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Articles

Privacy and the Economics of Personal Health Care Information

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I. Introduction

[V]ideo rental records are afforded more federal protection than are medical records.¹

Genetic science permits, to a previously unimaginable degree, predictions as to the illnesses that a person—and her immediate relatives—might

1. Sheri Alpert, *Smart Cards, Smarter Policy: Medical Records, Privacy, and Health Care Reform*, HASTINGS CENTER REP., Nov.-Dec. 1993, at 13, 13-23.

confront in the future. At the same time, information technology permits greater transmission, sharing, and storage of personal health care data at ever lower costs on a national and even international basis.² The combination of easy dissemination of highly sensitive data and use of these data to predict future health risks has already caused significant harm.³

Employers are gaining information regarding which employees, potential or present, might fall ill in the future and are utilizing it to deny them jobs or promotions.⁴ Insurance companies are using this same information to deny health care coverage for these individuals.⁵ And at least one Health Maintenance Organization (HMO) has permitted electronic access to complete psychiatric-session notes to all its employees, including nurses and clerical staff.⁶ No adequate legal protection currently exists in this area.⁷ As dissemination becomes easier technologically and more predictions are made of future illnesses, more people will lose jobs and health coverage unless health care information receives legal protection that shields it from inappropriate disclosure.

The critical issue is how the law should structure the use of personal medical data by government and private enterprise alike. Proposals have been introduced in the current Congress that would prevent uncontrolled access to health care data.⁸ Proponents of these measures typically justify them on fairness grounds or, even more broadly, through reliance on a perspective that views privacy as a right.⁹ In contrast, their opponents have

2. For a discussion of the benefits of electronic transmission of health care data on a national basis, see COUNCIL ON COMPETITIVENESS, *HIGHWAY TO HEALTH: TRANSFORMING U.S. HEALTH CARE IN THE INFORMATION AGE* at v (1996) and PAUL M. SCHWARTZ & JOEL R. REIDENBERG, *DATA PRIVACY LAW: A STUDY OF UNITED STATES DATA PROTECTION* 163-65 (1996).

Beyond national boundaries, international transmission of health care data in electronic form already takes place. See generally Paul M. Schwartz, *The Protection of Privacy in Health Care Reform*, 48 *VAND. L. REV.* 295, 324-31 (1995).

This Article will use the following terms interchangeably: personal health care data, personal health care information, and personal medical information. These terms refer to medical or health information that can be associated with an individually identifiable person.

3. See *infra* notes 173-87 and accompanying text.

4. See *infra* section II(C)(2).

5. See *infra* section II(C)(5).

6. See *infra* section III(A)(1).

7. See *infra* section III(A)(1).

8. See, e.g., Genetic Information Nondiscrimination in Health Insurance Act of 1997, S. 89, 105th Cong.; Fair Health Information Practices Act of 1997, H.R. 52, 105th Cong.; Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong. Similar bills have been introduced without success in previous Congresses. See, e.g., Medical Records Confidentiality Act, S. 1360, 104th Cong. (1995). For a discussion of these proposals, see Schwartz, *supra* note 2, at 344-46.

9. See, e.g., *The Fair Health Information Practices Act of 1994: Hearings on H.R. 4077 Before the Information, Justice, Transportation, and Agriculture Subcomm. of the House Comm. on Government Operations*, 103d Cong. 448 (1994) [hereinafter *Health Privacy Hearings*] (statement of Janlori Goldman, Director, ACLU, Privacy and Technology Project).

questioned the economic efficiency of privacy legislation.¹⁰ This debate appears to have reached a stalemate.¹¹

This Article argues, however, that a strong economic argument can be made in favor of informational privacy. It does so by carrying out an internal critique of the current conventional wisdom of law and economics concerning the inefficiency of data privacy. This Article evaluates and corrects certain conclusions of law and economics theorists by testing their arguments within a specific and complex American landscape. In a world far more simple than the one that we inhabit, unlimited disclosure of personal data *might* be economically efficient. Yet, in the current marketplace for health care and employment—and any such markets that we are likely to have in the future—a strong economic argument can be made in favor of privacy.

We begin by exploring the provocative views of Judge Richard Posner and Professor Richard Epstein, who argue against regulation and in favor of unconstrained access to information about individuals. Judge Posner advocates open disclosure of personal information.¹² In his view, data privacy primarily serves to allow individuals to carry out dishonest manipulations of the world around them.¹³ Richard Epstein finds that the full benefits of the enormous predictive power of genetic data will be reaped only if unrestricted access is provided to this information.¹⁴

This Article's second Part points out the weaknesses in these approaches and argues that neither absolute disclosure nor absolute secrecy for medical data will be socially optimal.¹⁵ It finds open access sometimes to have negative effects and privacy to have a potentially positive impact. Because much information may be both harmful and useful in different contexts for different reasons, an economically efficient

10. See H. JEFF SMITH, *MANAGING PRIVACY: INFORMATION TECHNOLOGY AND CORPORATE AMERICA* 206 (1994) (noting that lawmakers are "sensitive to the arguments about the economic instability that can be created by a number of overly restrictive laws").

11. See *id.* (observing that "all parties . . . seem to be reaching a position of gridlock"); see also Robert M. Gellman, *Can Privacy Be Regulated Effectively on a National Level?: Thoughts on the Possible Need for International Privacy Rules*, 41 VILL. L. REV. 129, 140 n.47 (1996) (highlighting the decrease in the level of support for a uniform federal health privacy statute from the 103d to the 104th Congress).

