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Privacy and Security Solutions for Interoperable Health Information Exchange

Report on State Medical Record Access Laws

Prepared for
RTI International
230 W Monroe, Suite 2100
Chicago, IL 60606

P. Jon White, MD, Director of Health IT
Agency for Healthcare Research and Quality
540 Gaither Road
Rockville, MD 20850

Jodi Daniel, JD, MPH, Director
Steven Posnack, MHS, MS, Policy Analyst
Office of Policy and Research
Office of the National Coordinator
for Health Information Technology
200 Independence Avenue, SW, Suite 729D
Washington, DC 20201

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Jodi Daniel, JD, MPH, Director
Steven Posnack, MHS, MS, Policy Analyst
Office of Policy and Research
Office of the National Coordinator
for Health Information Technology
200 Independence Avenue, SW, Suite 729D
Washington, DC 20201

Prepared by
Joy Pritts, JD
Kyle Kayne, JD
Robin Jacobson, JD
**Health Policy Institute &
O'Neill Institute for National and Global Health Law**
Georgetown University
3300 Whitehaven Street, NW, Suite 5000
Washington, DC 20007

Under subcontract with RTI International
3040 Cornwallis Road
Research Triangle Park, NC 27709

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EXECUTIVE SUMMARY

Background and Purpose

This report is one of a series produced under RTI International's contract with the Agency for Healthcare Research and Quality (AHRQ). The contract, entitled Privacy and Security Solutions for Interoperable Health Information Exchange, is managed by AHRQ and the Office of the National Coordinator for Health Information Technology (ONC). In the first phase of this project, 33 states and 1 territory (collectively referred to as states or state teams) conducted an assessment of variation in business practices, policies, and laws that might be perceived as barriers to electronic health information exchange, suggest possible solutions to these barriers, and prepare plans to implement these solutions. In doing so, the states focused on a number of different scenarios, including treatment, health information exchange, payment, research, and public health.¹ As a result, the states identified a number of state laws and policies addressing the limitations on disclosure of health information between health care providers and third parties that may impede electronic health information exchange.

The states also reported varied approaches to electronic health information exchange.² Although differing types of health information organizations are being proposed in a number of states, others have reported health record banks or personal health record (PHR) systems as the emerging primary model for exchanging health information in their states.³ These various approaches to exchanging health information raise a number of issues about individuals' ability to access their own health information. This report is intended to further the initial work of this project by analyzing state laws that are intended to require health care providers (specifically, medical doctors and hospitals) to afford individuals access to their own health information and to identify potential barriers about this aspect of health information exchange.

Findings

Nearly every state has some statutory or regulatory provisions that grant individuals the right to access their medical records maintained by health care providers. In some states, these provisions apply to a broad range of health care providers. In others, medical record access laws specifically apply only to particular categories of health care providers. For

¹ Dimitropoulos, L. (2007, July). *Privacy and Security Solutions for Interoperable Health Information, Exchange Assessment of Variation and Analysis of Solutions.*

² "Electronic health information exchange" is "[t]he electronic movement of health-related information among organizations according to nationally recognized standards." The National Alliance for Health Information Technology (2008, April). *Report to the Office of the National Coordinator for Health Information Technology on Defining Key Health Information Technology Terms.*

³ In addition, commercial vendors such as Google and Microsoft have begun to market personal health records (PHRs) as a means for patients to facilitate and control the exchange of their health information.

example, there may be different standards that apply to medical doctors (allopathic doctors), doctors of osteopathy, dentists, podiatrists, chiropractors, hospitals, and stand-alone clinics. In order to review the rights of access consistently across the states, this project primarily focuses on laws that govern medical doctors (hereinafter “doctors”) and/or hospitals.

Few states have medical privacy access provisions as extensive as those found in the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule. However, most states have moderately detailed laws governing access to medical records held by doctors and/or hospitals including provisions that expressly address: individuals’ right of access to their health information; the maximum time doctors and/or hospitals have to respond to such a request; and the maximum copying fees doctors and/or hospitals may charge for furnishing the record. The right to amend health information is the standard least likely to be addressed by state law. Table A-1 presents a high-level view detailing the states that have laws that address these various issues with respect to doctors and hospitals.

Scope of Medical Records to Which Patients Are Afforded Access

States use varying terms to describe the health information encompassed by individuals’ right of access, including, for example, patient records, health records, medical records, hospital records, and patient information. Few state laws specify that doctors and/or hospitals must furnish access not only to information in the medical record that they generated but also to any information included in their record that was generated by another health care provider. This has led some doctors and hospitals to conclude that they do not need to furnish the entire record in their possession. This practice impedes individuals’ ability to access their own information, effectively forcing them to request records from every health care provider they have seen. Clarifying the law in this area, by guidance or regulation, could potentially remedy this barrier to access.

Format of Information Furnished

Few state laws address the required format in which a medical record must be furnished. A handful of states do require that doctors and/or hospitals, upon request, provide an explanation of any code or abbreviation used in the record or in a form that is understandable to the patient. The standards of these states may serve as a best practice for affording patients access to electronic information. As a matter of practice, some electronic health record systems already link technical medical terms to medical dictionaries and articles explaining their meaning.

Deadlines for Responding to Requests

States laws vary with respect to the maximum period of time that doctors and/or hospitals have to respond to requests for medical records. Most states require doctors and/or hospitals to respond to requests for medical records within 30 days of receipt of request;

some states allow 60 days. These response times are based on copying of paper records and may not be as appropriate in an electronic environment.

Fees for Furnishing Copies

Some states allow doctors and/or hospitals to charge “reasonable” or cost-based fees for furnishing copies of medical records to individuals. However, the vast majority of states (41) establish specific fee schedules for maximum copying charges. Many state laws permit doctors and/or hospitals to charge search or retrieval fees in addition to a per-page charge. Under these state laws, maximum copying fees for one page (including search and retrieval fees) range from free to \$40.00, while maximum fees for copying 100 pages range from free to over \$180.00. These permitted fees are based, for the most part, on copying paper records. Theoretically, fees for providing access to electronic health records should be lower. However, few state laws address the charge for furnishing copies of electronic records. Those states that do address copying electronic data appear to base permitted fees on costs associated with copying paper records.

Record Retention Laws

Nearly every state has statutes or regulations that set medical record retention requirements for doctors and/or hospitals. Timeframes for retaining patient records generally are tied to the state statutes of limitations for negligence actions. Across all states, 10 years is the most common (mode) retention period for hospitals. The required retention period for doctors’ medical records ranged from 3 to 10 years with a mode of 7 years. The relatively short retention periods required in some states may preclude patients from gaining access to their medical records later in life if, for example, they choose to establish a personal health record.

Access to Records of Minors

As a general rule, parents have the right of access to the medical records of their minor children. The issue becomes more complicated when the minor lawfully consents to his or her own treatment. When this is the case, the HIPAA Privacy Rule defers to state law as to whether a health care provider⁴ may or may not *notify* parents of such treatment and whether the parents have *right of access* to the medical records associated with such treatment. State law in this area varies greatly regarding the conditions under which a minor may consent to his or her own health care and whether the health care provider may notify the parents of such treatment.

⁴ Our research with respect to minors focused on statutes and regulations that expressly address minors’ ability to consent to treatment for specific health conditions and the right of access to the related information. As these statutes are generally not sector-specific, the term “health care providers” as used with respect to minors’ records generally encompasses, but may be broader than, medical doctors and hospitals.

First, the age at which a person may lawfully consent to care varies with the health condition at issue. For general health care, the age of consent is generally 18 years old, but in some states is as young as 14. Minors in all states have the right to consent to testing and treatment for a sexually transmitted disease (STD). In many states, minors also have the right to consent to outpatient treatment for mental health issues and/or alcohol and substance abuse without parental permission. The age of consent for these various conditions may vary not only among states, but also within a given state. For example, in one state the age of consent is 12 years for treatment for an STD and 14 years for substance abuse.

