

APPENDIX C: Significance of the HIPAA Privacy Rule for Health Care of Adolescents

What are the federal medical privacy regulations?

The “Standards for Privacy of Individually Identifiable Health Information” are federal medical privacy regulations (often referred to as the “HIPAA Privacy Rule”) that broadly regulate access to and disclosure of confidential medical information. These regulations were promulgated by the Department of Health and Human Services (HHS) pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

When was the HIPAA Privacy Rule issued?

Proposed regulations were initially published in November 1999. Following the submission of thousands of comments, a final rule was published on December 28, 2000. The effective date of this final rule was postponed until April 14, 2001. Proposed modifications were published in March 2002. Following a public comment period, final modifications were issued on August 14, 2002.

What is the scope of the HIPAA Privacy Rule?

The HIPAA Privacy Rule addresses a broad range of issues related to the privacy of individuals’ health information. The Rule creates new rights for individuals to have access to their health information and medical records. It also specifies when an individual’s authorization is required for disclosure of confidential health information, referred to as “protected health information,” and when protected health information may be used or disclosed without authorization. The regulations also contain provisions that are specific to the health information of minor children.

Who must comply with the HIPAA Privacy Rule?

The HIPAA Privacy Rule applies to “covered entities,” which include health plans, health care providers, and health care clearinghouses. According to the way each of these is defined, the vast majority of health care professionals who provide care to adolescents are required to comply with the HIPAA Privacy Rule.

What is the implementation date for the HIPAA Privacy Rule?

Large health plans, health care providers, and health care clearinghouses were required to comply with the rules by April 14, 2003. Small health plans were required to comply with the rules by April 14, 2004.

Do the general requirements of the HIPAA Privacy Rule apply to the care of adolescents?

The HIPAA Privacy Rule contains numerous provisions that affect the confidentiality of information regarding health care provided to adolescents. Most of the general provisions of the HIPAA Privacy Rule are relevant, even though they are not specific to adolescents. They also are applicable to information about health care that is provided to younger children and to adults. Adolescents who are age 18 or older are adults and have the same rights under the Privacy Rule as other individuals who are adults. In addition, there are provisions of the Rule that address the specific issues related to the health information of minors, including adolescents who are under the age of 18 and not emancipated.

When may protected health information be used or disclosed without an individual’s authorization?

Generally, the HIPAA Privacy Rule permits a covered entity to use and disclose an individual’s protected health information without the individual’s permission for treatment, payment, or health care operations of its own. A covered entity may also disclose protected health information without an individual’s permission to other covered entities under specific circumstances. In particular, information may be disclosed to a health care provider for treatment or payment activities and in other specified situations.

Does the HIPAA Privacy Rule have special requirements that apply to public health?

Many public health agencies, organizations, and practitioners are covered entities under the HIPAA Privacy Rule and are required to comply with the Rule generally. The Privacy Rule also contains specific public health provisions. In particular, The HIPAA Privacy Rule allows covered entities to disclose an individual’s protected health information without the individual’s authorization for the purpose of controlling disease, injury, or disability. This

includes reporting of disease, injuries, births, and deaths, as well as conducting public health surveillance, investigations, and interventions.

Does the HIPAA Privacy Rule have special requirements that apply to research?

The HIPAA Privacy Rule contains numerous provisions that may affect the conduct of research. Researchers need to understand the relationship between the HIPAA Privacy Rule and the HHS and FDA Protection of Human Subjects regulations (45 CFR Part 46 and 21 CFR Parts 50 and 56). In addition there are important issues to understand about the specific application of the Privacy Rule to research. De-identified health information is not protected health information under the Rule. Protected health information may be used and disclosed for research with the written permission or authorization of the individual. In limited circumstances, protected health information may be used in research without an individual's authorization.

Does the HIPAA Privacy Rule have special requirements that apply to information in schools?

The HIPAA Privacy Rule specifies that information covered by the Federal Educational Rights and Privacy Act (FERPA) is not considered protected health information for purposes of the Privacy Rule. FERPA generally applies to information contained in a student's educational record, including some health information. However, some information in schools is protected under the Privacy Rule.

How does the HIPAA Privacy Rule treat adolescents who are minors and their parents?

When adolescents are unemancipated minors, their parents (including guardians and persons acting *in loco parentis*) generally are considered their "personal representatives." As personal representatives, parents exercise any rights under the Rule with respect to the minors' protected health information, including the right to access that information. However, parents are not automatically treated as the personal representatives of unemancipated minors who are considered "individuals" under the HIPAA Privacy Rule.

When is a minor an "individual" under the HIPAA Privacy Rule?

A minor is considered an individual under the HIPAA Privacy Rule in one of three specific circumstances. The first situation is one in which the minor has the right to consent to health care and has consented, such as when a minor has consented to treatment of an STI under a state minor consent law. The second situation is one in which the minor may legally receive the care without the consent of a parent, and the minor or another individual or a court has consented to the care, such as when a minor has requested and received court approval to have an abortion without parental consent or notification. The third situation is one in which a parent has assented to an agreement of confidentiality between the health care provider and the minor. In each of these circumstances, the minor is treated as the "individual" who may exercise rights under the Privacy Rule and the parent is not the personal representative of the minor. In these circumstances, the minor also may choose to have the parent act as the personal representative or not.