12. See Richard A. Posner, *The Right of Privacy*, 12 GA. L. REV. 393, 394-95 (1978).

13. See *id.* at 400 (stating that people "want to manipulate the world around them by selective disclosure of facts about themselves"). For other works by Judge Posner that adopt this same perspective, see RICHARD A. POSNER, *OVERCOMING LAW* 530-51 (1995) (noting that people universally present a "self" to the outside world) and Richard A. Posner, *Privacy, Secrecy, and Reputation*, 28 BUFF. L. REV. 1, 1 (1979) ("Blackening another's reputation by means of false accusations is closely related to enhancing one's own reputation by concealing discreditable facts about oneself . . .").

14. See Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 13 (1994).

15. See *infra* subpart II(C).

distribution of information is unlikely to exist at either extreme on the privacy/disclosure continuum.¹⁶

In its third Part, this Article considers the nature of an economically efficient regulation for health care information and argues that optimal distribution of personal health care information requires rules that are tied to and follow these data through various uses.¹⁷ In the electronic age, a health "record" per se no longer exists. Rather than a static record, a more fluid kind of dossier is being created based on how different software applications tie together different databases.¹⁸ Such sharing of personal information in networks prevents any abstract, noncontextual evaluation of the impact of disclosing a given piece of personal data and limits the usefulness of a one-dimensional standard imposing either disclosure or privacy.¹⁹

Once identifiable health information is created, it should remain protected health information that is subject to fair information practices. This Article will develop the necessary elements of an optimal legal regulation of health care data.²⁰ It identifies the core principles essential for health care privacy legislation and provides an explicit economic argument for this statutory approach. In light of existing market structures, the law should put in place fair information standards that provide a privacy safety net for all health care consumers.²¹ Within this legal structure, market incentives will play an important role.

Because a fundamental element in creating market efficiency is knowledge, this Article argues that increasing one's awareness of how her personal data are used must be part of the essential prescription for health care privacy.²² Such knowledge can be structured by a statutory establishment of "information forcing" default rules and a "notice of information practices" for health care consumers.²³ The information-forcing default rules will force a sharing of information about data processing by the party with the superior knowledge of the practices;²⁴ the notice documents will provide health care consumers with the information necessary for them to strike better bargains in the privacy market.²⁵ This Article concludes by applying its standards of fair information practice in various areas in which health care data are utilized.²⁶

16. *See infra* subparts II(B)-(C).

17. *See infra* subpart III(B).

18. *See infra* subpart III(A).

19. *See infra* subpart III(B).

20. *See infra* section III(B)(2).

21. *See infra* subpart III(B).

22. *See infra* subsections III(B)(2)(b)-(c).

23. *See infra* section III(B)(2).

24. *See infra* subsection III(B)(2)(a).

25. *See infra* subsection III(B)(2)(b).

26. *See infra* subpart III(C).

II. Personal Health Care Information and the Market

Most of the legal discourse about privacy in the United States concerns an individual's behavior and the government's ability to place limits on it.²⁷ Extensive case law has developed concerning the boundaries of the right to engage in such conduct as purchasing contraceptives,²⁸ obtaining an abortion,²⁹ and even schooling one's children at home.³⁰ In contrast, this Article's focus is on a different type of privacy: it looks at the use of personally identifiable information by government and private organizations. This branch of law has variously been termed informational privacy, data privacy, or, in a term popular outside of the United States, data protection law.³¹

In the computer age, increased attention must be paid to data privacy. Today, ever increasing amounts of personally identifiable data are used to make more critical decisions than ever before. Legislators, judges, administrators, and a range of private sector organizations are now struggling to establish meaningful standards for data privacy in the United States.³²

Despite this debate about the content of these standards, significant agreement generally does exist regarding the insufficiency of the current

27. For a discussion of the constitutional dimensions of case law on the right of privacy, see generally GEOFFREY R. STONE ET AL., *CONSTITUTIONAL LAW* 940-1039 (3d ed. 1996). For a brief sampling of the rich scholarly literature regarding this issue, see Robert Burt, *The Constitution of the Family*, 1979 SUP. CT. REV. 329, 387-95; Bruce C. Hafen, *The Constitutional Status of Marriage, Kinship, and Sexual Privacy—Balancing the Individual and Social Interests*, 81 MICH. L. REV. 463, 559 (1983); Louis Henkin, *Privacy and Autonomy*, 74 COLUM. L. REV. 1410, 1424-25 (1974); Jed Rubenfeld, *The Right to Privacy*, 102 HARV. L. REV. 737, 784 (1989); and J. Harvie Wilkinson III & G. Edward White, *Constitutional Protection for Personal Lifestyles*, 62 CORNELL L. REV. 563, 588-97 (1977).

28. See, e.g., *Carey v. Population Servs. Int'l*, 431 U.S. 678 (1977); *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Griswold v. Connecticut*, 381 U.S. 479 (1965).

29. See, e.g., *Planned Parenthood v. Casey*, 505 U.S. 833 (1992); *Webster v. Reproductive Health Servs.*, 492 U.S. 490 (1989); *Roe v. Wade*, 410 U.S. 113 (1973).

30. For a discussion of the home schooling movement, see Bill Roorbach, *Mommy, What's a Classroom?*, N.Y. TIMES, Feb. 2, 1997, § 6 (Magazine), at 30.

31. For an analysis of the scope of this area of law within both the public and private sectors, see generally SCHWARTZ & REIDENBERG, *supra* note 2. For examples of excellent traditional comparative studies of data privacy law in the public sector, see generally COLIN J. BENNETT, *REGULATING PRIVACY: DATA PROTECTION AND PUBLIC POLICY IN EUROPE AND THE UNITED STATES* (1992) (comparing the politics of data protection in Sweden, the United States, West Germany, and the United Kingdom) and DAVID H. FLAHERTY, *PROTECTING PRIVACY IN SURVEILLANCE SOCIETIES* (1989) (comparing the adoption and implementation of data protection at the national and state level in Germany, Sweden, France, Canada, and the United States). The intellectual genesis for much of data privacy law remains Warren and Brandeis's classic article from 1890. See Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193 (1890) (exploring existing law for a principle that could be invoked to protect personal privacy).