The standards governing parental right of access to the related health information are nuanced. Many state laws expressly give health care providers the discretion to notify parents of the treatment needed or received when a minor seeks health care in his or her own capacity. While giving the health care provider the discretion to notify parents of this treatment, many state laws also reserve the *right* of access to the related record to the minor who was treated. The net effect is that in many cases, the health care provider ultimately has the discretion to decide whether parents should receive information about a minor's treatment and the amount of information to disclose. Such discretion aligns with established professional ethics. However, it is difficult to implement such discretion in an electronic environment. Health care providers have suggested that they need to be able to segregate the information and to manage consents electronically.

Appendix A contains overview and detailed tables summarizing these findings.

Conclusion

Most state medical record access laws are designed to address records maintained in paper format. Many of the statutes and regulations do not truly facilitate, and in fact may impede, individuals' ability to obtain their health information in electronic format. Specifically, record retention requirements are relatively short in lieu of the goal of providing individuals with a longitudinal record. The relatively long time frame for responding to individuals' requests, while appropriate for paper records, does not reflect expectations for the accessibility of electronic information. Most relevant statutes and regulations do not expressly require doctors and hospitals to furnish health information electronically even if the records are maintained in that format. The permitted costs associated with obtaining copies of medical records can be significant and effectively hinder individuals' ability to access their records. In light of these factors, as more health care providers begin to maintain health information electronically, serious consideration should be given to reviewing and revising state medical record access laws so that they better comport with an electronic environment.

State laws that govern the rights of access to minors' health information when minors lawfully consent to treatment without the permission of their parents present particular

issues for electronic interoperability. These laws are often tied to the minors' ability to consent to treatment for serious, sensitive health conditions such as an STD, mental health issues, or alcohol and substance abuse. Not surprisingly, the access records laws pose some of the same issues as laws that address the disclosure of records related to adult sensitive medical conditions, such as the ability to segregate specific information in a record. Technical solutions are being developed to address some of these issues. Developers of health care systems that have already begun to confront these issues in an electronic environment may be able to offer insight into practical solutions for providing patient access under varying statutes and regulations.

1. BACKGROUND AND PURPOSE

In the first phase of this project, RTI International provided oversight to 33 states and 1 territory (collectively referred to as state teams) conducted an assessment of variation in business practices, policies, and laws that might be perceived as barriers to electronic health information exchange, suggest possible solutions to these barriers, and prepare plans to implement these solutions. The states focused on a number of different scenarios, including treatment, regional health information exchanges, payment, research, and public health. The resulting Assessment of Variation and Analysis of Solutions report, an earlier product of this project, presented an overview of the major areas states identified as presenting challenges to the privacy and security of electronic health information exchange. Because the project was focused on the exchange of health information between health care providers and third parties, the areas identified were primarily laws and practices that restrict or limit disclosure of health information (e.g., laws that require the health care provider to obtain the individual's consent prior to disclosing identifiable health information for treatment).

In reporting developing state models for the electronic exchange of health information, however, some states noted that they were not relying on the direct exchange of health information between health care providers, but intended to create health data banks or personal health records (PHRs), where individuals would primarily be in control of their own health information. In order for these models to succeed, individuals must be able to obtain access to their own health information to populate the health data bank or PHR.

1.1 Federal Law Overview: HIPAA

The Privacy Rule promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA Privacy Rule) establishes national standards protecting individuals' identifiable health information. Under the HIPAA Privacy Rule, covered entities, including most health care providers, are required to provide individuals with access to their protected health information upon request [see 45 C.F.R. § 164.524]. In addition, the HIPAA Privacy Rule grants individuals the right to amend their health information to make it more accurate or complete [see 45 C.F.R. § 164.526]. The standards set by these provisions are quite detailed. Among other things, the Rule

- defines the scope of information to which individuals have a right of access;
- sets time limits for covered entities to respond to requests;

- limits the fees that a covered entity may impose for providing copies of protected health information to a reasonable, cost-based amount;⁵
- establishes the limited grounds upon which a request for access may be denied;
- provides a means for reviewing the denial of access; and
- creates detailed procedures with which individuals may request that their protected health information be amended, and if appropriate, that the amended information be forwarded to others.

The HIPAA Privacy Rule requires health care providers to document that they have undertaken certain activities in compliance with the Rule and to retain such documentation, for a minimum of 6 years [45 C.F.R. §164.530(j)]. For example, a covered entity must document and retain a list of the record sets that are subject to access by the individual [45 C.F.R. § 164.524(e)]. The HIPAA Privacy Rule does not, however, require health care providers to retain the actual medical record for any specific time.

The HIPAA Privacy Rule also establishes standards that govern when a person is considered to be a “personal representative” of an individual, and the extent to which the personal representative may exercise the individual’s right to access and amend protected health information [45 C.F.R. 164.502(g)].

The HIPAA Privacy Rule preempts provisions of state law that are contrary to its standards. A state law provision is considered contrary and, therefore, is preempted if either

- a covered entity would find it impossible to comply with both the state and federal requirements; or
- the provision of state law stands as an obstacle to the objectives of HIPAA [45 C.F.R. §§ 160.202; 160.203].

The HIPAA Privacy Rule, however, does not preempt state law provisions about the privacy of individually identifiable health information that, while contrary to the HIPAA Privacy Rule, are more stringent than it. Under this preemption framework, state laws that provide individuals the right to access and amend health information that are greater than the rights in the HIPAA Privacy Rule remain in place.

State laws that govern health information related to treatment for which a minor has lawfully consented without the permission of his or her parents are an exception to this general preemption framework. In very general terms, when a minor lawfully consents to health care without the permission of the minor’s parents, the HIPAA Privacy Rule defers to state laws with respect to whether the health care provider must or may notify the parents of such treatment or provide the parent access to health information related to such treatment.

⁵ Copying fees set by state law are generally presumed to be reasonable; see discussion in Section 3.2.4.

Under this regulatory framework, state laws may affect the ability of individuals to access their health information in a number of ways. First, many states have statutory and regulatory provisions that afford patients access to their own health information. To the extent the provisions of these laws do not conflict with the HIPAA Privacy Rule or provide access that is greater than the HIPAA Privacy Rule, they remain in place. Additionally, in a number of areas the HIPAA Privacy Rule is silent or defers to state law, including the requisite time for retaining medical records, the reasonableness of charges for copying medical records, and the circumstances under which minors may consent to health care and the ability of the health care provider to notify parents of or provide them information about such treatment. State law continues to have a prominent role in these areas and, depending on the circumstances, has the potential to either facilitate or hinder individuals' ability to access their health information electronically.

1.2 Project Purpose

The purpose of this report is to identify and summarize key aspects of state laws that either afford individuals access to their own health information or have a direct impact on such ability (e.g., medical record retention standards). After summarizing these laws, we identify potential issues with respect to whether these laws, as currently written, will facilitate or impede an individuals' ability to access health information in an electronic environment.

2. METHODOLOGY

The underlying research for this project was originally conducted by Georgetown University in 2005–2007 under a grant from the National Library of Medicine. In that project, we identified and summarized state statutes and regulations that govern a patient’s right to see, copy, and amend his or her medical records. Because state laws differ in their approach to medical records access laws (some apply to a broad range of health care providers, while others specifically apply only to one sector, e.g., medical doctors), we limited our research to records maintained by medical doctors (allopathic doctors) and hospitals to make our research consistent across the states, yet manageable.

In this project, we updated our research by cite-checking the statutes and regulations that we had already identified in prior research to verify that they remained current. We conducted our cite checks using online legal research tools, including Lexis/Nexis, Westlaw and relevant websites operated by state governments. We searched not only under statutes, but also under “advance legislative service,” which contains statutes not yet codified, and Attorney General Opinions, which reflect the state’s attorney general’s interpretation of the statutes.

To the extent prior research had not identified a statute or regulation governing patient access to medical records (or the prior statute or regulation had been revoked), we conducted original research using the following terms:

- medical record
- health record
- patient record
- hospital record
- treatment record
- patient information
- patient access
- health care information
- patient right
- bill w/3 rights w/5 patient⁶
- hospital w/3 rights w/5 patient

⁶ “W/3” or “w/5” are connector search terms that require the primary search terms be present in a document within 3 or 5 words, respectively, of each other. In this case, the search will produce instances where the term “bill” is within 3 words of the term “rights,” and that “rights” appear within 5 words of the term “patient.” We used this phrase to identify statutes that are designated as “bill of rights.”

