, but do not require, a physician to inform parents that their minor daughter is seeking or receiving prenatal care when the doctor deems it to be in the minor’s best interest. • Four additional states allow a minor who can be considered “mature” to consent. • Thirteen states have no relevant policy or case law.
Abortion	<ul style="list-style-type: none"> • Two states and Washington, DC, explicitly allow all minors to consent to abortion services. • Twenty-one states require that at least one parent consent to a minor’s abortion, while 11 states require prior notification of at least one parent. • Five states require both notification of and consent from a parent prior to a minor’s abortion. • Six additional states have parental involvement laws that are temporarily or permanently enjoined (i.e., prohibited from taking effect). • Many states with laws requiring either parental consent or parental notification for minors to obtain an abortion include a judicial bypass procedure (i.e., a process under which a court can waive the requirement), an emergency exception, and/or an exception for cases of incest or abuse.* • Five states have no relevant policy or case law.

*Abigail English et al., *State Minor Consent Laws: A Summary*, 3rd ed. (Chapel Hill, NC: Center for Adolescent Health and the Law, 2010).
 Note: The minor consent law information in this chart was adapted from *State Policies in Brief: An Overview of Minors’ Consent Law* (New York: The Guttmacher Institute, August 1, 2012), www.guttmacher.org.

Title X program provide that “[a]ll information as to personal facts and circumstances obtained by the project staff about individuals receiving services must be held confidential and must not be disclosed without the individual’s documented consent, except as may be necessary to provide services to the patient or as required by law, with appropriate safeguards for confidentiality. Otherwise, information may be disclosed only in summary, statistical, or other form which does not identify particular individuals.”¹⁵ Thus, minors of any age may consent to family planning services when those services are supported by Title X funds.

Under the federal Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, whoever has the right to consent for the minor to receive health care services (typically a parent or guardian) may authorize the disclosure of such information. There are, however, three circumstances under which minors retain the sole right to control disclosure of their health information under the HIPAA Privacy Rule:

1. When state or other law does not require the consent of a parent or other person before a minor can obtain a particular health care service, and the minor consents to the health care service
2. When a court or other law authorizes someone other than the parent, guardian, or person acting in place of a parent to make treatment decisions for a minor
3. When a parent, guardian, or person acting in place of a parent agrees to a confidential relationship between the minor and a health care provider

A Challenge to Electronic Health Information Exchange

The legal framework can present challenges to electronic health information exchange. If parents provide consent for a health care provider to exchange information about their children through a health information exchange (HIE), such as a regional health information organization, that consent may not cover information relating to services to which the minors consented on their own. This means that if a health care provider disclosed such information through an HIE without the minor’s consent, that provider could be violating the law and/or the HIE’s privacy policies. In some cases, such as in the case of disclosures for treatment purposes, no patient consent may be necessary.¹⁶ However, some states require that health care providers obtain a patient’s consent to disclose information even for treatment purposes. Further, in some cases, providers must be careful not to reveal information to the minor’s parent or guardian — without the minor’s consent — about health care services to which the minor has consented on his or her own.

As an example, minors of any age in California may consent to medical care related to the prevention or treatment of pregnancy.¹⁷ The minor’s health care provider can disclose the minor’s medical records only with the authorization of the minor (unless the disclosure is for treatment or other purposes specifically authorized by law).¹⁸ Further, the provider is not permitted to inform a parent or legal guardian of the treatment without the minor’s authorization.¹⁹ To comply with these requirements, health care providers and HIEs must be able to distinguish the information in a minor’s record that is controlled by the minor from the information that is controlled by his or her parent.

Stakeholders are considering different ways to overcome the challenge of electronic exchange of minors’ health information; several are described below.

Data Segmentation

Data segmentation, “the process of sequestering from capture, access, or view certain data elements that are perceived by a legal entity, institution, organization, or individual as being undesirable to share,” allows health care providers and patients to choose:²⁰

- Which pieces of health information to share (ranging from discrete pieces to whole categories of information)
- Who can access which pieces of health information
- Under what circumstances different stakeholders can access the information (e.g., for treatment or research)
- For what length of time the information can be accessed

Conceptually, data segmentation would also allow health care providers to (1) separate sensitive health information, including information about services to which minors have consented on their own, from general medical information; and (2) withhold such information from exchange until they obtain any special consent that may be required by law.