What happens when a minor is the individual and the parent is not the personal representative?

When a minor is the individual and a parent is not the personal representative of the minor, the minor may exercise most of the same rights as an adult under the regulations. With respect to the specific question of whether a parent who is not the personal representative of the minor may have access to the minor's protected health information, the regulations defer to state or other applicable law. If state or other law explicitly requires information to be disclosed to a parent, the regulations allow a health care provider to comply with that law and to disclose the information. If state or other law explicitly permits, but does not require, information to be disclosed to a parent, the regulations allow a health care provider to exercise discretion to disclose or not. If state or other law prohibits disclosure of information to a parent without the consent of the minor, the regulations do not allow a health care provider to disclose it without the minor's consent. If state or other law is silent or unclear on the question, a covered entity has discretion to determine whether or not to grant access to a parent to the protected health information. In such cases the determination must be made by a health care professional exercising professional judgment.

What does the HIPAA Privacy Rule mean for health care providers in a specific state?

Every state has numerous laws that allow minors to give their own consent for health care. In addition, some states have laws that specify the circumstances under which parents may or may not have access to information regarding the care for which minors may give their own consent. The federal privacy regulations defer to those laws, and other laws, to the extent that they prohibit, permit, or require disclosure of information to parents. In particular, if state or other law is silent or unclear on the issue of parents' access to minors' confidential information, covered entities, including health providers, have discretion to determine whether or not to grant access to parents, as long as the decision is made by a health care professional exercising professional judgment. For adults, including adolescents age 18 or older, the federal regulations defer to state laws that provide stronger privacy protections than the federal rules, but if state laws provide weaker protection, the federal rules control.

What happens if a parent is suspected of domestic violence, abuse, or neglect?

When a parent is suspected of domestic violence, abuse, or neglect of a child, including an adolescent, a health care provider may limit the parent's access to and control over protected health information about the child by not treating the parent as the personal representative of the child.

How does a health care provider know what is required?

This overview does not provide legal advice. Health care providers should consult with legal counsel to understand how the HIPAA Privacy Rule applies to them and how to comply with the Rule.

Where can additional information about the HIPAA Privacy Rule be found?

REGULATIONS

- ❑ **Standards for Privacy of Individually Identifiable Health Information. 45 C.F.R. Parts 160 and 164.** This is the official codified version of the HIPAA Privacy Rule.
- ❑ **Standards for Privacy of Individually Identifiable Health Information. Final Rule, 65 Federal Register 82461 (Dec. 28, 2000).** This is the final rule issued in December 2000, including the extensive commentary from the Department of Health & Human Services that accompanied the rule itself.
- ❑ **Standards for Privacy of Individually Identifiable Health Information. Final Rule, 67 Federal Register 53182 (Aug. 14, 2002).** This is the final rule issued in August 2002 that contains the modifications to the December 2000 version, including the extensive commentary from the Department of Health & Human Services that accompanied the rule itself.
- ❑ **U.S. Department of Health and Human Services, Office for Civil Rights. Regulation Text. (45 CFR Parts 160 and 164) (Unofficial Version). Available at: <http://www.hhs.gov/ocr/combinedregtext.pdf>.** This is the unofficial merged version of the HIPAA Privacy Rule, the Security Standards, and General Administrative Requirements that have been officially codified in Title 45 of the Code of Federal Regulations, Parts 160 and 164.

WEBSITES

- ❑ CDC. <http://www.cdc.gov/privacyrule/>
- ❑ Health Privacy Project. <http://www.healthprivacy.org/>
- ❑ NIH. <http://privacyruleandresearch.nih.gov/>
- ❑ Office for Civil Rights. <http://www.hhs.gov/ocr/hipaa/>
- ❑ Note: Many of the organizations whose policies appear in this Compendium have posted materials about the HIPAA Privacy Rule on their websites. The addresses of those websites are included in Appendix A.

SUMMARIES

- ❑ Health Privacy Project. Summary of HIPAA Privacy Rule. Available at: http://www.healthprivacy.org/usr_doc/RegSummary2002.pdf.
- ❑ Office for Civil Rights, U.S. Department of Health and Human Services. OCR Privacy Brief: Summary of the HIPAA Privacy Rule. Available at: <http://www.hhs.gov/ocr/privacysummary.pdf>.

BOOKS, MONOGRAPHS, AND ARTICLES

- ❑ Centers for Disease Control and Prevention. HIPAA Privacy Rule and public health: Guidance from CDC and the U.S. Department of Health and Human Services. *MMWR* 2003; 52(Suppl):1-12.
- ❑ National Institutes of Health, U.S. Department of Health and Human Services. Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule. NIH Publication Number 03-5388. Available at: <http://privacyruleandresearch.nih.gov/>.
- ❑ English A, Ford CA. The HIPAA Privacy Rule and Adolescents: Legal Questions and Clinical Challenges. *Perspectives on Sexual and Reproductive Health*. 2004;36(2)180-186, March/April. Available at <http://www.guttmacher.org>.
- ❑ Weiss C, Dalven J. *Protecting Minors' Health Information under the Federal Medical Privacy Regulations*. New York: ACLU Reproductive Freedom Project, 2003. Available at: <http://www.aclu.org/ReproductiveRights>.