- record management

We used various fields (e.g., heading, full text) to narrow or broaden our search as appropriate. We also researched the table of contents for the applicable licensing statutes for hospitals and medical doctors. We researched the rules of the state medical examining boards, the state authorities generally responsible for enforcing the patient access provisions with respect to medical doctors, and the state hospital licensing authorities. We limited our research of case law to cases cited in case notes for the statutory or regulatory provisions.

We updated our research on record retention requirements for medical doctors and hospitals using similar methods.

We followed a slightly different procedure for our research on minors' rights with respect to health care information. We first updated research on the age of majority and emancipation by using the following terms:

- age w/15 majority
- emancipat!⁷
- minor w/15 disab!

We then conducted limited original research about minors' ability to consent to health care without parental permission. The scope of state law potentially applicable to this issue is extensive. Minors may consent to care for a variety of health conditions. The circumstances under which others may approve care for minors without parental consent vary widely. In order to keep this project manageable, we researched only statutes and regulations that address when minors may lawfully consent to health care without parental permission in the following circumstances:

- general health care based on life circumstances or status,
- testing and treatment for an STD and HIV/AIDS (often treated separately),
- outpatient mental health treatment, and
- outpatient alcohol and substance abuse treatment.

Our previous research had indicated that laws governing these health conditions are often condition-specific (as opposed to health care provider-specific). Accordingly, in addressing minors in the current project we expanded our research beyond medical doctors and hospitals and focused our current research instead on statutes and regulations that expressly address minors' ability to consent to treatment from health care providers (in a

⁷ The symbol "!" is used in a search as a "wildcard" to find variations on a root term. As used here, the term "emancipat!" will locate statutes and regulations that contain the word "emancipate" as well as variations such as "emancipated" and "emancipation."

more general sense) for these health conditions. With respect to each of these health conditions, we sought to determine whether, assuming the minor consents to such treatment without the permission of the minor's parents, state law expressly addressed:

- whether health care providers were permitted or required to disclose health information related to such treatment to parents; and
- whether parents have the right of access to the health information related to such treatment.

Due to limited resources, we did not address minors' rights to obtain treatment for pregnancy, contraceptives, or abortion.⁸ We also did not research other circumstances under which minors may be treated without parental consent, e.g., pursuant to court order.

Although this report focuses on the right of access to health information, we have also reviewed health care providers' rights or responsibilities to notify parents when minors receive or need care in the above circumstances. The ability of a health care provider to inform or notify a parent that a minor needs care is distinct from the parents' right of access to the minor's medical record. Generally (but not always), notification is at the discretion of the health care provider. In contrast, the right of access generally gives parents the right to examine and copy the minor's entire medical record upon request. We have included both parental notification and the right of access in this study because, although the concepts are distinct, they both involve the health care provider's disclosing health information to parents when the minor has consented to treatment without the parents' permission.

We reported our research results on a matrix we developed, breaking the information down into categories that are roughly equivalent to those of the HIPAA Privacy Rule, where pertinent. A sample copy of our data collection tool is attached as Appendix B.

⁸ The current project was designed to leverage existing research on individuals' rights of access to medical records. As the original research did not address minors' ability to consent to treatment for pregnancy, contraception, or abortion, addressing these issues now would require significant investment of time and resources. The Guttmacher Institute has recent state fact sheets addressing these issues available on their website at: <http://www.guttmacher.org/>.

3. FINDINGS

3.1 General Overview of State Medical Record Access Laws

Nearly every state has some statutory or regulatory provisions that grant individuals the right to access their medical records maintained by medical doctors and/or hospitals. Some states have fairly attenuated medical record access provisions that establish a general right of access with little to no detailed standards. Alaska statutes, for example, generally provide that a patient is entitled to inspect and copy records maintained by doctors and hospitals, but do not detail any related standards for executing or enforcing this right [Alaska Stat. § 18.23.005 (2008)]. At the other end of the continuum, a handful of states, including California, Maine, Maryland, Montana, New York, and Washington, have statutory frameworks governing patients medical record access that are as detailed as the HIPAA Privacy Rule. The access provisions in these latter states expressly include the right of access, mandatory response times, maximum fees for copying, grounds for and processes for denial of access, and the right to amend information (see Table A-1).

The vast majority of states fall between these two extremes, with moderately detailed laws governing access to medical records held by doctors and/or hospitals. Thirty-four states have statutes or regulations that expressly address individuals' right of access to their health information held by doctors and/or hospitals, the maximum time doctors and/or hospitals have to respond to such a request, and the maximum copying fee doctors and/or hospitals may charge. The right to amend health information is the standard least likely to be addressed by state law (see Table A-1). The complexity of these provisions varies greatly from state to state. Of course, where state law is silent, the HIPAA Privacy Rule supplies the standards for individuals' rights to access and amend their health information.

3.2 Specific Standards Related to Individual Access

This section of the report addresses in more detail state approaches to some of the specific standards related to the individual's right of access. Each subsection begins with a brief summary of the relevant HIPAA Privacy Rule provision to put the state law in the proper context. The subsection then provides an overview of state laws that address the issue, generally with respect to doctors and hospitals. Finally, the subsection highlights some of the existing or emerging issues the topic presents.

3.2.1 Scope of Information Covered by Access Laws

HIPAA Privacy Rule

The HIPAA Privacy Rule grants individuals the right of access to information in a "designated record set" [45 C.F.R. § 164.524]. For health care providers, this includes "medical records and billing records" and any other records used to make decisions about the individual [see

45 C.F.R. § 164.501 (defining “designated record set”). In promulgating the HIPAA Privacy Rule, the United States Department of Health and Human Services (HHS) explained that under this provision, the health care provider is required to furnish access to all such information in their possession regardless of whether they created it.⁹

State Laws

States use varying terms to describe the health information encompassed by individuals’ right of access, including, for example, patient records, health records, medical records, hospital records, and patient information. In many states, these terms are undefined [see, e.g., W. VA. Code § 16-29-1 (2008) (where state law gives individuals the right of access to all or a portion of the “patient’s record,” a term which is not defined in the statute or regulations)]. However, provisions in several states expressly define the relevant term in detail, specifically including in some instances medical records or information created by others [see, e.g., N.H. Code Admin. R. Ann. Med 501.02(f)(2) (2008)].

Challenges for an Electronic Environment

The fact that states use varying terms (or fail) to define health information that is subject to a right of access may prove problematic. One issue is whether the medical records or health information subject to the individual’s right of access includes material in the record that came from another source. Some health care providers apparently interpret access to medical records or health information as encompassing only information that was generated within their office or facility.¹⁰ In responding to an individual’s request for copies of medical records, some health care providers exclude any information in their possession that was obtained from other health care providers. While some state law provisions clearly define medical record access as including information furnished by other health care providers, most state laws governing doctors and hospitals do not expressly address this issue. The ambiguity in law on this issue, i.e., whether these health care providers must provide access to health information regardless of the originating source, may continue to prove problematic in an electronic environment where any particular health care provider likely will maintain data that originated from myriad sources.

⁹ See United States Department of Health and Human Services, *Standards for Privacy of Individually Identifiable Health Information, Final Rule, (Preamble, Final Rule)* 65 Fed. Reg. 82462, 82732 (Dec. 28, 2000).

¹⁰ Georgetown University’s Center for Medical Record Rights and Privacy has received a number of calls and e-mails from individuals who claim to have been denied access to records based on the health care provider’s belief that they only are required to furnish access to records that they have created.

3.2.2 Maximum Response Time

HIPAA Privacy Rule

In general, a health care provider must respond to the individual's request to inspect or obtain a copy their medical record no later than 30 days after receiving the request. If the information requested is not maintained or accessible to the health care provider on site, the health care provider may respond within 60 days. These deadlines may be extended up to 30 days if the covered entity provides the individual with a written statement of the reasons for delay and the date by which the covered entity will fulfill his or her request [45 C.F.R. 164.524(b)(2)].