32. For analysis of important deficiencies in the debate in the United States regarding standards for private sector information use, see Joel R. Reidenberg, *Setting Standards for Fair Information Practice in the U.S. Private Sector*, 80 IOWA L. REV. 497, 532-40 (1995). For a parallel discussion regarding the public sector, see Paul M. Schwartz, *Privacy and Participation: Personal Information and Public Sector Regulation in the United States*, 80 IOWA L. REV. 553, 613-18 (1995).

level of medical data privacy in the United States. A report by the Congressional Office of Technology Assessment concludes, "The present legal scheme does not provide consistent, comprehensive protection for privacy in health care information, whether it exists in a paper or computerized environment."³³ The Institute of Medicine's Committee on Regional Health Data Networks states that "the threats and potential harm" to individuals caused by disclosure of health information are "real and not numerically trivial."³⁴ Even more poignantly, Sheri Alpert, a government policy analyst, has observed that "video rental records are afforded more federal protection than are medical records."³⁵ As a final example of the inadequacy of data privacy for personal health information, consider the treatment of mental health records. One prominent psychiatrist, Dr. Denise Nagel, is so concerned about the failure of current regulation in this area that she advises patients "not to seek insurance reimbursement because that can mean their psychiatric records would no longer be private."³⁶ Other kinds of mental health professionals are issuing similar warnings to their clients.³⁷

A. *Posner and Epstein on Data Privacy*

Notwithstanding these institutional and individual complaints, a case has also been made in support of the current state of affairs regarding the use of personal data in general, and health care information in particular. This argument is an economic one; it is that wide access to personal information heightens economic efficiency and promotes social utility. Richard Posner and Richard Epstein advocate this viewpoint. We begin with Richard Posner's arguments for a disclosure-oriented approach.

1. *Posner's Case for Disclosure.*—In his exegesis of informational privacy, *The Right of Privacy*, Richard Posner is explicit about his starting point. Posner argues that privacy is best understood not as a preference,

33. OFFICE OF TECH. ASSESSMENT, 103D CONG., PROTECTING PRIVACY IN COMPUTERIZED MEDICAL INFORMATION 13 (1993) [hereinafter OTA, COMPUTERIZED MEDICAL INFORMATION].

34. COMMITTEE ON REG'L HEALTH DATA NETWORKS, INST. OF MED., HEALTH DATA IN THE INFORMATION AGE: USE, DISCLOSURE, AND PRIVACY 156 (Molla S. Donaldson & Kathleen N. Lohr eds., 1994).

35. Alpert, *supra* note 1, at 13. For similar views regarding the inadequacy of the current level of medical data privacy, see COUNCIL ON COMPETITIVENESS, *supra* note 2, at 44; Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 494-95 (1995); and Gina Kolata, *When Patients' Records Are Commodities for Sale*, N.Y. TIMES, Nov. 15, 1995, at A1 (reporting on congressional efforts to establish uniform rules for the disclosure of health records).

36. Kolata, *supra* note 35.

37. See Maggie Scarf, *Keeping Secrets*, N.Y. TIMES, June 16, 1996, § 6 (Magazine), at 38 (posing the question whether the Bennett-Leahy Bill will sufficiently protect therapist-patient privacy under managed care).

but as an "intermediate good."³⁸ People do not wish privacy for its own sake. Rather, privacy has an instrumental value, and functions as a form of "inputs into the production of income or some other broad measure of utility or welfare."³⁹ Privacy matters to the extent that it serves to increase wealth and social utility. Moreover, privacy has a close relation to wealth and utility because people not only exchange goods, but also try to "sell" themselves to the world by attempting to control the flow of information relating to them.⁴⁰

Posner views the mass of humankind as eager to lie about its achievements and personal characteristics for economic gain. As he skeptically observes, individuals

profess high standards of behavior in order to induce others to engage in social or business dealings with them from which they derive an advantage but at the same time they conceal some of the facts that these acquaintances would find useful in forming an accurate picture of their character.⁴¹

Privacy facilitates attempts by individuals "to manipulate the world around them by selective disclosure of facts about themselves."⁴² Dishonesty will prove the best policy for many if the law acts to protect personal information.

According to Posner, privacy can provide a considerable obstacle to efficient marketplace transactions through its effect on the ongoing exchange of personal data that is part of social life.⁴³ An individual who manipulates others by limiting access to her personal data has benefited from harmful information asymmetries. Thus, a legal order that recognizes overly generous data privacy interests prevents exchanges necessary to an efficient marketplace.⁴⁴ The Posnerian prescription is straightforward: privacy in personal information should be protected only to the extent to which it increases social utility and assigned away from individuals when it does not.⁴⁵

Posner also has a method for deciding how this assignment should be made. He views the task of evaluating informational privacy as beginning with the inquiry whether (1) personal information is "a byproduct of socially productive activity" and (2) "its compelled disclosure would

38. Posner, *supra* note 12, at 394.

39. *Id.*

40. *Id.* at 399-400.

41. *Id.* at 399.

42. *Id.* at 400.

43. *See id.* at 397-400.

44. *See id.* at 399-400.

