

2011

Skeletons in the Family Medical Closet: Access of Personal Representatives to Interoperable Medical Records

Leslie P. Francis

University of Utah S.J. Quinney College of Law, leslie.francis@law.utah.edu

Follow this and additional works at: <https://scholarship.law.slu.edu/jhlp>



Part of the [Health Law and Policy Commons](#)

Recommended Citation

Leslie P. Francis, *Skeletons in the Family Medical Closet: Access of Personal Representatives to Interoperable Medical Records*, 4 St. Louis U. J. Health L. & Pol'y (2011).

Available at: <https://scholarship.law.slu.edu/jhlp/vol4/iss2/5>

This Article is brought to you for free and open access by Scholarship Commons. It has been accepted for inclusion in Saint Louis University Journal of Health Law & Policy by an authorized editor of Scholarship Commons. For more information, please contact [Susie Lee](#).

SKELETONS IN THE FAMILY MEDICAL CLOSET: ACCESS OF PERSONAL REPRESENTATIVES TO INTEROPERABLE MEDICAL RECORDS

LESLIE P. FRANCIS*

Achieving the interoperability of electronic health records (EHRs) is a matter of urgent public policy discussion.¹ Protection for the security, privacy, and confidentiality of the information in EHRs is critical to public trust in this enterprise.² Included among privacy concerns is the right of individuals to request copies of their medical records.³ Less noticed are the implications of interoperability for access to individuals' medical records by their personal representatives. Access by individuals or their personal representatives is not a trivial matter, as Americans age and Medicare recipients are encouraged to download information in their EHRs at the push of a "Blue Button."⁴

Historically, paper medical records were siloed at the locations of providers or organizations creating them.⁵ State law governed patients' access to medical records, and many states placed significant limits on patients' rights to access their own records.⁶ All this has changed. The right of patients to access medical records is now enshrined in federal law.

* J.D., University of Utah; Ph.D., philosophy, University of Michigan; Distinguished Professor of Law and Philosophy and Alfred C. Emery Professor of Law, University of Utah.

1. See, e.g., PRESIDENT'S COUNCIL OF ADVISORS ON SCI. & TECH., EXEC. OFF. OF THE PRESIDENT, REPORT TO THE PRESIDENT REALIZING THE FULL POTENTIAL OF HEALTH INFORMATION TECHNOLOGY TO IMPROVE HEALTHCARE FOR AMERICANS: THE PATH FORWARD (2010), *available at* <http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf>.

2. See NAT'L COMM. ON VITAL & HEALTH STATISTICS, TOWARD ENHANCED INFORMATION CAPACITIES FOR HEALTH (2010), *available at* <http://www.ncvhs.hhs.gov/100526concept.pdf>.

3. The HIPAA Privacy Rule includes this right of access, 45 C.F.R. § 164.524 (2010).

4. For a description of the "Blue Button" initiative, see *Download My Data/Blue Button*, MEDICARE.GOV, <http://www.medicare.gov/navigation/manage-your-health/personal-health-records/blue-button-download.aspx?AspxAutoDetectCookieSupport=1> (last visited June 10, 2011).

5. See, e.g., Leslie P. Francis, *The Physician-Patient Relationship and a National Health Information Network*, 38 J.L. MED. & ETHICS 36, 36-49 (2010).

6. See, e.g., Ellen Klugman, Comment, *Toward a Uniform Right to Medical Records: A Proposal for a Model Patient Access and Information Practices Statute*, 30 UCLA L. REV. 1349, 1365-68 (1983).

Extensive incentives and legal requirements are pushing providers towards electronic records with increasingly sophisticated interoperability functions.⁷

Before interoperable EHRs, a personal representative accessing the medical record of an individual would likely see only paper records maintained by the team currently involved in the individual's care. Other records about that individual would remain in the offices in which they originally were created. For patient care, siloed office records have well-known disadvantages.⁸ For privacy, however, the picture is quite different.

Imagine Mother, age 64, is hospitalized for a stroke and Daughter is her health care decision-maker. Fully interoperable EHRs could include much that is not medically relevant to Mother's current care but that Mother would not want or expect Daughter to see. Records might feature not only Mother's recent medical history, but also her records from her gynecologist, including the pregnancy she ended at age 45. Or, they could include the records of Mother's visits to her internist for treatment for depression after Dad's death a few years back—treatment that Mother had proudly and carefully hidden from the rest of the family. As interoperability becomes more robust, metaphorical skeletons in the medical history closet will be increasingly on view to personal representatives making health care decisions for others. This confidentiality problem warrants ethical and legal attention that it has not yet received.

The situation of personal representatives, moreover, may be ethically complex. Although personal representatives are charged to act either as the individual would have wanted or in the individual's best interests, personal representatives may have important health interests of their own in accessing health records. Daughter may have health interests in understanding the circumstances of her conception, circumstances Mother may have wished to keep private.⁹ Information about heritable conditions may be critical to other family members' decisions about their own health care, but family

7. These incentives are a major part of the federal "stimulus package" investment in infrastructure. See American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, §§ 13001-424, 123 Stat. 115, 226-79 ("HITECH Act") (2009) (codified in scattered sections of 42 U.S.C.). See also *The Official Web Site for the Medicare and Medicaid Electronic Health Records (EHR) Incentive Programs*, CTRS. FOR MEDICARE & MEDICAID SERVS., U.S. DEP'T OF HEALTH & HUMAN SERVS., <http://www.cms.gov/ehrincentiveprograms/> (last modified May 17, 2011).

8. See, e.g., Nicolas P. Terry & Leslie P. Francis, *Ensuring the Privacy and Confidentiality of Electronic Health Records*, 2007 U. ILL. L. REV. 681, 691-707 (2007).

9. The American Society for Reproductive Medicine recommends, but does not require, parents to inform their offspring of their conception by methods of assisted reproduction. American Society for Reproductive Medicine, *Ethics Committee Report: Informing Offspring of their Conception by Gamete Donation*, 81 FERTILITY & STERILITY 527, 527-31 (2004).

members are not always willing to share this information.¹⁰ Interests of personal representatives may be less ethically compelling as well: for example, interests in assessing how much Mother's health care will cost, guessing how soon Mother is likely to die, or learning more family gossip.¹¹ On the other side, Daughter may not want to know some of this information, either; some people do not want to know the circumstances of their conception or whether they are at risk for certain heritable conditions.

Additional difficulties are introduced by variations in reasons for and selection of personal representatives for health care decision-making. "Personal representative," as used in this article, covers the range of individuals who make decisions for others who lack the legal capacity to make their own health care decisions. Personal representatives in this sense include parents making health care decisions for their minor children, court-appointed guardians or conservators making decisions for wards, individuals appointed as holders of durable powers of attorney for health care, and individuals recognized as decision-makers under state surrogate decision making statutes. In some cases, these personal representatives will have been selected by the individuals themselves. In other cases, there will be information available about the individuals' prior statements about preferences, expectations, or choices. The reasons for incapacity will vary too, including minority, cognitive disability (life-long or adult onset), or mental illness.

This article begins by describing current federal law about the rights of patients to access their own medical records. The description pays particular attention to restrictions on this right, including psychotherapy notes and endangerment. Federal law gives personal representatives the same rights as patients to access records as permitted by state law. The article then analyzes state law rights of access by personal representatives. In general, states treat access by personal representatives in all or nothing fashion; if there is a right of access, it is the right to access the entire record. A few states, however, have considered the problem in more nuanced ways. Several states allow patients to use advance directives to structure access to records. Several other states restrict the rights of the personal representative to access mental health or substance abuse treatment records. Some states

10. There has been considerable discussion in bioethics about the obligations of family members to share information about heritable conditions. See, e.g., David J. Doukas & Jessica W. Berg, *The Family Covenant and Genetic Testing*, 1 AM. J. BIOETHICS 2, 2-10 (2001) (AJOB Target Article accompanied by many commentaries in the pages following the article (pp. 11-34)).