State Laws

Medical record access laws in most states (40) establish a standard for the time permitted to doctors and/or hospitals for responding to individuals' requests for access to their records. Twelve states use a "reasonable"-type standard, which does not set specific deadlines. These states use a variety of terms for the standard that may vary slightly in meaning, including "reasonable time," "timely fashion," "promptly," and "without unreasonable delay."

Twenty-three states set express deadlines for doctors and/or hospitals to respond to an individual's request for medical records. The permitted timeframes for response range from 5 days to 60 days (for offsite records). A 30-day response time is the mode, with 12 states requiring responses within this timeframe. Of states that set a distinct deadline, only four permit doctors and/or hospitals a response time longer than 30 days, including any permitted delays. For an overview of these requirements see Table A-2. To review a summary of the text of each state's law with citations, see Table A-3.

Neighboring states may have disparate deadlines for responding to requests for medical records. California requires doctors to provide copies within 15 days, and neighboring Oregon sets a 30-day deadline [see Cal. Health & Safety Code § 123110(b) (2008); Or. Admin. R. 847-012-0000(5) (2008)]. Maryland doctors and hospitals must respond to a request for records within 21 days, while those in Virginia have 15 days to do so [Md. Code Ann., Health-Gen. § 4-309(a) (2008); Va. Code Ann. § 32.1-127.1:03(E) (2008)].

A few states set response times that distinguish between requests to inspect and requests to obtain copies of medical records. In California, for example, doctors and hospitals must respond to a request to inspect within 5 working days and to a request for copies within 15 days [Cal. Health & Safety Code § 123110(b) (2008)]. Similarly, doctors and hospitals in Nebraska are required to allow patients to inspect their records within 10 days and to furnish copies within 30 days [Neb. Rev. Stat. § 71-8403(3) (2008)].

Under state medical record access laws, the receipt of the request for access generally triggers the running of time for responding to the request (e.g., “within 15 days of receipt of request”). A few states, however, also use alternate events as the pertinent trigger. In Delaware, doctors and hospitals are required to produce medical records 45 days after the receipt of the request or 14 days after receipt of payment, whichever is later [Del. Code Ann. tit. 10, § 3926(a) (2008)]. Hospitals in South Carolina are required to furnish records within the latter of 45 days after the patient has been discharged or after the request was received [S.C. Code Ann. § 44-7-325(B) (2007)]. These alternative deadlines can essentially extend the time for furnishing access to medical records, and potentially impede access to a long-term hospital patient.

Challenges for an Electronic Environment

State medical record access law provisions governing the permitted time for responding to patient requests for records present a number of issues, particularly with respect to electronic health information exchange. First, some state law provisions governing response times set standards that appear to be contrary to the HIPAA Privacy Rule (i.e., those with baseline response dates later than 30 days). Second, the state laws that are not contrary to the HIPAA Privacy Rule remain in effect and vary from state to state. The result is that in situations where an individual requests their information from health care providers in multiple states they may need be aware of these disparate deadlines for responding to requests for medical records. Most importantly, perhaps, is that the express deadlines set seem premised on copying paper records versus affording access to electronic records. Twenty-two states allow doctors and/or hospitals at least 15 days to respond to a request for access to medical records, and 16 states permit at least 30 days. These timeframes may be reasonable for the production of paper copies but they appear lengthy in the context of electronic health records. Some time delay between creation of and individual access to a medical record is valid to ensure record accuracy and an opportunity for the health care provider to discuss the pertinent health information with the individual. However, in an electronic environment it would seem difficult to justify the 30–60 day response times permitted by today’s standards.

3.2.3 Format

HIPAA Privacy Rule

The HIPAA Privacy Rule requires health care providers to provide individuals with access to their protected health information in the form or format requested by the individual if it is readily producible in such format. If the information is not producible in such format, the health care provider must furnish the information in readable, hard copy form [45 C.F.R. § 164.524(c)(2)].

State Laws

The requisite format of health information to be provided to an individual upon request is generally not addressed by state law. A few states—Washington, Wyoming and Montana—have adopted the provisions of the Model Uniform Health Care Information Act of 1985. Under these provisions, if health care providers do not maintain the health information in the particular form requested, they are not required to create a new record or reformulate an existing record. However, upon request, doctors and hospitals must provide an explanation of any code or abbreviation used [Mont. Code Ann. § 50-16-541(2) (2007); Wash. Rev. Code § 70.02.080(2) (2008); and [Wyo. Stat. Ann. § 35-2-611(b) (2008)]. In addition, a few states require doctors and/or hospitals to furnish medical record information in a form that is understandable to the patient. Minnesota and Puerto Rico, for example, require doctors and hospitals to furnish records that are written in terms and language that the patient can reasonably be expected to understand [Minn. Stat. § 144.335; 24 P.R. Laws Ann. § 3043 (2004)]. Most state laws, however, are silent on this issue.

A few states have laws that expressly address individuals' right of access to health information maintained electronically. Georgia law, for example, provides that "Except as provided otherwise under federal law, upon receiving a request for a copy of a record from a patient . . . a provider shall provide copies of the record in either tangible or electronically stored form." [Ga. Code Ann. § 31-33-8 (2008)]. Illinois law is notable for expressly and clearly providing that "Records already maintained in an electronic or digital format must be provided in an electronic format when the patient requests them in that format." [735 Ill. Comp. Stat. 5/8-2001 (2008)]. The law accommodates record systems that do not allow for the creation or transmission of an electronic or digital record by permitting the doctor or hospital to provide paper copies in this situation [735 Ill. Comp. Stat. 5/8-2001 (2008)].

Challenges for an Electronic Environment

Individuals need to be able to understand the health information to which they are afforded access. Terms and codes used in medical records are not readily understood by the average health care consumer. A potential best practice may be requiring health care providers to furnish access to translations of codes or terms used in medical records, as some states already require, and some health care providers already do as a matter of practice (such as by linking medical terms to other medical dictionaries and other informative sites).

Confusion about the need to provide records in an electronic format upon request has surfaced repeatedly, particularly in discussions regarding the population of PHRs. Guidance or statutory or regulatory provisions that clarify this requirement may help alleviate some of this confusion.

3.2.4 Maximum Copying Fees

HIPAA Privacy Rule

The HIPAA Privacy Rule permits health care providers to impose a reasonable cost-based fee for copying protected health information upon an individual's request. The fee may include only the cost of copying, including the cost of supplies for and labor of copying the protected health information as well as postage [45 C.F.R. §164.524(c)(4)]. HHS has explained that because the HIPAA Privacy Rule only permits copying charges, health care providers "may not charge fees for retrieving or handling the information or for processing the request."¹¹ In determining whether fees are reasonable, HHS has stated, "Fees for copying and postage provided under state law are presumed reasonable, but not for other costs excluded under this rule."¹² Even if a fee is reasonable under state law, however, it also must be limited to the health care provider's costs pursuant to the HIPAA Privacy Rule.

State Laws

Almost every state has statutory or regulatory provisions that set the maximum fees doctors or hospitals may charge for providing copies of medical records (see Table A-1). The scope of state copying fee provisions in many states is often broader than that of the HIPAA Privacy Rule. State copying fee laws often apply to requests for records made by persons other than the subject of the health information, including requests made by other health care providers or by lawyers. In fact, some medical record copying fee standards are established in the state's evidentiary code [see, e.g., Ala. Code §12-21-6.1 (2007)].

In setting copying fees for medical records held by doctors and hospitals, laws in many states distinguish between furnishing copies from paper records and copying information in other formats. This report will first address paper records and then will address records in other formats.

Paper Records

A few states set a general "reasonable"-type standard for copying paper records. The vast majority (41), however, establish specific maximum dollar amounts for copying fees that may be imposed (see Table A-1). The method of computing allowable fees varies from state to state. Some states establish one set dollar amount per page (e.g., \$1.00 per page for all pages) [see, e.g., Fla. Stat. Ann. § 395.3025(1) (2008)]. Most state laws establish a sliding fee schedule with the per-page fee declining as the number of pages increases (see generally, Table A-4. Michigan, for example, permits doctors and hospitals to charge \$1.08 per page for pages 1–20; 54¢ per page for pages 21–50, and 22¢ per page for additional pages [see Mich. Comp. Laws § 333.26269 (2008)].