45. *See id.* at 398-401.

impair the incentives to engage in that activity.”⁴⁶ This two-pronged analysis quickly leads Posner to a judgment that corporate data and other trade secrets should generally be protected and most “facts about people” should not.⁴⁷

This conclusion is at least initially unconvincing. In a way that corporate privacy has not seized the public’s imagination, the extent of protection for information about people continues to be of tremendous social and legal concern.⁴⁸ Moreover, Posner’s introduction of a final concept—transaction costs—will not serve to reassure a skeptical reader. This term refers to the complicating factor that most existing markets are not frictionless, but function only as a result of sometimes quite costly bargaining among the affected parties.⁴⁹ Posner argues that transaction costs offer a final reason against assigning a privacy right to most people who wish to keep their personal data a secret.⁵⁰ For our purposes, his most useful example concerns direct-marketing lists.

Posner considers whether the law should allow a magazine to sell its list of subscribers without obtaining the consent of the concerned parties.⁵¹ His conclusion is affirmative, and it is based on transaction costs. Posner asserts that “the costs of obtaining subscriber approval would be high relative to the value of the list” for the magazines.⁵² He adds, “If, therefore, we believe that these lists are generally worth more to the purchasers than being shielded from possible unwanted solicitations is worth to the subscribers, we should assign the property right to the magazine; and the law does this.”⁵³ The assignment to publishers of exploitation rights regarding subscriber data is held to be desirable because it reaches an efficient result without subjecting the parties to costly negotiations that would reduce the overall efficiency of their exchange.⁵⁴

As this example indicates, Posner is willing to sidestep the workings of the market, which would require parties to agree to any transaction

46. *Id.* at 403.

47. *Id.* at 404. But for an argument on law and economics grounds that some corporate data should not be protected, but shared with employees, see Kent Greenfield, *The Curious Absence of Federal Fraud Protection in the Labor Market*, 107 *YALE L.J.* (forthcoming Dec. 1997).

48. Indeed, the decisive moment in the birth of the phrase “right to privacy” occurred in the context of personal informational privacy. See Warren & Brandeis, *supra* note 31. One aspect of this right, which concerns the media’s reporting of facts about people, has received new attention due to the tragic death of Princess Diana. See Cass R. Sunstein, *Reinforce the Walls of Privacy*, *N.Y. TIMES*, Sept. 6, 1997, at A23.

49. For a general introduction, see A. MITCHELL POLINSKY, *AN INTRODUCTION TO LAW AND ECONOMICS* 11-14 (2d ed. 1986).

50. See Posner, *supra* note 12, at 398-99.

51. See *id.* at 398.

52. *Id.*

53. *Id.*

54. See *id.* at 399.

regarding subscription information, for the greater goal of market efficiency. In some instances, this shortcut may be justifiable; here, it seems more reflexive than the result of detailed analysis. We will return to this point in a subsequent section concerning transaction costs and information asymmetries;⁵⁵ let us first explore Richard Epstein's arguments regarding open access to genetic data.

2. *Epstein's Advocacy of Open Access to Personal Genetic Information.*—While Posner considers the value of informational privacy by examining legal issues relating to different kinds of personal data, Richard Epstein centers his analysis on one type of personal information—genetic data. Like Posner, Epstein constructs an argument based on economic considerations and reaches similar conclusions. In his view, unrestricted access to personal genetic data has a large potential for increasing social wealth.⁵⁶ Setting legal restrictions on access to genetic information will, in contrast, permit the advances of science to be “frittered away.”⁵⁷

To Epstein, genetic data represent a potential treasure trove for society. Genetic science is making available new kinds of predictive data, and Epstein argues that this personal information should be utilized by many more people than the individual to whom it directly refers. In particular, genetic testing offers employers a critical opportunity to reduce labor costs and otherwise improve the efficiency of their operations.⁵⁸ Once assigned open access to information, employers and insurers will make economically efficient use of genetic data.⁵⁹ Indeed, due to their rational nature, these groups “have no incentive to discriminate against [workers] whose genetic conditions pose no future risk.”⁶⁰

In contrast to the benefits from disclosure of genetic information, Epstein believes that legal limits on access to these data will reduce social wealth. Such restrictions create information asymmetries that cause market inefficiencies. As we have seen, this argument is also at the heart of the Posnerian approach to informational privacy.⁶¹ Data privacy and prohibitions against genetic discrimination create “an elaborate set of cross-subsidies that reduces the total level of social wealth as it transfers wealth

55. See *infra* section II(C)(1).

56. See Epstein, *supra* note 14, at 16 (noting that “the regulated information is . . . valuable to the employer who is systematically denied access to it,” and concluding that employers will initiate costly strategies to offset such losses).

57. *Id.* at 23.

58. See *id.* at 22, 21-22 (pointing out that social losses are “generated by the higher capital expenditures that could be averted if only certain workers were hired for particular tasks”).

59. *Id.* at 18.

60. *Id.*

61. See *supra* notes 41-44 and accompanying text.

between parties."⁶² These cross-subsidies transfer wealth from employers and genetically healthy workers to those who will suffer from genetic illnesses in the future.⁶³

In an earlier paper, George Stigler made a similar point in a more general context.⁶⁴ He argued that limits on access to personal information lump together heterogeneous groups and create a "redistribution of income . . . within the enlarged class."⁶⁵ In this view, restrictions on access to personal genetic information represent a tax on employers and the genetically fit.⁶⁶ Moreover, by creating differences in knowledge about future disabling conditions, these limits on data flows encourage devious behavior.⁶⁷ With more information than outside parties, persons with genetic defects will obtain opportunities and benefits that employers and insurers would otherwise deny them. As Epstein warns, "The person who wants privacy need not apply for the position or the insurance coverage. But he should not be able to have it both ways and at someone else's expense."⁶⁸ Full disclosure should be the norm, and, in some instances, Epstein believes an individual's failure to reveal her personal genetic information should even be regarded by the law as fraudulent behavior.⁶⁹

Epstein's chief prescription for a social response to the impact of genetic data is minimalistic. Society should "do nothing collectively at all, at least through the government."⁷⁰ Fortunately, even in Epstein's world of entirely efficient actors, the quality of mercy will not be strained. Epstein states, "Today enormous charitable efforts are made on behalf of the handicapped."⁷¹ In addition to this prescribed reliance on charity, Epstein expects future technical innovations to increase the productivity of disabled workers and make firms more likely to hire them.⁷² If political realities make an avoidance of governmental activism impossible, however, Epstein grudgingly advocates an open subsidy program under which the government funds "the additional costs associated with hiring or insuring individuals with genetic defects."⁷³

62. Epstein, *supra* note 14, at 18.

63. *Id.*

64. See George J. Stigler, *An Introduction to Privacy in Economics and Politics*, 9 J. LEGAL STUD. 623, 630, 624-33 (1980).