11. For a sympathetic discussion of the interests of other family members in the costs or burdens of their relatives' care, see John Hardwig, *Is There a Duty to Die?*, HASTINGS CTR. RPT., Mar./Apr. 1997, at 34.

differentiate rights of access of the personal representative depending on whether the patient is a person with mental illness or cognitive disability. The examples are quite limited, however. An additional problem is whether access rights of the personal representative should differ depending on whether the individual represented is a person with mental illness or with cognitive disabilities.

This article provides four recommendations:

- o Advance directive statutes should permit competent patients to designate the extent to which their personal representatives should have access to interoperable medical records.
- o Absent a directive, the presumption should be that the personal representative has access only to records that are needed for decision making about the patient's care.
- o Interoperable medical records should be designed to allow special management of sensitive types of medical information (such as mental health information or treatment for substance abuse). When patients have identified types of information as sensitive, personal representatives should not have access to that information except as necessary for emergency care.
- o These principles should apply whether the patient is a person with mental illness or a person with cognitive disability. For persons with cognitive disabilities, however, prior preferences may be more difficult to ascertain.

I. INDIVIDUAL RIGHTS TO ACCESS ELECTRONIC HEALTH RECORDS: THE ROLE OF FEDERAL LAW

The Health Insurance Portability and Accountability Act (HIPAA) is the federal statute governing the privacy and security of certain health information.¹² Under HIPAA,¹³ the Department of Health and Human Services (HHS) issued the HIPAA Privacy Rule.¹⁴ In 2009, Congress passed the Health Information Technology for Economic and Clinical Health Act (HITECH Act).¹⁵ Along with extensive incentives for use of health information technology, the HITECH Act also enhances protections for

12. Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 26, 29, and 42 U.S.C.).

13. *Id.* § 264.

14. 45 C.F.R. §§ 160, 162, 164 (2010).

15. *See* American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, §§ 13001-424, 123 Stat. 115, 226-79 ("HITECH Act") (2009) (codified in scattered sections of 42 U.S.C.).

health information security and privacy.¹⁶ HIPAA preempts conflicting state law, but not consistent state laws that protect privacy more stringently.¹⁷ For several purposes important to this article and discussed below, particularly the rights of personal representatives, HIPAA largely defers to state law.

The HIPAA Privacy Rule incorporates many (but not all) of Fair Information Practice Principles (FIPPs) which are widely accepted as guidelines for the protection of identifying information about individuals.¹⁸ Core to FIPPs are the rights of individuals to know what information about them is being collected and how it is being used. Individuals must also be able to correct mistakes in personally identifiable information about them held by others.

Following these FIPPs principles, the HIPAA Privacy Rule provides to the individual a right of access to “protected health information.”¹⁹ An individual’s request for disclosure of medical records is a required disclosure under HIPAA.²⁰ This right is limited, however, to what is called a “designated record set.” Information in the designated record set includes medical records, billing records; “enrollment, payment, claims adjudication, and case or medical management record systems maintained by or for a health plan;” or other information used, in whole or in part, to make decisions about individuals.²¹ Of interest to individuals, the designated record set as thus defined does not include data collected for research, data collected for peer review, or data collected for quality improvement.

16. *Id.* §§ 13400-24.

17. HIPAA § 264(c).

18. FIPPs were introduced in 1973 by the U.S. Department of Health, Education and Welfare in a proposal for practices to govern automated personal data systems. See RECORDS, COMPUTERS AND THE RIGHTS OF CITIZENS: REPORT OF THE SECRETARY’S ADVISORY COMMITTEE ON AUTOMATED PERSONAL DATA SYSTEMS (1973), available at <http://aspe.hhs.gov/DATACNCL/1973privacy/tocprefacemembers.htm>. In 1980, the Organization for Economic Cooperation and Development (OECD) adopted the “Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data,” which include core FIPPs. See *Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data*, ORG. FOR ECON. COOP. & DEV., http://www.oecd.org/document/18/0,3343,en_2649_34255_1815186_1_1_1_1,00.html. The European Union’s data protection directive, Directive 95/46/EC, likewise rests on FIPPs. See *Directive 95/46/EC of the European Parliament and the Council of 24 October 1995*, OFFICIAL J. EUR. COMMUNITY, no. L. 281, 1995, at 31, 31-39, available at http://ec.europa.eu/justice/policies/privacy/docs/95-46-ce/dir1995-46_part1_en.pdf. For a general history of FIPPs, see ROBERT GELLMAN, FAIR INFORMATION PRACTICES: A BASIC HISTORY (2011), available at <http://bobgellman.com/rg-docs/rg-FIPshistory.pdf>.

19. 45 C.F.R. § 160.103 (2010). “Protected health information” is a HIPAA term of art. For purposes of this article, it can be defined as information that is about health, individually identifiable, and created or possessed by a health care provider, health care plan, or health care clearinghouse.

20. *Id.* § 164.502(a)(2)(i).

21. *Id.* § 164.501.

The HITECH Act enhanced patients' ease of access to health information in electronic form. If requests are "clear, conspicuous, and specific," individuals may request copies of information in EHRs in electronic form sent to designated entities.²² This provision allows patients to request copies of their information to be sent directly to personal health records, for example. It does not, however, expand the information to which individuals have access beyond the designated record set.

The HIPAA Privacy Rule imposes important limits on patients' rights of access. The HITECH Act does not change these limits. These important limits on the right of access include psychotherapy notes and disclosures that might cause danger to individuals themselves or to others.

"Psychotherapy notes" are given special protection under the Privacy Rule, both from disclosures to the patient and to third parties. Disclosure of psychotherapy notes to third parties requires specific authorization on the part of the patient, with exceptions enumerated in the Privacy Rule.²³ Psychotherapy notes, however, are a quite limited set of mental health information. Psychotherapy notes include contents of conversations during therapy sessions, provided these are separated from the rest of the individual's medical record. They exclude information about prescription medication and monitoring, types and frequency of treatment, clinical test results, and summary accounts of the patient's status (including "diagnosis, functional status, the treatment plan, symptoms, prognosis, and progress to date").²⁴ Although it includes "clinical tests," the present definition does not include results of testing that is part of a mental health evaluation.²⁵ Thus, much mental health information that patients might want to protect is not

22. See American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, §§ 13001-424, 123 Stat. 115, 226-79 ("HITECH Act") (2009) (codified in scattered sections of 42 U.S.C.).

23. 45 C.F.R. § 164.508(a)(2) (2010). There are exceptions to this: use of the notes by their originator for treatment, use for training purposes, and use by the treating entity for defense in a legal action. *Id.* § 164.508(a)(2)(i). *Jaffee v. Redmond*, 518 U.S. 1 (1996), recognizes a federal psychotherapist-patient privilege. *Jaffee* influenced the decision to give special protection to psychotherapy notes in HIPAA, rather than extending special protections to many types of sensitive information. Psychotherapy Notes, 65 Fed. Reg. 82,652 (Dec. 28, 2000). For an excellent discussion of the HIPAA Privacy Rule's treatment of psychotherapy notes, see Daniel B. Lord, *The Pitfalls of HIPAA: The Sticky Wicket of Psychotherapy Notes*, 29 ALASKA BAR RAG, July-Sept. 2005, at 34-35.

24. 45 C.F.R. § 164.501 (2010).