There are a number of technical challenges that make data segmentation difficult. To be segmented, electronic health information must be structured and coded so that computers can distinguish between different types of health information (e.g., information about services to which a minor consented versus information about services to which a parent consented) and consistently treat them separately. Today, much electronic health information is unstructured, having been entered into electronic systems using free-text fields that computers cannot easily segment.

While some electronic health record (EHR) products are capable of segmenting information at the health care encounter level, they may not be able to segment

ancillary services, such as prescriptions and laboratory results that are generated during an episode of care to which a minor consented. It is difficult to ensure, after the patient’s initial provider encounter, that information generated by other health care stakeholders, such as pharmacies and laboratories, will be identified — on an ongoing basis — as subject to the same special consent requirements as the information generated during the initial encounter. Similarly, while there are a number of consent management software products that enable

When Data Segmentation Matters: Two Scenarios

Mary, 16, went to Dr. Smith to get a prescription for birth control pills. She told Dr. Smith that her parents didn’t know she was sexually active and asked that he not share this information with them. Dr. Smith has an EHR and is connected to the local HIE. Neither his EHR nor the HIE, however, has the ability to identify and segregate information about the prescription from other patient information to which Mary’s parents have provided consent. Later that year, Mary is hospitalized and found to have high blood pressure. The hospital is also connected to the HIE, and the physician treating her in the hospital accesses her data and notes that she is on birth control pills, which could be a potential factor in her high blood pressure. The physician discloses this information when discussing Mary’s condition with her parents. Because of the lack of data segmentation, the hospital physician inadvertently disclosed information to Mary’s parents that she should not have shared.

Tom, 17, provided consent to receive an HIV test in a state where health care providers may not share HIV test results without the minor’s consent. Tom did not provide consent for his doctor to share his positive test result. Tom’s doctor made a note of Tom’s positive HIV test result in the free text field of his EHR, which is sent to the local HIE along with the other contents of Tom’s medical records. Tom’s parents had provided consent for Tom’s doctor to share their son’s records through the HIE earlier in the year. Despite Tom’s parents’ HIE consent, if another health care provider learned of Tom’s positive HIV status through the HIE — because the information was not tagged and separated — it could be in violation of the state’s minor consent law.

patients to control who sees which pieces of their health information, they often cannot ensure that prescriptions or laboratory results generated after the patient's provider visit are segmented and protected on an ongoing basis.

Separate Medical Records

Some stakeholders have suggested that health care providers could safeguard the confidentiality of minors' health information by creating wholly separate medical records for those episodes of care to which minors consent on their own and by withholding those records from exchange as appropriate. But other stakeholders have suggested that because individual health care encounters often include services to which minors have consented on their own as well as services to which their parent consented, use of a separate medical record may not be an adequate solution. Stakeholders further assert that even if a health care provider is able to maintain a separate record for information about health care services to which minors have consented on their own, the health care provider would likely have difficulty restricting the record from exchange through the HIE as necessary.

Blanket Consent and Blanket Exclusion

These challenges have led some health care providers and HIEs to use cumbersome approaches to enable the electronic exchange of minors' health information, such as obtaining consent from both the parent and minor for all disclosures of minors' records, or simply excluding minors of a certain age from the HIE.

For example, New York State's HIE privacy and security policies permit the exchange of information about minors under 10 years of age based on parent or guardian consent under the assumption that those minors are unlikely to have consented to services on their own; thus the state's minor consent laws are unlikely to be implicated. However, for the exchange of information about services to which older minors consented on their own, the minor's consent is required. But as a practical matter, most health care providers and HIEs are unable

to identify and block such information if a minor has not provided the required consent, so information about minors 10 years of age or older is generally excluded from the state's HIE.²¹

Other Strategies

Other HIEs have chosen to facilitate exchange of health information about minors but have made it clear to patients and health care providers that not all information about health care services to which minors have consented on their own can be excluded from exchange when such exclusion is necessary.

The state of Nebraska, for example, operates a statewide health information exchange network called the Nebraska Health Information Initiative (NeHII). Patients' health information is automatically exchanged through NeHII unless the patient opts out. NeHII's privacy policy requires participating providers to remove from the health information that they make available through NeHII records that fit into the following categories: (1) federally funded alcohol and substance abuse services protected under 42 C.F.R. Part 2, (2) emergency protective custody proceedings, (3) predictive genetic testing performed for genetic counseling, (4) HIV testing, (5) STD testing or treatment of minors consented to by the minor, and (6) mental health treatment in Iowa. NeHII's participating providers accomplish this by identifying and segmenting the electronic laboratory codes associated with these types of records. Recognizing that segmenting health information by laboratory codes may not prevent all sensitive information from being shared, however, NeHII alerts participants and patients that information about test results may be available or referred to elsewhere in the patient's record.²²

At least one HIE in California, the San Diego Beacon Community, operates in a similar manner. Still other HIEs in California and throughout the country have not yet addressed the question of whether and how to segment information about services to which minors have

consented on their own from other information being exchanged through the HIE.