65. *Id.* at 630.

66. See *id.* at 631.

67. See Epstein, *supra* note 14, at 12-13.

68. *Id.* at 13.

69. See *id.* at 12-13, 19.

70. *Id.* at 20 (emphasis omitted).

71. *Id.* For a discussion of (1) how current trends in the market for health care services are likely to diminish the provision of charity care and (2) why the provision of health care through charity is inefficient, see *infra* text accompanying notes 223-28.

72. See Epstein, *supra* note 14, at 20.

73. *Id.* at 21, 20-21.

This analysis applies a law and economics approach to a specific kind of personal health care data. As we shall see, an extreme privacy right would, in fact, be a poor tool for fashioning a law regarding the use of medical data.⁷⁴ At the same time, however, an excessive reliance on non-privacy, that is on disclosure, will also fail society. Nevertheless, Epstein believes that *any* limits on access to genetic information threaten labor market efficiency. He argues that protecting informational privacy will inevitably have ugly results: "Along the road, truth is discouraged and lies are protected, promoted and necessary."⁷⁵ Despite the fervency with which Epstein presents these views regarding the invariably negative consequences of informational privacy, one can doubt the existence of this particular slippery slope for a number of reasons.

B. *The Fallacy of Free Disclosure*

Our analysis begins with a brief consideration of the practice of medicine in the United States and continues with scrutiny of the current state of genetic science. This Article will also explore the financing of health care services and the nature of the relevant insurance markets. Such analysis is necessary if the law and economics perspective is to be true to itself. Its advocates must take the market and science seriously—not by constructing a fantasy, but by considering the structure of the world in which we live. To be sure, dangers are present in this endeavor: when we seek to complicate a reductionist approach in order to reproduce more of the complexity of the world, the result may be so ornate that our model is unreliable either for predictive purposes or as a basis for policy interventions.⁷⁶ Nevertheless, I will point to a series of situations in which unrestricted disclosure of personal data will not lead to the promised economic benefits.

1. *The Economics of Medical Information.*—The practice of medicine increasingly depends on the large-scale comparison and analysis of personal medical information.⁷⁷ As a result, health care institutions view personal medical information as a critical strategic resource.⁷⁸ From this

74. See *infra* section II(B)(1).

75. See Epstein, *supra* note 14, at 14.

76. Judge Posner has made a similar point by warning of the danger of "complicationism." RICHARD A. POSNER, *ECONOMIC ANALYSIS OF LAW* 17 (4th ed. 1992).

77. See INSTITUTE OF MED., *THE COMPUTER-BASED PATIENT RECORD* 19-23 (Richard S. Dick & Elaine B. Steen eds., 1991) (describing the ever-increasing demand for patient care data among health care practitioners).

78. See Jon L. Ruckle, *An Essential Technology*, in *HEALTH INFORMATION: MANAGEMENT OF A STRATEGIC RESOURCE* 669, 669 (Mervat Adelhak et al. eds., 1996) [hereinafter *HEALTH INFORMATION*] ("Information systems are *the* essential, enabling technology which allows other organizational, technical, and operational solutions to succeed." (emphasis in original)); see also *infra* note 99 and accompanying text.

perspective, the paper medical record appears as a relic from another era. Delays and high costs are associated with manually pulling paper records from file rooms, duplicating them, and sending them to all the parties who provide, regulate, and finance health care services.⁷⁹ Indeed, studies of the economics of health care reveal that as much as one-half of a typical nurse's time and one-third of a physician's time are spent performing clerical tasks.⁸⁰ The net cost of all this documentation is enormous; as a recent article in the financial press points out, as much as forty percent of the current cost of running a hospital involves "storing, collecting, and moving information."⁸¹ The possibilities for cost-savings or even additional income are enormous if the processing of personal medical data can be improved.⁸²

As a result of a growing desire to streamline and speed the use of personal medical information, private and public institutions have expressed a strong interest in utilizing computer-based patient records and are investing heavily to develop and install the necessary devices.⁸³ Statistics indicate the critical importance of health care management, which is the discipline that combines information technology and medical science.⁸⁴ One Wall Street analyst forecasts that the total annual revenue of the health care information systems industry in the United States, which was \$980 million in 1993, will reach \$2.4 billion in 1997.⁸⁵ This expert foresees an increase to \$4.3 billion in annual revenues within the next four years.⁸⁶ Electronic systems that move information are becoming as essential to health care as the roof over the head of physicians and patients.

Enormous changes have taken place in the way medical services are provided in the United States. At one time, a physician's "practice was

79. See Randolph C. Barrows, Jr. & Paul D. Clayton, *Privacy, Confidentiality, and Electronic Medical Records*, 3 J. AM. MED. INFORMATICS ASS'N 139, 146-47 (1996) (maintaining that computer-based medical records are more cost-efficient and readily accessible than paper-based medical records).