25. See, e.g., *APAPO Builds on Work to Protect Psychological Testing Data*, AM. PSYCH. ASS'N PRACTICE ORG. (Oct. 27, 2010), <http://www.apapracticecentral.org/update/2010/10-27/testing-data.aspx>. For an overview of the importance of protecting privacy in mental health treatment with particular attention to the inadequacies of HIPAA, see Paul S. Appelbaum, *Privacy in Psychiatric Treatment: Threats and Responses*, 159 AM. J. PSYCH. 1809, 1809-18 (2002).

included within the special HIPAA protection for psychotherapy notes. The HITECH Act requires a study of this definition of psychotherapy notes with respect to test results that are part of a mental health evaluation.²⁶ The Substance Abuse and Mental Health Services Administration (SAMHSA) is currently conducting this study in cooperation with the Office for Civil Rights (OCR) within HHS.²⁷

The Privacy Rule lists exceptions to the requirement of specific patient authorization for the use or disclosure of psychotherapy notes. These exceptions include use by the originator of the notes for treatment purposes and use or disclosure by the covered entity for its own training purposes.²⁸ Other exceptions include disclosures to HHS for review of compliance with HIPAA²⁹ or for oversight of the health care provider originating the notes.³⁰ These uses, while not uncontroversial, could be justified in terms of the interests of patients in receiving good care.³¹ However, other disclosures of psychotherapy notes permitted without patient authorization are not at all in the interests of patients. It is perhaps predictable that permitted disclosures would include defense of the covered entity against a suit brought by the individual.³² Disclosures of psychotherapy notes permitted without authorization include disclosures required by law if the conditions applicable to the legal purpose are met,³³ disclosures of information about decedents to coroners and medical examiners,³⁴ and disclosures needed to avoid a

26. See American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, § 13424(f), 123 Stat. 115, 226-79 ("HITECH Act") (2009) (to be codified at 42 U.S.C. § 17954).

27. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., PUBLIC DISCUSSION ON CONFIDENTIALITY AND PRIVACY ISSUES RELATED TO PSYCHOLOGICAL TESTING DATA (2010) [hereinafter PUBLIC DISCUSSION ON CONFIDENTIALITY], available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/ebrochure-la.pdf>.

28. 45 C.F.R. § 164.508(a)(2)(i)(A)–(B) (2010). "Covered entity" is a HIPAA-defined term meaning health care provider, health plan, or health care clearinghouse. *Id.* § 160.103. Under this provision, the entity within which the patient was treated may use the notes for training purposes, but the notes may not be disclosed outside the institution for similar purposes.

29. *Id.* § 164.502(a)(2)(ii).

30. *Id.* § 164.512(d).

31. For a discussion of the controversies involved in the use of patients' records without authorization in quality assurance, see HEALTH CARE QUALITY IMPROVEMENT: ETHICAL AND REGULATORY ISSUES (Bruce Jennings et al. eds., 2007).

32. 45 C.F.R. § 164.508(a)(2)(i)(C) (2010).

33. *Id.* § 164.512(a).

34. *Id.* § 164.512(g) (2010). These disclosures must be for the purpose of identifying a decedent, determining cause of death, or fulfilling other legal duties. *Id.* § 164.512(g). In promulgating the Privacy Rule, HHS explained this exception as follows:

In general, we have severely limited disclosures of psychotherapy notes without the individual's authorization. One case where the information may prove invaluable, but

serious and imminent threat to health or safety.³⁵ The category of disclosures permitted without authorization because they are required by law includes reports of abuse, neglect, or domestic violence.³⁶ The category also includes disclosures for judicial and administrative proceedings, including disclosures in response to judicial orders, subpoenas, or other legal processes.³⁷

The special protection HIPAA gives psychotherapy notes extends to protecting the information from patients themselves. That is, HIPAA excludes psychotherapy notes from patients' own rights of access.³⁸ The study of whether to include test results within the definition asks specifically whether patients "need to know, or have an interest in, inspecting or obtaining a copy of such information?"³⁹ In comparison to protecting mental health treatment information from access by third parties, surprisingly little has been written about shielding such records from access by patients themselves. Perhaps the justification is paternalistic: patients would find such records disturbing. It seems likely that this is a core question in the study of patient access to results of mental health testing. Perhaps the concern is that access to such records would undermine the efficacy of the therapeutic relationship. Another justification—although not centered in the interests of patients—would be the practical interests of treating

authorization by the individual is impossible and authorization by a surrogate is potentially contraindicated, is in the investigation of the death of the individual. The final rule allows for disclosures to coroners or medical examiners in this limited case. 65 Fed. Reg. 82,650, 82,654 (Dec. 28, 2000). Presumably, the concern about authorization from surrogates here is that the surrogate may be implicated in the death.

35. 45 C.F.R. § 164.512(j)(1)(i) (2010). For these disclosures, the covered entity must in good faith believe that the use or disclosure is needed to avert "a serious and imminent threat to the health or safety of a person or the public" and that the disclosure is to a person reasonably able to avert the threat (including the target). *Id.* § 164.512(j)(1)(i). This is essentially the "Tarasoff" exception to the authorization requirement. *See Tarasoff v. Regents of the University of California*, 131 Cal. Rptr. 14, 20 (Cal. 1976).

36. 45 C.F.R. § 164.512(c) (2010). The disclosure must be required by law, and limited to the relevant legal requirements). *Id.* § 164.512(c)(i). Either the individual must agree to the disclosure, or the covered entity must either believe the disclosure is needed to avert serious harm (to the individual or other victims) or (if the individual is incapacitated and cannot give consent) represent that the disclosed information will not be used against the individual and that without disclosure immediate law enforcement activities will be adversely affected. *Id.* § 164.512(c)(iii)(A)–(B).

37. *Id.* § 164.512(e). For disclosures not supported by a court order, the covered entity must also receive "satisfactory assurance" that "reasonable efforts" have been made to give notice to the individual. *Id.* at § 164.512(e)(ii)(A).

38. *Id.* § 164.524(a)(i).

39. PUBLIC DISCUSSION ON CONFIDENTIALITY, *supra* note 27. The study also asks whether third parties may have an interest in obtaining this information. *Id.*

professionals in not having their notes open to review by their patients.⁴⁰ The denial of a patient's request for access to psychotherapy notes is not subject to review.⁴¹

Another important justification for denial of a patient's request to access records is endangerment of the patient or others.⁴² The judgment of endangerment is a professional judgment to be made by a licensed health care professional. Access can also be denied if a record contains information about someone else that might endanger them.⁴³ An example would be a medical record that contains judgments about the suspected source of an infection, when this information would not otherwise be available to the patient. Denials of access on grounds of endangerment are reviewable.⁴⁴

As mentioned above, HIPAA preempts contrary but not more stringent state laws about privacy and security. The exact parameters of preemption are explained in the regulations. State laws are "contrary" to HIPAA if covered entities "would find it impossible" to comply with both the federal and the state requirements.⁴⁵ They are also "contrary" if the state law "stands as an obstacle" to the achievement of the purposes of the statutory requirement to protect privacy⁴⁶ or to the purposes of the administrative simplification provisions of the Social Security Act.⁴⁷ State law provisions are "more stringent" if they prohibit an otherwise permitted disclosure, unless the disclosure is to HHS or to the individual.⁴⁸ They are also "more stringent" if they permit individuals greater rights to access or amend their health information, or if they permit individuals to access more information than permitted by the Privacy Rule.⁴⁹ Thus states may expand the individual right of access to health information, but may not contract it. States may

40. However, neither the American Psychiatric Association's annotations to the Principles of Medical Ethics nor ethics opinions treat confidentiality and disclosure of medical records to patients. *See, e.g.*, AM. PSYCH. ASS'N, THE PRINCIPLES OF MEDICAL ETHICS (2010 ed. 2010), available at <http://www.psych.org/MainMenu/PsychiatricPractice/Ethics/ResourcesStandards/Principles-of-Medical-Ethics-2010-Edition.aspx?FT=.pdf>.