Because many HIEs are still in the early stages of development, they are often exchanging information for treatment only, a purpose that may not require a patient's affirmative consent. Thus, in these situations, the risk that an HIE or its participants may be violating a state's minor consent laws by exchanging information without the minor's authorization about services to which a minor consented on his or her own are small and may be limited to risks associated with unauthorized disclosure to the minors' parents.

Progress on Possible Solutions to the Challenge of Minor Consent

Recognizing that electronic health information exchange can improve health care for minors, the health information technology (HIT) community is working to craft solutions that will enable providers to electronically exchange minors' health information without violating their privacy rights.

HIT vendors are experimenting with new product functionality that would enable comprehensive data segmentation, and HIEs are testing new consent management strategies through pilot programs.²³ The federal government is supporting the cause through efforts like its Data Segmentation Initiative, which is developing standards to electronically tag and separate sensitive health information and thus enable health care providers to share selected, but not all, pieces of information in an EHR. Among other activities, the Data Segmentation Initiative is building on a December 2010 report of the President's Council of Advisors on Science and Technology (PCAST), which encouraged the federal government to enable more granular protection of health information privacy. Specifically, the report recommended use of a universal electronic exchange language based on tagged data elements, including use of metadata to tie consumer privacy preferences to specific pieces of health

information. According to PCAST, health information should be separated into the smallest pieces possible for exchange. These pieces should then each be accompanied by metadata (i.e., data about the data) that describe if and how each piece of health information can be shared, among other information.

While this and other types of information segmentation may help address the minor consent challenge, they are unlikely to serve as a magic bullet. Health care providers will still have to navigate thorny issues: knowing when minors have the right to consent on their own to health care services, knowing how to obtain such consent, and ensuring that the electronic exchange of information about health care services to which minors have consented on their own does not inadvertently lead to inappropriate disclosure to those minors' parents or guardians. However, the increased ability to tag and separate discrete items of data will be a significant step toward facilitating the electronic exchange of health information about minors.

AUTHORS

Helen R. Pfister and Susan R. Ingargiola
Manatt Health Solutions

ABOUT THE FOUNDATION

The California HealthCare Foundation works as a catalyst to fulfill the promise of better health care for all Californians. We support ideas and innovations that improve quality, increase efficiency, and lower the costs of care. For more information, visit us online at www.chcf.org.