80. See Ralph A. Korpman, *Electronic Medical Records*, 1994 MED. PRAC. MGMT. 282, 283.

81. Kambiz Foroohar, *Rx: Software*, FORBES, Apr. 7, 1997, at 114.

82. See Korpman, *supra* note 80, at 283.

83. In an illustration of the occasional necessity of spending money to save money, one blue-ribbon committee has predicted that virtually every medical information system currently in operation will be replaced in the next five to ten years. See COUNCIL ON COMPETITIVENESS, *supra* note 2, at 48.

84. See generally HEALTH INFORMATION: MANAGEMENT OF A STRATEGIC RESOURCE (Mervat Abdelhak et al. eds., 1996); DANA C. MCWAY, LEGAL ASPECTS OF HEALTH INFORMATION MANAGEMENT (1996).

85. See Charles Clark, *Health Care Information Systems*, VALUE LINE INVESTMENT SURV., Jan. 3, 1997, at 682, 682.

86. See *id.* In comparison to the rapid increase in investments in health care information systems, total governmental and private spending for medical facilities construction has been increasing at a significantly slower rate and, in fact, even has declined for the last two years for which full data are available. See U.S. DEP'T OF COMMERCE, STATISTICAL ABSTRACT OF THE UNITED STATES 112 (1996).

largely invisible to his peers, . . . and unconstrained by external institutions.”⁸⁷ As Professor Timothy S. Jost writes of this period, “In ordinary day to day life, . . . the physician answered to no one but himself.”⁸⁸ Today, information technology renders accessible to external observation the staggering amount of data involved in the diagnosis, treatment, and billing of patients. A tradition of deference to the medical profession and its definition and application of professional standards has been replaced by a model of control through processing and use of personal information. A widening audience of outsiders monitors the behavior of doctors, nurses, and patients.⁸⁹ As two physicians have written, “Medicine is increasingly a spectator sport.”⁹⁰

The provision, regulation, and financing of health care in the United States and other industrial nations depend on outside access to personal health care data. In addition to allowing this external monitoring of physicians and patients, the sharing of personal medical data plays a fundamental role in the shift to large, integrated systems for providing health care in the United States. Under a single corporate umbrella, an integrated delivery system now provides medical care by coordinating the services of numerous health care professionals located in hospitals, clinics, and outpatient facilities.⁹¹ The computer is essential to this transformation because it permits both the collection of extensive personal health data and the rapid sharing of such information. As an essay in the *New England Journal of Medicine* notes, the computer is seen “as a device to transform the medical record into a semipublic record used routinely for a wide range of investigations.”⁹² This aspect of information technology has been heightened by the introduction of computer-based health care records.

When stored within these electronic dossiers and used within networked systems that link different sites, personal data become

87. Timothy Stoltzfus Jost, *Oversight of the Quality of Medical Care: Regulation, Management, or the Market?*, 37 ARIZ. L. REV. 825, 831 (1995).

88. *Id.*

89. See Barrows & Clayton, *supra* note 79, at 141 (“The notion of confidentiality in health care has a strong professional tradition that has suffered progressive erosion due to third-party reimbursement schemes, managed care and other health care organization structures, and the perceptions and culture of professionals within modern health care systems.” (citation omitted)).

90. Steffie Woolhandler & David U. Himmelstein, *The Deteriorating Administrative Efficiency of the U.S. Health Care System*, 324 NEW ENG. J. MED. 1253, 1253 (1991) (noting that doctors, nurses, and patients perform before an enlarging audience of efficiency experts, utilization reviewers, and cost managers).

91. See OFFICE OF TECH. ASSESSMENT, 103D CONG., BRINGING HEALTH CARE ONLINE: THE ROLE OF INFORMATION TECHNOLOGIES 84 (1995) [hereinafter OTA, BRINGING HEALTH CARE ONLINE] (noting that some Integrated Delivery Systems “are making the investments needed to develop ‘enterprise-wide’ information systems to allow exchange of clinical and administrative information among various components”).

92. Beverly Woodward, *The Computer-Based Patient Record and Confidentiality*, 333 NEW ENG. J. MED. 1419, 1421 (1995).

“multifunctional.”⁹³ The computer changes personal information into a fluid form and allows it to be applied in many different kinds of administration and decisionmaking.⁹⁴ Personal health care information is now transmitted electronically among the computers of hospitals, insurers, governmental regulators, and physicians—each of whom may use it for different purposes.⁹⁵ Such data-sharing already functions as part of statewide computer networks⁹⁶ and soon will be extended on a nationwide and even international basis.⁹⁷ In the words of Clifford Stoll, “[L]ots

93. Paul Schwartz, *Data Processing and Government Administration: The Failure of the American Legal Response to the Computer*, 43 HASTINGS L.J. 1321, 1339-41 (1992).

94. *See id.* A good example of multifunctionality relates to the fashion in which the computer has not only revolutionized the administration of health care, but also has formed the basis for creating new kinds of medical tools, including such current staples of modern medical practice as Magnetic Resonance Images (MRIs) and Computer Assisted Tomography Scans (CAT scans). *See* DOROTHY NELKIN & LAURENCE TANCREDI, DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION 30 (1989). Computerized medical devices create digitized data from the time of the patient's first encounter with the health care system. This information can be used in treatment and billing, as well as in outside oversight of physician decisionmaking.

95. *See* OTA, BRINGING HEALTH CARE ONLINE, *supra* note 91, at 79-122 (discussing generally those differing uses for networks of health care information).