¹¹ *Preamble, Final Rule*, 65 Fed. Reg. 82557.

¹² *Id.*

In addition to per-page copying costs, laws in many states establish an additional flat fee for responding to requests for copies of medical records (see Table A-4). Although various terms are used to describe these fees (e.g., search, retrieval, handling, processing, base charge, preparation), they all appear to serve the same purpose of compensating the doctor or hospital for employee time spent in processing the request for copies of health information. For a summary of the text of these statutes on a state-by-state basis, see Table A-5. Some state medical associations have advised their members that, under the HIPAA Privacy Rule, these fees may not be charged to individuals requesting their own medical records.¹³

The fees that individuals may be required to pay to obtain copies of their records vary widely from state to state. One state, Kentucky, stands out by affording all individuals the right to one free copy of their medical record¹⁴ [see Ky. Rev. Stat. Ann. § 422.317 (2008)]. Most states, however, have fee schedules that allow doctors and hospitals to charge for furnishing copies. Because states have different methods of computing fees, it is difficult—not impossible—to compare statutory provisions across state lines based solely on the language of the law. To provide a consistent method of comparing states' copying fees, we computed sample copy fees based on an individual's request for a one-page record (e.g., an immunization summary) and for a record containing 100 pages. In computing these sample fees, we assumed that the doctor and/or hospital charged the search or handling fee permitted under state law.¹⁵ The fee that an individual would be required to pay for the first page of his or her record ranged from 25¢ to \$40.06. Permitted copy fees for 100 pages ranged from \$23.50 to \$185.42 (see Table A-4).

Non-Paper Formats

In setting copy fees, many states differentiate between paper records and other types of records. In some states, laws that set per-page copying fees for paper records often establish reasonable fees or actual cost-based fees for non-paper records. Some state laws single out x-rays and similar tracings for this distinct treatment. Others broadly apply to "record formats other than paper" or to "materials that cannot be copied on a standard photocopy machine." Compare, for example, Conn. Gen. Stat. §19a-490b(a) (2008) (that establishes a cost-based fee specifically for duplicating x-rays) with Mich. Comp. Laws § 333.26269(1)(c) (2008) (that sets cost-based fees for reproducing any medical record that is in some form or medium other than paper) and Kan. Stat. Ann § 65-4971 (2007) (setting

¹³ The Maryland Board of Physicians notes that the HIPAA Privacy Rule does not allow a charge for a preparation fee for records provided directly to the patient and, therefore, that the \$21.00 preparation fee applies only if the records are sent to another provider. See Maryland Board of Physicians, http://www.mbp.state.md.us/pages/faq_records.htm (accessed September 11, 2008).

¹⁴ Providers may charge \$1.00 per page for additional copies.

¹⁵ This assumption was based on the fact that Georgetown University's Center for Medical Record Rights and Privacy has received a number of calls and e-mails from individuals who claim to have been charged search or retrieval fees when they have requested a copy of their medical record.

reasonable fees for health care record information that cannot be routinely duplicated on a standard photocopy machine).

A few states expressly address copy fees for electronic health information. Illinois sets per-page copying fees for paper records.¹⁶ The Illinois statute then expressly provides that a doctors and hospitals may charge 50 percent of this paper-based per page fee for “electronic records, retrieved from a scanning, digital imaging, electronic information or other digital format in an electronic document.” The electronic per-page charge includes the cost of each CD-ROM, DVD, or other storage media [735 Ill. Comp. Stat. 5/8-2001 (2008)]. In contrast, Ohio law, while recognizing the existence of electronic data, makes no distinction between paper and electronic records for purposes of copying fees. Under Ohio law, doctors and hospitals may charge the same per-page fee¹⁷ for data recorded electronically or on paper [Ohio Rev. Code § 3701.741(A) & (B)(1) (2008)]. It is interesting to note that under either of these fee schedules, an individual could potentially pay more than \$25.00 to obtain 10 pages of electronic health information.

Copying fees may prove to be prohibitively expensive for people who need medical records to support their claims or appeals related to Social Security disability or similar benefits. At least 15 states address this issue by requiring doctors and/or hospitals to furnish free copies of medical records requested to support such claims or appeals (see Tables A-4 and A-5). Individuals are typically limited to one free copy and often must provide verification of their application or appeal [see, e.g., Mass. Gen. Laws ch. 112, § 12CC (2008); Minn. Stat. § 144.292, subd. 6(d) (2007); Nev. Rev. Stat. § 629.061 (2007)].

Challenges for an Electronic Environment

High copying costs may deter individuals from accessing their own health information. Search and retrieval fees that are permitted under state law may add a significant amount to the cost of obtaining copies. More states should clarify that these fees may not be charged by HIPAA-covered entities.

It would be reasonable to assume that copying costs should decline as medical records are moved into electronic format. However, existing state laws setting medical record copying fees appear to be largely based on furnishing copies of paper records. Few state laws address whether these fees are applicable to requests for copies of health information in electronic format.¹⁸ As more health care providers adopt electronic health records, it may be

¹⁶ The maximum copying fees permitted for paper records in Illinois are: \$23.78 for handling and mailing; and 89¢ per page for pages 1–25; 59¢ per page for pages 26–50; and 30¢ per page for additional pages [735 Ill. Comp. Stat. 5/8-2001 (2008)].

¹⁷ Copying fees are \$2.74 per page for the first 10 pages; 57¢ per page for pages 11–50; and 23¢ per page for additional pages.

¹⁸ The lower costs of providing medical records in electronic format may mean that a health care provider must charge less for such access due to the HIPAA Privacy Rule’s provision that fees be both reasonable and cost-based.

appropriate for states to reevaluate their fee schedules to determine whether the permitted fees make sense in an electronic environment.

3.2.5 Medical Record Retention Period Requirements

HIPAA

The HIPAA Privacy Rule does not set standards for the retention of medical records.

State Law

Nearly every state has statutes or regulations that set medical record retention requirements for medical doctors and/or hospitals. Forty-five states have such express requirement for hospitals, and 27 states have similar provisions for medical doctors. State laws vary widely with respect to required retention periods. For hospitals, state laws impose retention periods ranging from 5 years from the date of discharge to “permanently,” for adult records. A 10-year retention period is the mode for hospitals. Medical doctors are generally required to keep records for shorter periods of time. State record retention requirements for doctors range from 3 to 10 years, with a mode of 7 years (see Table A-6).

Retention periods for adult patient records are usually computed from the last date of services (for doctors) or the date of discharge (for hospitals) (see Table A-7). Retention periods are often based on the state statutes of limitations for negligence actions; see, for example, Ala. Admin. Code r. 545-X-4-.08 (2007) (providing that doctors should maintain records “[a]s long as may be necessary to treat the patient and for medical legal purposes”).

Records for minor patients generally must be kept for a longer period of time, usually computed from the date the minor attains his or her majority. In New York, for example, hospitals must retain records of adult patients at least 6 years from the date of discharge. The records of minor patients must be retained either 6 years from the date of discharge or 3 years after the patient reaches age 18, whichever is longer [N.Y. Comp. Codes R & Regs. tit. 10 § 405.10 (a)(4) (2008)]. Approximately 20 other states have similar frameworks that, as a practical matter, provide longer retention periods for minor patient records (see Table A-7). These longer timeframes for retaining minor patient records are tied to the tolling of state statutes of limitations for negligence actions while a person is a minor.¹⁹

A few states establish a two-tiered system for retaining medical records. Full records may be destroyed after a specified number of years provided that summary or core information

¹⁹ The statute of limitations for bringing a negligence action is generally tolled (suspended) while a patient is a minor. Once the minor reaches the age of majority, the statute of limitations for such actions generally begins to run. In other words, the provider must maintain the medical records of minor patients until the patient is no longer able to sue for negligence. See generally, The American Health Information Management Association, *Practice Brief Retention of Health Information*, available at http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_012545.hcsp?dDocName=bok1_012545 (last updated June 2002).

is retained longer. For example, Hawaii law provides that medical records may be destroyed after 7 years provided that the doctor or hospital retains specified basic information (e.g., diagnoses, discharge summary) for 25 years [Haw. Rev. Stat. § 622-58 (2008)]. Additional examples are Kan. Admin. Regs. § 28-34-9a(d)(1) (requiring hospitals to retain the full record for 10 years and a summary record for 25 years) and Mont. Admin. R. § 37.106.402(1), (4) (2008) (permitting hospitals to abridge a medical record after 10 years to form a core medical record that must be retained an additional 10 years). These provisions demonstrate the approach some states employ to strike a balance between the need for key health information and the practical aspects of retaining vast volumes of data.