41. 45 C.F.R. § 164.524(a)(2)(i) (2010).

42. *Id.* § 164.524(a)(3)(i).

43. *Id.* § 164.524(a)(3)(ii). This does not apply if the other person is a health care professional.

44. *Id.* § 164.524(a)(3)-(4). Impartial review procedures are required.

45. 45 C.F.R. § 160.202 (2010).

46. *Id.* § 160.202(2); Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. No. 104-191, § 264, 110 Stat. 1936 (codified at 42 U.S.C. § 1320d-2 note).

47. 45 C.F.R. § 160.202 (2010); Social Security Act, Title XI, 42 U.S.C. §§ 1301-1320d-8 (2009).

48. 45 C.F.R. § 160.202 (2010).

49. *Id.* § 160.202.

therefore expand the individual right of access to psychotherapy notes despite the exception in the Privacy Rule.⁵⁰

II. HIPAA AND THE RIGHTS OF PERSONAL REPRESENTATIVES

In general, HIPAA treats personal representatives as individuals themselves would be treated.⁵¹ This means that personal representatives recognized under state law would have all the rights that individuals themselves would have to access medical records. For adults and emancipated minors, HIPAA simply defers to determinations of authority under applicable law.⁵² For deceased individuals, HIPAA also defers to state law governing the authority of personal representatives.⁵³

For unemancipated minors, the interplay between HIPAA and state law is more complex and more protective of the minor's confidentiality. HIPAA does not defer to state law determinations of authority to access records in cases in which the minor's consent to treatment is sufficient under state law, the minor consents to the treatment, and the minor has not requested that the person seeking access be treated as a personal representative.⁵⁴ An example would be state laws allowing minors to consent to treatment for sexually transmitted diseases; in such cases, HIPAA would not defer to state laws allowing access to parents unless the minor has requested that the parent be treated as a personal representative. HIPAA also does not defer to state law cases in which the unemancipated minor has the legal right to obtain treatment without the consent of another, and has consented to the treatment or the treatment has been authorized by law.⁵⁵ Abortion is an example; HIPAA would protect the record even if state law were to grant parents the right of access. HIPAA also protects the record of an unemancipated minor when the personal representative of the minor has

50. For a state explanation of this, see *HIPAA Preemption Charts*, N.Y. STATE DEP'T OF HEALTH (last updated Oct. 15, 2002), http://www.health.state.ny.us/nysdoh/hipaa/hipaa_preemption_charts.htm.

51. 45 C.F.R. § 164.502(g)(1) (2010).

52. *Id.* § 164.502(g)(2).

53. *Id.* § 164.502(g)(4). The American Psychiatric Association has noted that there may be important differences between the ethical and legal rights of personal representatives to access the records of decedents. See AM. PSYCH. ASS'N, OPINIONS OF THE ETHICS COMMITTEE ON THE PRINCIPLES OF MEDICAL ETHICS 24, 25 (2009), available at <http://www.psych.org/MainMenu/PsychiatricPractice/Ethics/ResourcesStandards/OpinionsofPrinciples.aspx>. APA Ethics Op. D.4.h responds to an inquiry from a treating psychiatrist of a patient who committed suicide. The psychiatrist asks whether there is an obligation to release records to the apparently abusing father who requested the records as executor of his son's estate. The opinion concludes that the father does not have an ethical right to the patient's records, although whether the father has a legal right is a different question. *Id.*

54. 45 C.F.R. § 164.502(g)(3)(i)(A) (2010).

55. *Id.* § 164.502(g)(3)(i)(B).

assented to a confidentiality agreement with respect to the health care service in question.⁵⁶ When the parent of an unemancipated minor is not the personal representative of the minor, and there is no applicable state or other law concerning access, decisions about access by the parent should be made according to professional judgment by a licensed health care provider.⁵⁷

In situations of possible abuse, neglect or endangerment, however, HIPAA does not defer to state law concerning access of personal representatives to records.⁵⁸ The covered entity must have a “reasonable belief” that the individual has been or may be the subject of domestic violence or abuse or that regarding someone as the personal representative would endanger the individual, and must exercise “professional judgment” that access to the information is not in the best interest of the individual.⁵⁹

III. RIGHTS TO ACCESS RECORDS UNDER STATE LAW

State laws vary widely in what they provide—or fail to provide—about the rights of individuals or their personal representatives to access medical records. States also vary in whether they provide any formal mechanisms for individuals to use to restrict the rights of their personal representatives to view some or all of their medical record. In addition, many state statutes in this area are not, to say the least, models of clarity. The discussion that follows is not intended as an exhaustive presentation of every state’s laws. Rather, the goals of the discussion are to describe the remarkable variety among state laws in this area and to call attention to significant gaps in confidentiality protections when personal representatives have the right to access medical records.

A. *A Preliminary Note about Minors*

Many states require special handling for the records of unemancipated minors. Some states are highly protective of these minors’ rights to shield their records from parents or others who may make decisions for them. New York, for example, states that minors over the age of twelve may be notified of a request for disclosure of medical records; if the minor objects to the disclosure, the provider may deny the request.⁶⁰ In New York, providers also may refuse access by a parent or guardian on determining that the information would have a detrimental effect on the provider’s professional

56. *Id.* § 164.502(g)(3)(i)(C).

57. *Id.* § 164.502(g)(3)(ii)(C).

58. *Id.* § 164.502(g)(5).

59. 45 C.F.R. § 164.502(g)(5) (2010).

60. N.Y. PUB. HEALTH LAW § 18(3)(c) (McKinney 2002 & Supp. 2010).

relationship with the minor, the minor's care, or the minor's relationship with parents or guardian.⁶¹

In addition, some states provide special protections for particular types of information concerning minors. For example, in Michigan, minors age fourteen or older may receive outpatient mental health services without the consent or knowledge of their parents or guardians.⁶² When a minor receives these services, the parent or guardian may not be informed without the minor's consent, unless the mental health professional determines there is a compelling need for disclosure because of a substantial probability of harm to the minor or to another.⁶³ In Illinois, a parent or guardian of a child who is at least twelve but not yet eighteen may only inspect or copy mental health records if the patient child is "informed and does not object or if the therapist does not find that there are compelling reasons for denying the access."⁶⁴ In New York, information concerning a minor's abortion or treatment for venereal disease may not be released to parents or guardians.⁶⁵

Because state laws about minors vary so greatly and introduce an additional layer of complexity, this article focuses on access to medical records concerning adults and emancipated minors. However, the need under state law for special handling of records concerning sensitive information about minors poses difficulties for the introduction of systems allowing minors or their parents access to these records electronically.⁶⁶ Addressing these issues for adults may provide methods that can be helpful in the case of minors as well.

B. Similar Treatment for Access Rights of Principals and Access Rights of Personal Representatives

Some states have laws that give individuals or their personal representatives rights to access medical records but are silent concerning rights under guardianship or advance directive statutes. These states

61. *Id.* § 18(2)(c).

62. MICH. COMP. LAWS § 330.1707(1) (2011).

63. *Id.* § 330.1707(1)-(2). These services may not include pregnancy termination or psychotropic drugs. Services should promote the relationship to the parent or guardian and not undermine the values instilled in this relationship. These services are also limited in time or number of visits. *Id.* § 330.1707.