96. Wisconsin offers a good example of a functioning statewide system for sharing electronic patient records. In that state, Aurora Health Care, a nonprofit organization that owns 9 hospitals and 18 professional practice groups in the state, utilizes computer-based health records within its own health care delivery system. *See* AURORA HEALTH CARE, AURORA HEALTH CARE AT A GLANCE 2 (1996). It also makes these records available as part of a Community Health Information Network (CHIN), which seeks to facilitate the communication of patient clinical and financial data throughout a series of health care entities. *See id.*

The Massachusetts Health Data Consortium provides another example of a statewide approach to electronic health care information. *See* AFFILIATED HEALTH INFO. NETWORKS OF NEW ENGLAND, MASSACHUSETTS HEALTH DATA CONSORTIUM, INC., AFFILIATED HEALTH INFORMATION NETWORKS OF NEW ENGLAND: 1997 PUBLIC MEETING REPORT (on file with the *Texas Law Review*). As part of its introduction of a comprehensive health information data system, the Consortium has enlisted an impressive group of health care providers, insurers, employers, government representatives, and health service researchers. *See id.* One of its focuses is on providing advice and guidance for health care organizations that are implementing electronic data interchanges. *See id.* at 1 (Report of EDI Business Transactions Group).

More rural parts of the United States also make use of this technology. In Phillips County, Arkansas, for example, the Helena Regional Medical Center is being linked electronically with 13 clinics, 4 pharmacies, and 1 community health center. *See* George Waldon, *Telecom Project Could Transform Health Care*, 13 ARK. BUS., Feb. 1996, at 1, 19-25.

As a final example of the electronic transmission of personal health care data, the Institute of Medicine's Committee on Regional Health Data Networks has advocated the creation of powerful “health database organizations” that are to play a critical role in the future delivery of medical services. *See* COMMITTEE ON REGIONAL HEALTH DATA NETWORKS, *supra* note 34, at 40-90. This Committee of the Institute of Medicine proposes that these entities have “access to (and possibly control of) databases and a primary mission to publicly release data and the results of analyses done on the databases under their control.” *Id.* at 54.

97. Beyond state boundaries, the Clinton Administration's National Information Infrastructure (NII) initiative has sought to encourage the national transmission of medical information. By increasing electronic transfers of health care data, the NII seeks “to significantly expand access to health care, improve its quality, and reduce its costs.” COUNCIL ON COMPETITIVENESS, *supra* note 2, at v (emphasis omitted). One expert already predicts that “information systems linked to the National

of little computers have taken over where once giant mainframes roamed."⁹⁸

This reliance on multifunctional electronic records used within and without integrated health care systems helps make personal health care information one of the key assets in medicine today.⁹⁹ Under these circumstances, a Posnerian analysis suggests that maximizing social utility requires assigning to others an ability to access personal health care data. As Posner writes, "Secrecy is an important method of appropriating social benefits to the entrepreneur who creates them while in private life it is more likely to conceal discreditable facts."¹⁰⁰ While this approach suggests an important insight, it also misses much that is important. Its insight is that the rhetoric of a right to control one's information will prove to be a limited policy tool in the computer age because the sharing of personal data has become essential to political, commercial, and communal life.

Information Infrastructure are destined to play a central role" in a transition to health care provided in a cost-conscious, managed-care environment. J. Michael Fitzmaurice, *Health Care and the National Information Infrastructure*, in HEALTH INFORMATION, *supra* note 78, at 685, 685.

Much about the NII is, however, uncertain. In particular, the respective roles of the government and private sector in its development and operation remain unsettled. See U.S. DEP'T OF COMMERCE, PUTTING THE INFORMATION INFRASTRUCTURE TO WORK: A REPORT OF THE INFORMATION INFRASTRUCTURE TASK FORCE COMMITTEE ON APPLICATIONS AND TECHNOLOGY 41-46 (1994) (outlining the challenges facing the NII and the roles it could possibly play in the near future). In this vacuum, the private sector is actively seeking commercial development of the NII's health care applications. See Rob Hof, *Netscape Wasn't Enough*, BUS. WK., June 24, 1996, at 6. The entrepreneur responsible for Netscape, the most popular browser on the World Wide Web, is already setting up "an online service to help doctors, insurers, and patients exchange data and do business over the Internet." *Id.*

Beyond national boundaries, international transmission of health care data in electronic form is possible. The electronic transmission of other kinds of personal information already takes place on a global basis. See Schwartz, *supra* note 2, at 332-33. With no end in sight to the information revolution, increasing amounts of personal data are now circulating the globe. See *id.* at 331-33. For example, medical information located in the employment records of international corporations is the type of medical data most likely to be transferred internationally. See *id.* at 331. In addition, all large pharmaceutical companies market their products internationally and sometimes are required by national regulatory authorities to collect and share information regarding experiences with their products in foreign countries. See *id.* at 332 (noting that the U.S. Food and Drug Administration requires such sharing). These data will increasingly be collected and transmitted in electronic form. See generally OTA, BRINGING HEALTH CARE ONLINE, *supra* note 91, at 123-58.

98. CLIFFORD STOLL, SILICON SNAKE OIL: SECOND THOUGHTS ON THE INFORMATION HIGHWAY 94 (1995).

99. As one health care professional has observed:

Data will be a prime possession in the evolving health care environment. Managed care organizations, [pharmacy benefit managers], and manufacturers will be driven by actionable information that can be converted into knowledge that will guide strategic business decisions. Health care professionals will be just as data-driven, and the informatics systems will provide patient-level data to support medical decisions at the point of care.

Robert P. Navarro, *User Applications of Health Economic Data*, 1996 MED. INTERFACE 82, 82.

100. Posner, *supra* note 12, at 404.

Yet, the weakness of Posner's approach, as we will see in the next section, is that a preference for free disclosure of personal data is also likely to be of limited use.¹⁰¹ Neither extreme of absolute privacy or of free disclosure will best serve society.