Challenges for an Electronic Environment

One of the anticipated benefits of electronic health records is the potential for a lifelong longitudinal record. The relatively short period medical records must be retained in some states (some as short as 3 years) may hamper this potential benefit.

In addition, differing state record retention requirements may pose a problem with ensuring the accuracy and completeness of electronic health records because records likely will not be retained for consistent periods of time. Difficulties may be exacerbated in federated systems, where records remain at their original source. For example, records from the same episode of care may be maintained in multiple states with different record retention requirements. Even though the records were created at the same time, they likely will not be retained for the same period of time. When records regarding the episode of care are requested at a later date, it is possible that the requesting party may (knowingly or unknowingly) receive only *some* of the relevant records, others having been deleted or destroyed as permitted by shorter retention requirements. The result can be an incomplete, potentially misleading, medical record that may lead to inappropriate care.

It may be useful to reevaluate whether the statute of limitations for negligence actions should be the primary factor underlying medical record retention standards. Perhaps it is time to focus on the potential need of the medical record for care over the life expectancy of the populace, along with the decreasing costs associated with retaining records in electronic versus paper or microfiche format.

Encouraging the use of PHRs, where consumers control their own records, may also help alleviate potential issues regarding medical record retention.

3.2.6 Access to Minors' Health Information

Some of the more complex issues arising from the right of access to medical records occur regarding records of minor patients. When parents consent to care for minor children, the parents generally have the rights associated with the medical records. The issue becomes much more complicated when minors lawfully consent to their own care.

HIPAA Privacy Rule

Generally, an individual who is an adult or an emancipated minor has the right of access to his or her own medical record. With respect to unemancipated minors, the HIPAA Privacy Rule defers to state or other applicable laws that address the ability of a parent, guardian, or other person acting *in loco parentis* (collectively, “parent”) to obtain health information about a minor child. In most cases, parents have the authority to make health care decisions about their minor children. When this is the case, under the HIPAA Privacy Rule, the parent is the “personal representative” of the minor child and can exercise the rights about the minor’s protected health information.

However, there are times when a parent is not the personal representative for certain health information about a minor child. These exceptions generally track the ability of certain minors to obtain specific types of health care without parental consent under state or other laws, or standards of professional practice. In specific, the HIPAA Privacy Rule provides that the parent is not the minor’s personal representative in the following three circumstances:

- 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;
- when a court determines or other law authorizes someone other than the parent to make treatment decisions for a minor; or
- when a parent agrees to a confidential relationship between the minor and the health care provider.

When a minor obtains health care services under any of these three circumstances, the minor generally has the authority to control the health information related to such services. However, this does not mean that the minor has total control over this health information. For more details about these guidelines, see 45 C.F.R. § 164.502(g)(3)(ii) and Office for Civil Rights, HHS, *Guidance on Personal Representatives* (April 3, 2003), available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/personalrepresentatives.pdf>.

Health care providers may also disclose or grant access to information related to such health care to the minor’s parents in certain circumstances. When minors obtain health care in the above circumstances, the HIPAA Privacy Rule defers to state (or other) law with respect to whether a health care provider may or must disclose or grant access to information related to such treatment to parents. Under the HIPAA Privacy Rule if state law:

- permits or requires a health care provider to disclose or provide access to such information to a parent, then the provider may disclose or provide access to the parent;

- prohibits providing access or disclosing to the parent, then the health care provider may *not* disclose or provide the parent access to such information; and
- is silent or unclear about parental access, the health care provider may use professional judgment to decide if the parents may have access.

See 45 C.F.R. § 164.502(g)(3)(ii) and Office for Civil Rights, HHS, *Guidance on Personal Representatives*, (April 3, 2003), available at: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/personalrepresentatives.pdf>.

State law, therefore, largely determines whether parents may or must be notified of a minor's health condition treatment or allowed access to the minor's related health information.

State Laws

State law determines when and if minors may consent to their own health care services.²⁰ Many states also have statutes addressing when a health care provider²¹ may or must notify the parents of the minor's health condition or treatment as well as who has the right of access to a minor's record in this circumstance (see Table A-8).

The ability of a health care provider to inform or notify a parent that a minor needs care is distinct from the parents' right of access to the minor's medical record. Health care provider notification generally (but not always) is at the discretion of the health care provider, who may, using professional judgment determine whether information should be disclosed to the minor's parents and the timing and extent of such disclosure. In contrast, the right of access generally gives the parent, the right to examine and copy the minor's entire medical record upon request.²²

This section of the report first discusses the age of majority, as well as emancipation, to address the point of delineation when persons most often have/do not have the capacity to consent to their own health care. The report is then divided into subsections organized along the following topics:

- general health care based on life circumstances or status,
- testing and treatment for an STD and HIV/AIDs (often treated separately),
- outpatient mental health treatment, and
- outpatient alcohol and substance abuse treatment.

²⁰ See Methodology in previous section for a description of the limited issues addressed in this section.

²¹ As used in this section, the term "health care provider" is broader than doctors and hospitals. We use this term because we found that, unlike record retention or general access statutes, state law addressing minors' right to consent to health care services often was not readily categorized as applying to doctors or hospitals.

²² The provider, of course, has a limited ability to deny access under the Privacy Rule.

Under each of these subsections, the report first discusses the minor’s right to consent to treatment under state law, and then turns to the health care providers’ discretion to notify parents of the treatment needed or sought and the parents’ right of access to health information related to the treatment.

Age of Majority and Emancipation

Minors are presumed to lack the capacity to make health care decisions. Accordingly, health care providers are generally required to secure parents’ consent to treat minor children.²³ Traditionally, there have been exceptions to this general rule such as for medical emergencies when there is no time to obtain parental consent.²⁴

Once individuals reach the age of majority, they generally may consent to their own health care. In the vast majority of states, individuals attain the age of majority at 18. The exceptions are Alabama and Nebraska, where the age of majority is 19, and Mississippi, Pennsylvania, and Puerto Rico, where the general age of majority is 21 [Ala. Code § 26-1-1(a) (2008); Neb. Rev. Stat. § 43-2101 (2008); Miss. Code Ann. § 1-3-27; (2008); P.R. Laws Ann. tit. 31, § 971 (2005)].

Emancipated minors generally are deemed to have the full rights of adults to make decisions on their own behalf. The laws of many states establish formal court proceedings through which minors may become emancipated [see, e.g., Me. Rev. Stat. Ann. tit. 15, § 3506-A (2008); N.M. Stat. Ann. § 32A-21-3 (2008) and Table A-9]. In some states, minors may also become emancipated by virtue of marriage, by joining the armed services, or in other circumstances [see e.g., S.D. Codified Laws § 25-5-24 (2008); see also Table A-9 for more examples]. Courts may also determine that a minor is emancipated based on common law principles.²⁵

Right to Consent to Care Based on Life Status or Circumstances

In many states, minors, while not technically emancipated, may consent to their own health care based on their life status or circumstances. For example, several states have laws that provide that minors who are married or who are living apart from their parents and managing their own financial affairs may consent to their own health care²⁶ [see, e.g., Burns Ind. Code Ann. § 16-36-1-3 (2008); Alaska Stat. § 25.20.025 (2008)]. In a few states, a minor has the right to consent to care based solely on the minor’s age. For

²³ See generally, Hartman, R. G. (2001). “Adolescent Decisional Autonomy for Medical Care: Physician Perceptions and Practices.” 8 *University of Chicago Law School Roundtable* 87.

²⁴ Boonstra, H. and Nash, E. (2000, August). “Minors and the Right to Consent to Health Care.” *The Guttmacher Report on Public Policy*. Some states have codified this emergency exception (see Table A-9).