64. 740 ILL. COMP. STAT. 110/4(1), (3) (LexisNexis 2010). Interestingly, there is no similar limit for the holder of a DPA for mental health treatment. 740 ILL. COMP. STAT. ANN. 110/4(7) (West 2010).

65. N.Y. PUB. HEALTH LAW § 17 (McKinney 2002 & Supp. 2010).

66. NCVHS Committee on Privacy, Confidentiality, and Security: AAP Response to Committee Questions, NAT'L COMM. ON VITAL & HEALTH STATISTICS, <http://www.ncvhs.hhs.gov/100615p07.pdf> (last visited June 16, 2011).

apparently do not differentiate between the rights of individuals themselves or the rights of their representatives. Kentucky is an example, requiring that health care providers furnish a copy of a medical record upon the written request of a patient, the patient's attorney, or the patient's authorized representative.⁶⁷ The Kentucky guardianship statute authorizes the guardian to consent to medical care but makes no mention of medical records.⁶⁸ The advance directive statute likewise is silent about access to medical records by an authorized surrogate decision maker.⁶⁹ Several other states have similar non-differentiating statutes.⁷⁰ Vermont has statutes that are silent but with the additional twist that individuals may use advance directives to specify others in addition to their agents who may receive health records.⁷¹ Another variation is silence in some statutes but the right to differentiate in others; in Utah, for example, there is no mention of medical information in the guardianship statute⁷² but the advance directive statute allows the principal to limit the agent's right to receive medical information.⁷³

Some state statutes specify that guardians or holders of the durable power of attorney (DPA) have the same rights as individuals would have to access their medical records. For example, Alabama law states that "[r]equests for copies of any medical records must be accompanied by a current valid duly executed authorization and release which has been signed by the recipient or by one legally authorized to act on behalf of the recipient."⁷⁴ The Alabama advance directive and default surrogate decision-

67. KY. REV. STAT. ANN. § 422.317(1) (LexisNexis 2005).

68. *Id.* § 387.660 (2010).

69. *Id.* § 311.629 (2007).

70. KAN. STAT. ANN. § 65-4971 (2002 & Supp. 2010) (copies of health care records to patient or patient's authorized representative); *id.* § 59-3075(b)(5) (2005 & Supp. 2010) (guardianship); *id.* § 58-629 (DPA for health care). Other states with non-differentiating statutes include: Arkansas, ARK. CODE ANN. § 16-46-106 (1999 & Supp. 2009) (patient or attorney right to medical record; curiously, guardian omitted from first but not subsequent sections of this code provision); *id.* § 28-65-301 (2004 & Supp. 2009) (duties of guardian); *id.* § 20-13-104 (2005) (durable power of attorney for health care); Indiana, IND. CODE ANN. § 30-5-5-16(b) (West 2009) (designated health care agent); Louisiana, LA. REV. STAT. ANN. § 40:1299.58.1 (2008) (DPA for health care; DPA statute for mental health is different); *id.* § 28:227(C) (2010); Michigan, MICH. COMP. LAWS ANN. § 330.1631(3) (West 1999 & Supp. 2011) (guardianship); *id.* § 33.26265(1) (West 2011) (access to medical records); *id.* § 700.5506(1) (decision-maker for health care); New Jersey, N.J. STAT. ANN. § 8:42-11.2(a)(5) (West 2010) (access to medical records); *id.* § 26:2H-61(a), (e) (patient representative); *id.* § 26:2H-110 (mental health representative); North Carolina, N.C. GEN. STAT. § 35A-1241(3) (2010) (guardianship).

71. VT. STAT. ANN. tit. 18, § 9419 (Supp. 2010) (access to medical records); *id.* tit. 14, § 3069 (guardianship statute); *id.* tit. 18, § 9702(a)(11) (advance directive statute).

72. UTAH CODE ANN. § 75-5-312(2)(c) (2011).

73. *Id.* § 75-2a-117(Part I)(E).

74. ALA. CODE § 22-5A-6(d) (2006).

making laws are silent about access to medical records⁷⁵ but the Alabama DPA statute provides that the DPA “may, for the purpose of making a health care decision, request, review, and receive any information, oral or written, regarding the principal’s physical or mental health, including medical and hospital records. . . .”⁷⁶ In Illinois, the default surrogate decision maker statute provides that the surrogate has the same powers as the principal with respect to medical records⁷⁷ and the DPA statute provides that the agent has the same power as the principal “whether the records relate to mental health or any other medical condition. . . .”⁷⁸ The language in Georgia’s recommended DPA form states explicitly that the health care agent “will have the same access to [the principal’s] medical records”⁷⁹ The Maryland statute is to the same effect.⁸⁰ Mississippi gives DPAs for health care the authority to make any health care decisions the principal could have made while having capacity,⁸¹ including the right to “request, receive, examine, copy and consent to the disclosure of medical or any other health care information.”⁸²

Idaho law has even more sweeping provisions about access to medical information by the holder of the DPA. The Idaho DPA form statute provides explicitly that the DPA may “[r]equest, review and receive any information, verbal or written, regarding [the patient’s] physical or mental health including, but not limited to, medical and hospital records.”⁸³ This form is a “HIPAA Release Authority” that authorizes release of “all of [the principal’s] individually identifiable health information and medical records regarding any past, present or future medical or mental health condition” including information regarding HIV status, sexually transmitted diseases, mental illness, and alcohol or drug abuse.⁸⁴ As this is a “HIPAA release,” it may be

75. *Id.* § 22-8A-11. The advance directive act does allow patients to limit the decisions that a health care agent may make, however. *Id.* § 22-8A-6.

76. *Id.* § 26-1-2(4).

77. 755 ILL. COMP. STAT. ANN. 40/25(e) (LexisNexis 2010).

78. *Id.* § 45/4-10(c)(4) (effective July 1, 2011).

79. GA. CODE ANN. § 31-32-4 (2009).

80. MD. CODE ANN., HEALTH-GEN. § 5-603(Part I)(G)(2) (LexisNexis 2009).

81. MISS. CODE ANN. § 41-41-205(2) (2010).

82. *Id.* § 41-41-217.

83. IDAHO CODE ANN. § 39-4510(5)(A) (Supp. 2010).

84. *Id.* § 39-4510(5)(B). This statute does not apparently recognize the possibility that confidentiality protections under the Substance Abuse and Mental Health Services Act (SAMHSA) may be more stringent than those under HIPAA. See CTR. FOR SUBSTANCE ABUSE TREATMENT, SUBSTANCE ABUSE AND MENTAL HEALTH SERVS. ADMIN., U.S. DEP’T OF HEALTH & HUMAN SERVS., THE CONFIDENTIALITY OF ALCOHOL AND DRUG ABUSE PATIENT RECORDS REGULATION AND THE HIPAA PRIVACY RULE: IMPLICATIONS FOR ALCOHOL AND SUBSTANCE ABUSE PROGRAMS (2004), available at <http://www.samhsa.gov/HealthPrivacy/docs/SAMHSAPart2-HIPAAComparison2004.pdf>.

meant to be limited to uses and disclosures that HIPAA recognizes with authorization, but there is no explicit statement about whether the authority would also include psychotherapy notes under mental illness records or records of treatment for substance abuse that are protected under the federal Substance Abuse and Mental Health Services Administration (SAMHSA) regulations. HIPAA does not require authorization to permit the personal representative to have whatever access to medical records is permitted by state law, although it should be noted that this "HIPAA release" would not meet HIPAA requirements for authorization of a use or disclosure of psychotherapy notes.⁸⁵ Importantly, the Idaho form also invites patients to specify any limits on the availability of information, just as they might specify limits on the treatment decisions that the DPA might make, although this requires explicit "opt in" statement and thus may not be exercised by many patients. The exact language of this invitation reads: "You can also include a statement of your desires concerning other matters relating to your health care, including a list of one or more persons whom you designate to be able to receive medical information about you"⁸⁶

Like Idaho, South Carolina includes a HIPAA authorization in the DPA form.⁸⁷ The form provides access to all medical records, including mental health records, with no exception for psychotherapy notes. The actual language of the authorization reads:

"all individually identifiable health information and medical records shall be released without restriction to my health care agent(s) and/or my alternate health care agent(s) named above including, but not limited to, (i) diagnostic, treatment, other health care, and related insurance and financial records and information associated with any past, present, or future physical or mental health condition including, but not limited to, diagnosis or treatment of HIV/AIDS, sexually transmitted disease(s), mental illness, and/or drug or alcohol abuse and (ii) any written opinion relating to my health that such health care agent(s) and/or alternate health care agent(s) may have requested."⁸⁸

The DPA form invites patients to include any limitations on choices about care, but this invitation is silent about inclusion of limits on access to information.