ENDNOTES

1. This Issue Brief focuses on the effect of minor consent laws on query-based health information exchange that is facilitated by third-party intermediaries, such as RHIOs. However, this is not to suggest that minor consent laws do not also pose a challenge to other types of electronic health information exchange, including direct, push-model exchange that occurs through secure messaging and other channels.
2. *See, e.g.*, Cal. Health & Safety Code §§ 123110 and 123115, which provide that where a minor is authorized by law to consent to treatment, the right of access with respect to those records rests with the minor, not the parent. *See also* Cal. Civ. Code § 56.11, which provides that a minor may authorize a health care provider to disclose medical information obtained in the course of furnishing services for which the minor could lawfully consent and that the minor's legal representative (e.g., parent or guardian) may not provide authorization for such disclosure.
3. Cal. Family Code § 7050(e)(1). A minor is emancipated if the minor has entered into a valid marriage, whether or not the marriage has been dissolved; the minor is on active duty with the armed forces of the United States; or the minor has received a "declaration of emancipation" from a court. Cal. Family Code § 7002.
4. Specifically, a minor may consent for his or her medical or dental care if he or she meets the following three requirements: (1) the minor is 15 years of age or older; (2) the minor is living separate and apart from the minor's parents or guardian, with or without the consent of a parent or guardian, and regardless of the duration of this separation; and (3) the minor is managing the minor's own financial affairs, regardless of the source of the minor's income. Cal. Family Code § 6922(a).
5. Minors of any age may consent for the performance of an abortion. *See American Academy of Pediatrics v. Lundgren*, 16 Cal. 4th 307 (1997).
6. Cal. Family Code § 6929(b) provides that a minor who is 12 years of age or older may consent to medical care and counseling relating to the diagnosis and treatment of a drug- or alcohol-related problem.
7. Cal. Health & Safety Code § 121020 and Cal. Family Code § 6926(a) provide that minors 12 years of age or older are able to consent to HIV testing and treatment. If HIV/AIDS services are funded in full or in part by Title X, minors of any age may consent.
8. Cal. Family Code § 6926(a) provides that a minor who is 12 years of age or older and who may have come into contact with an infectious, contagious, or communicable disease may consent to medical care related to the diagnosis or treatment of the disease if the disease or condition is one that is required to be reported to the local health officer, or is a related sexually transmitted disease, as may be determined by the State Director of Health Services.
9. Cal. Family Code § 6924(b) provides that a minor who is 12 years of age or older may consent to mental health treatment or counseling on an outpatient basis, or to residential shelter services, if both of the following requirements are satisfied: (1) the minor, in the opinion of the attending professional person, is mature enough to participate intelligently in the outpatient services or residential shelter services and (2) the minor would present a danger of serious physical or mental harm to self or to others without the mental health treatment or counseling or residential shelter services or is the alleged victim of incest or child abuse.
10. Cal. Family Code § 6925 provides that a minor of any age may consent to medical care related to the prevention or treatment of pregnancy.
11. Cal. Family Code § 6927 provides that a minor who is 12 years of age or older and who is alleged to have been raped may consent to medical care related to the diagnosis or treatment of the condition and the collection of medical evidence with regard to the alleged rape.

12. Cal. Family Code § 6928(b) provides that a minor of any age who is alleged to have been sexually assaulted may consent to medical care related to the diagnosis and treatment of the condition, and the collection of medical evidence with regard to the alleged sexual assault.
13. *See, e.g., Cardwell v. Bechtol*, 724 S.W.2d 739 (Tenn. 1987), in which a 17-year-old patient made an unaccompanied visit to an osteopathic physician who performed a spinal manipulation for back pain. The patient's parents subsequently sued the physician, claiming that the minor could not consent to treatment. The court found that the minor had the maturity to consent based on her age, good grades, maturity, and the fact that she had been permitted by her parents to exercise substantial discretion.
14. 42 U.S.C. § 300 et seq.
15. 42 C.F.R. § 59.11.
16. *See, e.g.,* Cal. Civ. Code § 56.10(c), which provides that a health care provider or health plan may disclose medical information to health care providers, health plans, contractors, or other health care professionals or facilities for purposes of diagnosis or treatment of the patient without the patient's authorization. *See also* 45 C.F.R. § 164.506(c), which provides that a HIPAA-covered entity is permitted to use and disclose protected health information, without an individual's authorization, for its own treatment, payment, and health care operations activities.
17. Cal. Family Code § 6925.
18. Cal. Civ. Code §§ 56.10, 56.11. *See also* M. Simmons et al., *Understanding Confidentiality and Minor Consent in California: An Adolescent Provider Toolkit*, 1st revised ed. (San Francisco: Adolescent Health Working Group, San Francisco Health Plan, 2003).
19. Cal. Health & Safety Code §§ 123110(a), 123115(a). *See also* M. Simmons et al., *Understanding Confidentiality and Minor Consent in California: An Adolescent Provider Toolkit*, 1st revised ed. (San Francisco: Adolescent Health Working Group, San Francisco Health Plan, 2003).
20. Melissa Goldstein and Alison Rein, *Data Segmentation in Electronic Health Information Exchange: Policy Considerations and Analysis* (Washington, DC: Office of the National Coordinator for Health IT, September 29, 2010), www.healthit.hhs.gov.
21. After consulting with specialists in adolescent medicine, policymakers and stakeholders in New York determined that it is unlikely that a minor under the age of 10 would be consenting to receive health services on his or her own. *See* NYeHealth Collaborative Privacy & Security Minor Consent Tiger Team, *Barriers to the Exchange of Pediatric Health Information*, July 2010, www.nyehealth.org.
22. "NeHII: Sharing Information for Better Health Care," accessed September 27, 2012, www.nehii.org.
23. For a discussion of potential technical solutions as advanced by stakeholders in New York, *see* NYeHealth Collaborative Privacy & Security Minor Consent Tiger Team, *Barriers to the Exchange of Pediatric Health Information*, July 2010, www.nyehealth.org.