²⁵ This project did not research common law principles, but mentions them here to provide wider context of the issues.

²⁶ Note that in some states these circumstances would qualify the minor as being fully emancipated. Thus, while the HIPAA Privacy Rule clearly distinguishes between the rights of emancipated and unemancipated minors, the line is not drawn nearly so clearly by state law.

example, although the age of majority is 19 in Alabama, a minor in that state who is 14 or older may consent to any medical, dental, health or mental health services [Ala. Code § 22-8-3 (2008)]. Similarly, minors in Oregon who are 15 or older may consent to hospital care, medical, dental, or surgical diagnosis [Or. Rev. Stat. § 109.640 (2007)]. See also 35 Pa. Stat. Ann. § 10101 (2008) (providing that minors 18 and older may consent to health care, although the age of majority is 21). In a few other states, any minor who has the maturity to comprehend the nature of and risks inherent in the proposed health care has the right to consent to that care [see Idaho Code § 39-4503 (2008); Ark. Code. Ann. § 20-9-602 (2008)].

Of the 30 states that permit minors to consent based on their life status or circumstance,²⁷ 13 states have laws that expressly permit the health care provider to notify the parents of treatment given or needed by the minor [see, e.g., Ky. Rev. Stat. Ann. § 214.185(6) (2008)]. In eight states,²⁸ parents do not have the right of access to the minor's records related to treatment obtained in these circumstances [see, e.g., Md. Code Ann., Health-Gen. § 4-301(k)(4)(ii) (2008); Cal. Health & Safety Code §§ 123110(a) (2008); 123115(a) (2008)]. Several of these states have both types of provisions, i.e., the law permits the health care provider to inform the parents of treatment but does not give the parent the right to access the minor's health information. This structure essentially leaves it to the health care provider's discretion to determine the appropriate level of information to share.

Sexually Transmitted Disease and HIV/AIDS

Every state permits minors to consent to testing and treatment for an STD (see Table A-8). Thirty-three of these states expressly include the right to consent to testing and treatment for HIV/AIDS, while an additional three (Connecticut, New Mexico, and New York) permit minors to consent to testing, but not treatment for HIV without parental consent [see Conn. Gen. Stat. § 19a-582(a) (2008); Conn. Gen. Stat. § 19a-592(a) (2008); N.M. Stat. Ann. § 24-2B-3 (2008); and N.Y. Pub. Health Law § 2781 (2008)]. Some states permit health care providers to test and or treat minors for venereal disease or an STD without expressly referring to HIV (either in the statute itself or in related regulations that either implement the provision or generally define terms), although presumably the condition is included.

Most states (21) permit minors to consent to treatment and testing for these conditions without setting age limits. Twelve states, however, expressly establish age limits on minors for testing and treatment of an STD, ranging from 12 years to 16 years, with 14 years being the mode [see, e.g., N.J. Stat. Ann. § 9:17A-4 (2008) (allowing minors 13 and older to consent to testing and treatment for HIV)].

²⁷ This figure does not include states that permit providers to furnish care without parental consent in emergency situations or when the provider is unable to contact the parents to obtain consent, as these "emergency" exceptions may trigger different notification requirements.

²⁸ California, Indiana, Maine, Maryland, Minnesota, Montana, and New York.

In 26 states the health care provider may or must notify the parents of treatment given to or needed by a minor who seeks testing or treatment for an STD (including HIV) on his or her own. One jurisdiction, Iowa *requires* a health care provider to notify parents of a positive HIV test²⁹ [Iowa Code § 141A.7(3) (2008)]. In 14 other states, the health care provider has broad discretion to notify the parents of treatment “given or needed” [see, e.g., Ark. Code Ann. § 20-16-508 (2008)].

Yet other states restrict notification to situations where the condition will seriously jeopardize the minor’s health or where notification is essential to the life or health of the minor. For example, Missouri, Montana, and Oklahoma permit the health care provider to notify the parents of the minor’s testing or treatment if the minor has tested positive for any STD while New Hampshire permits such notification only with respect to a positive HIV test. In all these states, if the test result is negative, the health care provider is prohibited from disclosing any information related to testing to the parents [see, e.g., Mo. Rev. Stat. § 431.062(3) (2008); Mont. Code Ann. § 41-1-403 (2007); Okla. Stat. tit. 63, § 2602(A)(3) (2008)].

Just two jurisdictions, Florida and Guam, have statutory provisions expressly prohibiting health care providers from informing the parents of the minor’s STD-related testing or treatment without the minor’s consent [see Fla. Stat. Ann. § 384.30(2) (2008) and Guam Code Ann. tit. 19, § 1111(c) (2007)].

Laws in 16 states expressly provide that the minor, not the parent, has the right of access to health information or records related to testing or treatment for which the minor has consented [see Md. Code Ann. § 50-16-521 (2008)]. A number of these states (9) simultaneously give the health care provider the discretion to notify the parents of the testing or treatment if appropriate [see Md. Code Ann. § 50-16-521 (2008)]. However, the laws of the majority of states that afford minors the right to consent to testing and treatment for STDs/HIV are silent about who has the right of access to records related to such testing or treatment.

Outpatient Mental Health

Twenty-eight states have statutes and/or regulations that expressly permit minors to consent to outpatient mental health treatment (see Table A-8). Nineteen of these states expressly set minimum age limits for a minor to consent to outpatient mental health treatment, ranging from 12 years to 16 years, with 14 years being the mode [see, e.g., Tenn. Code Ann. §§ 33-1-101 (2008); 33-8-202 (2008); Ala. Code 22-8-4 (2008); and Fla. Stat. Ann. § 394.4784]. Six states limit the minor’s right to consent without parental permission to verbal therapy and expressly exclude medication (or psychotropic medication,

²⁹ The District of Columbia requires notification of a positive STD test, but only when the minor refuses treatment [see D.C. Mun. Regs. tit. 22, § 602.7 (2008)].

more specifically) [see, e.g., D.C. Code § 7-1231.14(b); D.C. Mun. Regs. tit. 22, § 600.7 (2008); and Ohio Rev. Code § 5122.04(A), (B) (2008)].

In 18 states the health care provider may or must notify the parents of treatment given to or needed by a minor who seeks outpatient mental health treatment on his or her own. In four of these states, the health care provider has broad discretion to notify the parents of treatment “given or needed” [see, e.g., Ky. Rev. Stat. Ann. § 214.185(6) (2008)]. Eight states restrict notification to situations where there is a need to disclose based on potential harm to the life or health of the minor (or similar standards) [see, e.g., N.C. Gen. Stat. § 90-21.4 (2008)]. One state, Kansas, generally *requires* health care providers to notify parents when a minor obtains outpatient mental health care without parental consent, and two others, California and Oregon, require the health care provider to involve the parents in the treatment unless inappropriate [see Kan. Stat. Ann. § 59-2949 (2007); Kan. Op. Att’y Gen. 2004-22 (2004); Cal. Fam. Code § 6924(d) (2008); and Or. Rev. Stat. § 109.680 (2007)].

Two jurisdictions, the District of Columbia and Connecticut,³⁰ expressly provide that a health care provider generally may not notify a parent of such treatment or disclose any information related to the treatment without the consent of the minor [see D.C. Code §§ 7-1202.01 (2008); 7-1201.02 (2008); 7-1202.05 (2008); and Conn. Gen. Stat. §§ 19a-14c (2008); 20-7c(c) (2008)].

Laws in six states expressly provide parents at least a limited right of access to records related to outpatient mental health treatment for which a minor has consented [see, e.g., 740 Ill. Comp. Stat. 110/2 (2008) and 110/4 (2008); and Minn. Stat. § 144.294, subd. 3(a) (2007)]. Three of these states give parents the right of access to summary information, such as diagnosis and medications [see, e.g., Fla. Stat. Ann. §§ 394.4615 (2008)].

Two states give parents the right of access to medical records when the minor is below a specified age. In New York, parents have the right of access to the minor’s records when the minor who has consented to treatment is under 12 [N.Y. Mental Hygiene Law § 33.16(c)(3) (2008)]. In New Mexico, the parents have a similar right of access when the minor is under 14 [N.M. Stat. Ann. § 32A-6A-24(C) (2008)].