85. 45 C.F.R. § 164.508(b)(3)(ii) (2010) (authorization for disclosure of psychotherapy notes may only be combined with authorization for disclosure of other psychotherapy notes). These regulations have specific requirements for consent to disclosure, but these do not include the HIPAA requirement for separate authorization. *Id.* § 2.31.

86. IDAHO CODE ANN. § 39-4510(4) (Supp. 2010).

87. S.C. CODE ANN. § 62-5-504 (2009).

88. *Id.*

C. Increased Access Rights for Principals Extended to Personal Representatives?

HIPAA preemption allows states to implement more stringent privacy protections than HIPAA requires. As described above, this includes giving individuals more extensive rights to access their health information than HIPAA requires. One potentially unnoticed consequence of this extension, however, is that these same rights may be extended to personal representatives. If individuals are given more rights than HIPAA, and their personal representatives are given equivalent rights, the personal representative would also have the extended rights.⁸⁹ A few states have statutes with explicit statements that give individuals rights to access their health information that extend beyond their rights under HIPAA.

New York may be one example of this complex interplay. New York grants patients more extensive rights than HIPAA and grants the rights of patients to personal representatives, and provides special protection for minors from access to their records. New York gives patients, their surrogates, or their legally appointed guardians, the rights to request copies of medical records and to obtain access to patient information.⁹⁰ New York also gives "qualified" persons rights of access to medical records, including attorneys who hold powers of attorney authorizing access.⁹¹ The right includes copies of "all x-rays, medical records and test records including . . . original mammograms"⁹² This right also includes psychotherapy notes insofar as they are not "personal notes of the said physician or hospital"⁹³ and thus extends more broadly than HIPAA.⁹⁴ Providers may also refuse access that might "reasonably be expected to cause substantial and identifiable harm" to the patient or another.⁹⁵ New York's statute granting the authority to appoint an agent does not include this restriction, however. This statute provides that health care agents appointed by competent adults have the right to receive medical information and records "necessary to make informed decisions regarding the principal's health care"

89. The HIPAA provisions regarding rights of personal representatives as described above do not require an authorization as between the individual and the personal representative. 45 C.F.R. § 164.502(g) (2010).

90. N.Y. PUB. HEALTH LAW §§ 17, 18 (McKinney 2002 & Supp. 2010).

91. *Id.* § 18(1)(g).

92. *Id.* § 17. Laboratory tests include, but are not limited to, tests administered in clinical laboratories or blood banks. *Id.*

93. *Id.*

94. Although New York defines "personal notes and observations" as "a practitioner's speculations, impressions (other than tentative or actual diagnosis) and reminders," this definition cannot be construed to include information relied on for treatment, in which case HIPAA would require disclosure. *Id.* § 18(1)(f).

95. N.Y. PUB. HEALTH LAW § 18(3)(d).

"[n]otwithstanding any law to the contrary."⁹⁶ A similar right is given to statutory surrogates for incompetent adult patients.⁹⁷ An important limit in these statutes, however, is that the right of access is to information needed to make informed care decisions.

Massachusetts may be similar to New York. Massachusetts provides that patients or their authorized representative are permitted to inspect health records.⁹⁸ At the discretion of the psychotherapist, this includes the entire record unless it would adversely affect the patient's well-being.⁹⁹ In Massachusetts, health care agents have the authority to make any decisions that the principal can make.¹⁰⁰ Health care directives also may include any limitations that are to be placed upon the agent's authority.¹⁰¹ Agents have the right to receive "any and all medical information necessary to make informed decisions regarding the principal's health care, including any and all confidential medical information that the principal would be entitled to receive."¹⁰² As in New York, the right of access is restricted to information needed for health care decisions and this may be an important limit.

Oregon also extends the patient's rights of access to health information¹⁰³ to include psychotherapy notes.¹⁰⁴ Personal representatives have the same rights as principles, unless these rights are limited by the terms of appointment or by federal law.¹⁰⁵ For holders of a DPA for mental health treatment, the right to review records is limited to records related to the treatment at issue.¹⁰⁶

Except to the extent the right is limited by the appointment or any federal law, a health care representative for an incapable principal has the same right as the principal to receive information regarding the proposed health care, to receive and review medical records and to consent to the disclosure of medical records.¹⁰⁷

Under a durable power of attorney for mental health, the attorney in fact has the same right as the principal to review medical records, but only that related to that treatment.

96. N.Y. PUB. HEALTH LAW § 2982(3).

97. *Id.* § 2994-d(3)(c).

98. MASS. GEN. LAWS ANN. ch. 112, § 12CC (West Supp. 2003).

99. *Id.*

100. *Id.* ch. 201D, § 5 (West 2004 & Supp. 2010).

101. *Id.* § 4(iii).

102. *Id.* § 5.

103. OR. REV. STAT. § 192.518 (2009).

104. OR. ADMIN. R. 847-012-0000(3)(b) (2011).

105. OR. REV. STAT. § 127.535 (2009 & Supp 2010).

106. *Id.* § 127.712.

107. *Id.* § 127.535(3).

Texas may be another example of a state that gives patients more extensive rights to disclosure of their medical records than does HIPAA, and then extends those rights to personal representatives. Patients or their personal representatives¹⁰⁸ are entitled to access to medical information unless the physician determines it will be harmful to their physical, mental, or emotional health.¹⁰⁹ Patients also are entitled to access the content of confidential mental health records, unless the professional determines that access to the record would be harmful to the patient's physical, mental, or emotional health.¹¹⁰ A guardian has the duty to provide the ward with medical care and to consent to medical, psychiatric, and surgical treatment.¹¹¹ There is no statement in the Texas guardianship statute about access to medical records or to mental health records specifically on the part of the guardian.¹¹² The Texas DPA statute is similarly silent regarding access of the holder of a DPA to medical or to mental health records.¹¹³

Nebraska emphasizes the importance for patients to have access to their medical records: "Patients need access to their own medical records as a matter of fairness to enable them to make informed decisions about their health care and correct inaccurate or incomplete information about themselves."¹¹⁴ There is an exception for mental health records if the treating provider determines that authorization would not be in the best interest of the patient.¹¹⁵ Nebraska makes no statement, however, that rights to access mental health records exclude psychotherapy notes.

Nevada may also have extended rights of patients to access medical records beyond HIPAA and, by implication, have extended the rights of personal representatives as well. In Nevada, patients, or representatives with written authorization from the patient, may inspect health care records.¹¹⁶ DPAs are given the right "to request, review and receive any information, verbal or written, regarding my physical or mental health, including, without limitation, medical and hospital records"¹¹⁷

108. TEX. OCC. CODE ANN. § 159.005 (Vernon 2004).

109. *Id.* § 159.006.

110. TEX. HEALTH & SAFETY CODE ANN. § 611.0045 (Vernon 2010).

111. TEX. PROB. CODE ANN. § 767(a)(3)–(4) (Vernon 2003 & Supp. 2010).

112. *See id.* § 767(a) (guardian has a duty to provide ward with medical care).

113. *See* TEX. HEALTH & SAFETY CODE ANN. § 166.152 (Vernon 2010) (describing the scope and duration of DPA authority).

114. NEB. REV. STAT. § 71-8401 (2003).

115. *Id.* § 71-8403(1).

116. *Id.* § 629.061 (2010).

117. *Id.* § 162A.860.

D. Restrictions on Access to Certain Types of Records

Some states have separate DPA statutes for mental health treatment. These or other statutes may give special protection from disclosure for mental health records. South Dakota is an example of a state with a separate DPA for mental health with separate powers to receive information. In South Dakota, patients or their designees have the right to request copies of their medical records from licensed health care providers¹¹⁸ or from health care facilities, with the exception of chemical dependency treatment facilities.¹¹⁹ Patients have the right to execute a DPA to make health care decisions on their behalf.¹²⁰ Holders of a DPA and other persons authorized to make health care decisions for others have the same rights as patients to consent to disclosure of medical records.¹²¹ Providers and facilities are insulated from liability for disclosures of medical records when, in good faith, they believe that the request for the record is made by an individual authorized to request it.¹²² South Dakota has additional provisions for mental health records. Patients have the right to access their mental health records.¹²³ Patients also have the right to execute a power of attorney to consent to mental illness treatment.¹²⁴ In South Dakota, holders of a DPA for mental health treatment have the same rights as those they represent to receive or consent to disclosure of medical records relating to mental health treatment, unless the patient's declaration of the power limits that right.¹²⁵ By contrast, South Dakota's general DPA for health care does not contain the same mention of the possibility that the declarant might wish to limit the right to access treatment records. Similarly, in Pennsylvania, the mental health DPA form invites specifications of limits on rights to receive information,¹²⁶ but the general DPA for health care statute does not.¹²⁷ In Louisiana, general DPA powers do not include provisions for restriction of access to information¹²⁸ but DPA powers for mental health treatment do.¹²⁹

118. S.D. CODIFIED LAWS § 36-2-16 (2004).

119. *Id.* § 34-12-15.

120. *Id.* § 59-7-2.1 (2009).

121. *Id.* § 34-12C-6 (2004).

122. *Id.* § 59-7-8 (2009) (requests from attorneys-in-fact or agents); *id.* § 34-12C-7 (requests from any person believed to be authorized).

123. S.D. CODIFIED LAWS § 27A-12-26.1 (2004). There are exceptions for information provided by a third party under assurances of confidentiality accompanied with a determination that access would be detrimental to the patient's health. *Id.*

124. *Id.* § 27A-16-3.

125. *Id.* § 27A-16-7 (the statute also provides that the right may be limited by federal law).

126. 20 PA. CONS. STAT. ANN. § 5833(b)(1), (c) (West 2005).

127. *See id.* § 5471.

128. *See* LA. REV. STAT. ANN. § 40:1299.58.1 (2008) (general DPA statute).

In Colorado, access to mental health records by personal representatives is limited. Although patient records are available to personal representatives, mental health records or other records that would have a significant negative psychological impact on the patient are excluded from this requirement.¹³⁰ In Iowa, mental health providers may disclose information to the spouse, parent, adult child, or adult sibling of patients with chronic mental illness when three factors are met, including direct involvement in the patient's care.¹³¹ Disclosures are limited to diagnosis and prognosis, medications, and a description of the patient's treatment plan.¹³² Georgia has an unusual example of limits on the right to receive mental health records in the case of decedents. In Georgia, estate executors, administrators, or spouses (in the absence of the appointment of an executor or administrator) have the right to request records of decedents,¹³³ but this right specifically excludes the right to receive records regarding psychiatric, psychological, or other mental health treatment.¹³⁴ West Virginia also limits access to mental health information.¹³⁵ Indiana similarly limits access to mental health information, alcohol or drug abuse treatment information, and information about communicable diseases.¹³⁶

In Minnesota, personal representatives have the same right as the principal to access medical records.¹³⁷ However, the mental health information that can be released to a spouse, parent, child, sibling of a patient, or direct care giver is limited.¹³⁸ Providers must ask patients if they agree to the disclosure.¹³⁹

E. Recognizing Patient Preferences: Limiting Access to the "Need to Know"

Several states tie the personal representative's access to health information to the "need to know." In Montana, providers may disclose health information without a patient's consent based on the recipient's need to know.¹⁴⁰ This would limit disclosures to the information needed to make the care decisions at hand. Patients also may instruct their providers not to

129. *Id.* § 28:227(C) (2009) (authorizing access to information regarding mental health treatment and mental health records related to treatment).

130. COLO. REV. STAT. § 25-1-801(1)(a) (2010).

131. IOWA CODE ANN. § 228.8(1) (West 2009).

132. *Id.* § 228.8(4).

133. GA. CODE ANN. § 31-33-2(a)(2)(A)-(D) (2009).

134. *Id.* § 31-33-4 (Supp. 2010).

135. W. VA. CODE § 16-29-1 (West 2011).

136. IND. CODE ANN. §§ 16-39-1-1, 16-39-1-3 (2008).

137. MINN. STAT. § 145B.08 (2010).

138. *Id.* § 144.294.

139. *Id.* § 144.294, Subd. 3(a)(5).

140. MONT. CODE ANN. § 50-16-529 (2009).

make such disclosures. In Florida, surrogates have the authority to make health care decisions for patients during incapacity¹⁴¹ and the authority to access appropriate medical records.¹⁴² “[H]ealth care decision” is defined to include the right to access all of the principal’s records that are reasonably necessary for the health care surrogate to make decisions involving the health care of the principal.¹⁴³

Limiting access to the need to know sets the default position so that personal representatives will not automatically have access to the full medical record. This may be the default position that best reflects the preferences of most patients. It gives personal representatives the information that they need to make medical decisions. It does not give personal representatives unlimited authority to see information in the record outside of that needed for care. Although this approach may best reflect what patients in general would want, it may not reflect the preferences of some patients, who may want their personal representatives to have either greater or lesser access to their records. Montana’s addition of the possibility for patients to instruct their providers not to make disclosures respects the choices of patients with these different preferences.

F. Recognizing Patient Preferences: Inviting Patients to Limit the Power of DPAs or Surrogates to Access Medical Records

Some states have DPA statutory provisions that the holder of the DPA has the same rights as the patient to access health care information, unless the advance directive specifies otherwise.¹⁴⁴ These statutes are of the “opt in” variety and require positive action on the part of the directive’s maker. If patients are less likely to use “opt in” possibilities than their preferences reflect, these options may be underutilized.¹⁴⁵ These statutes do, however,

141. FLA. STAT. § 765.205(1)(a) (2010).

142. *Id.* § 765.205(1)(d).

143. *Id.* § 765.101(5)(c).