Laws in nine states expressly provide that the minor, not the parent, has the right of access to health information or records related to outpatient mental health treatment for which the minor has consented [see, e.g., Md. Code Ann. Health-Gen. § 4-301(k)(4)(1) (2008)]. Four of these states simultaneously give the health care provider the discretion to notify the parents of the treatment if appropriate [Md. Code Ann. Health-Gen. § 4-301(k)(4)(1) (2008)]. However, the laws of half of the states that afford minors the right to consent to

³⁰ In Connecticut, a minor generally may consent only to a limited number of outpatient sessions without parental involvement unless the provider determines it would be contrary to the patient’s treatment.

outpatient mental health treatment are silent about who has the right of access to records related to such treatment.

Outpatient Alcohol and Substance Abuse Treatment

The vast majority of states (48) have statutes and/or regulations that expressly permit minors to consent to outpatient treatment for alcohol and substance abuse (see Table A-8). Fifteen of these states expressly set minimum age limits for a minor to consent to outpatient alcohol or substance abuse treatment with 12 years as the mode (see Table A-8).

Twenty-five states have laws expressly providing that the health care provider may notify the parents of treatment given to or needed by a minor who seeks outpatient treatment for alcohol or substance abuse [see, e.g., Ga. Code Ann. § 37-3-8(c) (2008) and Haw. Rev. Stat. § 577-26(a) (2008)]. Seven states generally prohibit health care providers from notifying parents of such treatment [see, e.g., Conn. Gen. Stat. § 17a-688(d) (2008) and Iowa Code § 125.33 (2008)].

Laws in 17 states expressly provide that the health care provider may not disclose information to parents without the minor's consent [see, e.g., D.C. Mun. Regs. tit. 22, § 602.5 and § 602.6 (2008) and Fla. Stat. Ann. § 397.501(e)(1) (2008)]. Seven states expressly direct health care providers to disclose such information only in accordance with federal law (or in accordance with 42 C.F.R. part 2) [see, e.g., 20 Ill. Comp. Stat. 301/30-5(bb) (2008) and Burns Ind. Code Ann. § 16-39-1-9 (2008)].

Challenges for an Electronic Environment

State laws governing minors' ability to consent to health care and the right to disclose or access related health information are complex and are a challenge to implement electronically.

Age of consent to treatment and the related right of access to the related medical record varies from state to state and by medical condition. A parent might have the right of access to the general medical care of a minor, but not the right of access to information related to specific treatment within the same record. It is not surprising that some health care providers have found it difficult to implement electronic health records with respect to adolescents.³¹

To resolve these issues, the American Academy of Pediatrics recently suggested that electronic health record systems be able to support privacy policies that vary by age and according to presenting problem and diagnosis. The Academy recommended that such systems be able to separate information. To the extent a system is able to record consent

³¹ Landro, L. (Aug. 24, 2005). "Parents Barred from Teen Health Files." *The Wall Street Journal*.

for treatment, they recommended that it should be able to record when consent is provided by a minor versus the minor's parents.³²

The Substance Abuse and Mental Health Services Administration and the Veterans Administration are currently collaborating with HL7 and HITSP to explore options for some of these technical issues, including the segregation of data and the management of individuals' consents to disclose information.³³ These efforts may identify solutions that would alleviate some of the difficulties identified with managing minors' health records electronically.

³² Gotlieb, E. (July 31, 2008). Testimony before the U.S. House of Representatives Committee on Small Business, "Cost versus Confidentiality: The Unforeseen Challenges of Electronic health Records in Small Business Practices." On behalf of American Academy of Pediatrics.

³³ See, e.g., HL7 DataConsent Models, available at http://www.hl7.org/v3ballot2008SEP/html/domains/uvmr/uvmr_DataConsent.htm#RCMR_DO000010UV-Consent-ic
http://www.hl7.org/v3ballot2008SEP/html/domains/uvmr/uvmr_CompositePrivacyConsentDirective.htm#RCMR_DO000010UV-Privacyconsent-ic

4. CONCLUSION

Most state medical record access laws are designed to address records maintained in paper format. Many of the statutes and regulations do not truly facilitate, and in fact may impede, individuals' ability to obtain their health information in electronic format. In specific, record retention requirements are relatively short in lieu of the goal to furnish individuals with a longitudinal record. The relatively long time frame for responding to individuals' requests, while appropriate for paper records, does not reflect expectations for the accessibility of electronic information. Most relevant statutes and regulations do not expressly require health care providers who maintain health information electronically to furnish it in that format. In light of these factors, as more health care providers begin to maintain health information electronically, serious consideration should be given to reviewing and revising state medical record access laws so that they better comport with an electronic environment.

State laws that govern the rights of access to minors' health information when minors lawfully consent to treatment without the permission of their parents present particular challenges to electronic health information exchange. These laws are often tied to the minors' ability to consent to treatment for serious, sensitive health conditions such as an STD, mental health issues, or for alcohol and substance abuse. Not surprisingly, the access records laws pose some of the same issues as laws that address the disclosure of records related to adult sensitive medical conditions, such as the ability to segregate specific information in a record. Technical solutions are being developed to address some of these issues. Health care systems that have already begun to confront these issues in an electronic environment may be able to offer insight into practical solutions.

APPENDIX A: OVERVIEW AND DETAILED TABLES

- A-1a. General Overview of State Medical Records Access Laws: Medical Doctors
- A-1b. General Overview of State Medical Records Access Laws: Hospitals
- A-2a. Overview of Maximum Time Permitted Under State Laws for Medical Doctors to Respond to Patient Requests for Medical Records
- A-2b. Overview of Maximum Time Permitted Under State Laws for Hospitals to Respond to Patient Requests for Medical Records
- A-3. Maximum Time Permitted Under State Laws for Doctors and Hospitals to Respond to Patient Requests for Medical Records
- A-4. Overview: State Law, Maximum Fees Doctors and Hospitals May Charge Patients for Copies of Medical Records
- A-5. Overview of State Law: Maximum Fees Doctors and Hospitals May Charge Patients for Copies of Medical Records
- A-6a. Overview: State Medical Record Laws: Minimum Number of Years Adult Patient Medical Records Must Be Retained by Medical Doctors
- A-6b. Overview: State Medical Record Laws: Minimum Number of Years Adult Patient Medical Records Must Be Retained by Hospitals
- A-7. State Medical Record Laws: Minimum Medical Record Retention Periods for Records Held by Medical Doctors and Hospitals
- A-8a. Overview: State Laws Expressly Granting Minors the Right to Consent to Health Care without Parental Permission and Addressing Disclosure of Related Health Information to Parents—Sexually Transmitted Disease and HIV/AIDS
- A-8b. Overview: State Laws Expressly Granting Minors the Right to Consent to Health Care without Parental Permission and Addressing Disclosure of Related Health Information to Parents—Outpatient Mental Health
- A-8c. Overview: State Laws Expressly Granting Minors the Right to Consent to Health Care without Parental Permission and Addressing Disclosure of Related Health Information to Parents—Outpatient Alcohol and Substance Abuse
- A-9a. State Laws Expressly Granting Minors the Right to Consent to Health Care without Parental Permission and Addressing Disclosure of Related Health Information to Parents Based on Life Circumstances or Status
- A-9b. State Laws Expressly Granting Minors the Right to Consent to Health Care without Parental Permission and Addressing Disclosure of Related Health Information to Parents Based on Sexually Transmitted Disease and HIV/AIDS
- A-9c. State Laws Expressly Granting Minors the Right to Consent to Health Care without Parental Permission and Addressing Disclosure of Related Health Information to Parents Based on Outpatient Mental Health
- A-9d. State Laws Expressly Granting Minors the Right to Consent to Health Care without Parental Permission and Addressing Disclosure of Related Health Information to Parents Based on Outpatient Alcohol and Substance Abuse

APPENDIX B: DATA COLLECTION TOOL

- B-1a. Data Collection Tool: [Insert State Name] Laws Giving Individuals Right to Access Medical Records [Insert Date]
- B-1b. Data Collection Tool: [Insert State Name] Laws Giving Individuals Right to Amend Medical Records [Insert Date]