144. *E.g.*, ALASKA STAT. § 13.52.070(a) (2008); CAL. PROB. CODE § 4678 (West 2009); DEL. CODE ANN. tit. 16, § 2509(a) (2003 & Supp. 2010); D.C. CODE § 21-2206(a)(2) (2001 & Supp. 2010); HAW. REV. STAT. § 327E-8 (2010); IOWA CODE ANN. § 144B.7 (West 2005); ME. REV. STAT. ANN. tit. 18-A, § 5-808 (2010); MO. REV. STAT. § 404.840 (2000); NEB. REV. STAT. § 30-3417(4) (1995); N.H. REV. STAT. ANN. § 137-J:9(II)(a) (2005 & Supp. 2010); N.M. STAT. § 24-7A-8 (West 2010) (general DPA); *id.* § 24-7B-10 (mental health DPA); N.C. GEN. STAT. § 32A-25.1(a) (2009); N.D. CENT. CODE § 23-06.5-08 (2002 & Supp. 2009); OHIO REV. CODE ANN. § 1337.13(A)(3) (West 2004); 20 PA. CONS. STAT. ANN. § 5456(d) (West 2010); R.I. GEN. LAWS § 23-4.10-2 (2008); TENN. CODE ANN. § 68-11-1809 (2006); TEX. HEALTH & SAFETY CODE ANN. § 166.157 (Vernon 2011); WIS. STAT. ANN. § 155.30 (West 2006 & Supp. 2010); WYO. STAT. ANN. § 35-22-409 (2009).

145. For reasons to think that cognitive bias reduces the likelihood that people will use “opt in” strategies, see RICHARD H. THALER & CASS R. SUNSTEIN, *NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS* 83-87, 108-10 (2008).

at least point out to people making advance directives the possibility that they might want to limit access to their medical information.

In Utah the advance directive statute requires a “yes” or “no” choice by the maker of the directive concerning whether the health care agent has the power to access medical records. This power applies whether or not agents can speak for themselves.¹⁴⁶ Structuring the advance directive in this way does not introduce the possibility of cognitive bias in an “opt in” or “opt out” structure.

IV. RECOMMENDATIONS

State laws about the access of personal representatives to health records vary widely. Some states simply assume that personal representatives have the rights of principals; others state this explicitly. Some states expand the right of individuals to access their medical records beyond disclosures required under HIPAA, without apparently considering whether this expanded access applies to personal representatives. Some states have special limits for rights to access certain types of information, particularly mental health information, substance abuse treatment information, or information about contagious disease. Some states may reflect patient preferences for limits by delineating access on a “need to know” basis, unless patients have specified otherwise. Some states’ advance directive statutes invite patients to set limits on access to medical information by their decision makers on an “opt in” basis. One state’s form has a “yes” or “no” choice for access to medical records for personal representatives.

From the point of view of respect for patient autonomy, this situation is far from ideal. It is not surprising however as many advance directive statutes were drafted before the quite recent groundswell in support of interoperable electronic health records. In light of this situation, this article makes four recommendations.

First, advance directive statutes should explicitly ask patients to designate the extent to which their personal representatives should have access to interoperable medical records. Ideally, the suggested advance directive form would identify specific types of information that patients may or may not want their personal representatives to see: information about mental health treatment, substance abuse treatment, or reproductive history, for example. The form should include options for “all” information, for information only on a “need to know” basis, or for no information. Structured this way, statutes would bring the issue to patients’ attention. It will require them to make a choice and thus avoid the potential for cognitive bias introduced by “opt in” or “opt out” mechanisms. A form structured with

146. UTAH CODE ANN. § 75-2a-117(2)(Part I (E)) (Supp. 2010).

specific choices prompts patients to decide what types of information they would—or would not—want to have shared with their personal representatives.

In many circumstances, patients will not have exercised such choices. This occurs when personal representatives have been designated for individuals, rather than being chosen through the patient's advance directive. It will also happen when patients have designated their decision-maker but without specifying authority to access information in their medical records. This last situation arguably is the circumstance with most advance directives today: patients are invited to specify the care they would (or would not) wish to receive, and to designate their decision-maker for health care. They are not, however, reminded that their decision-maker is also most likely being given authority to access their medical records or confronted with a choice in this regard.

A second recommendation is, therefore, that in these circumstances of absence of choice, the default position should be that personal representatives' access to medical information should take place on a "need to know" basis. That is, personal representatives should have access to information in the record that is needed to make care decisions, rather than access to the entire record. Limiting access in this way is most likely to reflect what patients would want. The purpose of a personal representative for health care decisions is, after all, to make health care decisions. These decisions should be informed on a need to know basis. It is unlikely that patients understand the design of interoperable records, and it is likely that patients would be surprised to find the scope of the information that may ultimately be accessible through these vehicles. Setting the default position as "need to know" would thus avoid the surprise of many Mothers about their Daughters' access to their medical records.

At present, interoperable medical records are not designed to allow special management of types of information that patients may regard as sensitive. There is discussion on the federal level of encouraging the development of capacities for interoperable health records to incorporate information management structures that will better reflect patient preferences for the management of designated categories of sensitive health information.¹⁴⁷ These categories may include psychotherapy notes and mental health treatment information, substance abuse treatment information, genetic information, information about treatment for sexually transmitted diseases, and reproductive information. The access of personal

147. See, e.g., Letter from Justine M. Carr, Chairperson, Nat'l Comm. of Vital Health & Statistics, to Kathleen Sebelius, Sec'y, U.S. Dep't of Health & Human Servs., Recommendations Regarding Sensitive Health Information (Nov. 10, 2010), available at <http://www.ncvhs.hhs.gov/101110lt.pdf>.

representatives to health records is an additional reason for encouraging this development. A third recommendation is that as capacities for separate management of designated categories of sensitive information become available, advance directives should be structured to take advantage of these developments.

Finally, these recommendations should apply both to patients with mental illness and to patients with cognitive disabilities. Despite the recognition that some patients have dual diagnoses of both mental illness and cognitive disabilities, access to the medical records of these groups of patients might seem to raise different issues, a possibility that warrants further discussion.

Patients with personal representatives because of mental illness will have at least some mental health treatment records. As described above, there is significant confusion and variation in state laws concerning the rights of both patients and their representatives to mental health treatment records. Under HIPAA, and in most states, neither patients nor their representatives have access to psychotherapy notes. From the perspective of patient autonomy, this limit is difficult to justify. Leaving aside this more general concern, an additional problem from the perspective of autonomy is that some state statutes may allow personal representatives the ability to access mental health records that patients themselves could not. If patient autonomy is to be given priority, however, patients' choices about whether their representatives should be able to see these records should be honored, just as patients' choices should be honored about other types of records. Personal representatives may object that they need access to these records to make treatment decisions. In cases in which individuals have not made provisions about their personal representatives' access to records, mental health records would, like other records, be available on a need to know basis. If individuals have specified that they do not want their representative to see mental health records, however, autonomy requires respecting this restriction—just as it does for other patients who choose to limit their representatives' access to their information.

For patients with cognitive disabilities, especially if these disabilities are longstanding, prior preferences may be difficult to ascertain. As explained above, in these cases records should be available on a need to know basis. Personal representatives may argue that the need for protection warrants access to certain types of records that patients may consider sensitive, especially records about sexual history where there is a risk of exploitation. On the default "need to know" approach, these records would be available if they are relevant to current decisions about protecting the patient. The only cases in which they would not be available would be cases in which the patient has specified in advance either that the representative should not

have access to any records, or that the representative should not have access to records in a designated category.

These four recommendations are autonomy-centric. They give patients the right to specify in advance whether their representatives should be able to access medical records. Where patients have not specified, they urge access on a “need to know” basis, so that representatives will have the information that is relevant to making health care decisions. They are designed to allow those patients who wish control to exercise it. They are also designed to respect what is likely to be the assumption of most patients: that they would be surprised to discover that the current power and promise of interoperable medical records is not only to improve care, but also to open everything to view.