Currently, more individuals are employed in activities relating to the gathering, coordination, and analysis of information than in manufacturing.¹⁰² The term "information society" captures this economic and social reality, and much of the data at stake are personal—that is, they refer to identifiable individuals.¹⁰³ The United States government relies upon the collection and processing of personal information to manage itself and to distribute and administer social services, and the private sector is no less reliant upon access to personal information.¹⁰⁴ Records exist of our physical health, workday performances, telephone calls, use of credit, and cyberspace behavior.¹⁰⁵

Society will not be served well if the law maximizes the boundaries of an individual right of control over personal data. Indeed, enormous and shared benefits result from some level of public and private sector scrutiny of personal information; one need only think of the screening through access to data banks of applicants for positions of trust in hospitals, nuclear plants, and the financial-service industry.¹⁰⁶ Knowledge is power, after all, and communal life depends upon each person's access to information about the parties with whom she will interact. At the same time, however, Posner's general position placing a disclosure interest above informational privacy will not be successful. The weakness of this approach can be

101. See *infra* section II(B)(2).

102. See JAMES R. BENIGER, *THE CONTROL REVOLUTION: TECHNOLOGICAL AND ECONOMIC ORIGINS OF THE INFORMATION SOCIETY* 21-22 (1986) (addressing the origins and the impact of the information society).

103. See *id.* For the origins of the phrase "information society," see FRITZ MACHLUP, *THE PRODUCTION AND DISTRIBUTION OF KNOWLEDGE IN THE UNITED STATES* 362-76 (1962).

104. See Schwartz, *supra* note 93, at 1332-43 (discussing the government's reliance on the data processing model of bureaucracy and the role of the computer therein). For a pathbreaking article that considers possible positive economic externalities inherent in the government's collection of personal information, see Anthony T. Kronman, *The Privacy Exemption to the Freedom of Information Act*, 9 J. LEGAL STUD. 727, 737 (1980).

105. See Schwartz, *supra* note 93, at 1332-43. For a discussion of privacy problems in cyberspace, see Walter S. Mossberg, *Threats to Privacy On-Line Become More Worrisome*, WALL ST. J., Oct. 24, 1996, at B1 (detailing the industry practice of capturing an internet user's World Wide Web viewing history); Stephen H. Wildstrom, *Privacy and the Cookie Monster*, BUS. WK., Dec. 16, 1996, at 22 (explaining that servers can track the actions of users registered at a web site and then sell this information to advertisers and other interested parties); Stephen H. Wildstrom, *They're Watching You Online*, BUS. WK., Nov. 11, 1996, at 19 (describing the creation of log files of an internet browser's World Wide Web site record and the collection of the user's interests).

106. For example, federal law establishes a National Practitioner Data Bank. See 42 U.S.C. §§ 11101, 11131-11152 (1994). Federal regulations not only require the filing of reports with this Data Bank, but create powerful incentives for hospitals to request information from it when granting clinical privileges and appointments to their staff. See *id.* § 11101; 45 C.F.R. §§ 60.1-60.14 (1996).

illustrated by consideration of the supposed marvels that Epstein believes will follow from unlimited access to personal genetic data.

2. *The Economics of Modern Genetic Science.*—As we have seen, Epstein is a zealous believer in the predictive power of genetic science and argues that personal genetic data will be of inestimable economic value for employers and insurers in weeding out unsuitable and otherwise undesirable workers.¹⁰⁷ Despite the enormous benefits that genetic science has brought humankind and its potential for even greater achievements, Epstein misunderstands this science and ignores its potential for causing social harm. Put simply, unrestricted access to these data is not a source of boundless social wealth. Epstein's mistaken view stems from his result-oriented approach to science. He utilizes genetic science to end at a pre-ordained point, which is a judgment regarding the powerful predictive nature of genetic data and the concomitant need for wide disclosure of this bounty. A different and more persuasive reading of the science of modern genetics has far different implications for data privacy.

The critical breakthrough in modern genetics occurred in 1953 with James Watson and Francis Crick's identification of the double-helix structure of DNA, the substance out of which most organisms' genetic material is formed.¹⁰⁸ Building on this discovery, scientists began to explore the process by which DNA is copied.¹⁰⁹ The copying of DNA is important because of this mechanism's critical role in the inheritance of traits and the creation of genetic mutations.¹¹⁰ As R.C. Lewontin points out, DNA itself is best understood as the bearer of critical "information that is read by cell machinery in the productive process."¹¹¹

Scientists who practice human molecular genetics are moving beyond the study of DNA's role in cell production and seeking to map the entire human genome.¹¹² The human genome consists of the three billion base pairs of DNA found in the loci of chromosomes in the human species.¹¹³ Some scientists have argued that the identification of the human genome—the totality of the genetic material in a typical human cell—will mark an

107. See *supra* notes 58-60 and accompanying text.

108. See J.D. Watson & F. Crick, *A Structure for Deoxyribose Nucleic Acid*, 1953 NATURE 737, 739.

109. See PHILIP KITCHER, *THE LIVES TO COME: THE GENETIC REVOLUTION AND HUMAN POSSIBILITIES* 23-64 (1996).

110. See *id.* at 60-63.

111. R.C. Lewontin, *The Dream of the Human Genome*, N.Y. REV. BOOKS, May 28, 1992, at 31, 33.

112. See *id.* This work is being carried out as the Human Genome Project in the United States and by the Human Genome Organization abroad. See CHRISTOPHER WILLS, *EXONS, INTRONS AND TALKING GENES: THE SCIENCE BEHIND THE HUMAN GENOME PROJECT* 24-26 (1991).

113. See KITCHER, *supra* note 109, at 41.

essential breakthrough in our understanding of how our bodies function and how they fail.¹¹⁴ With considerable public financial support in the United States and abroad, experts have made significant progress in mapping this structure.¹¹⁵

Genetic science already has been able to show how the manifestation of certain diseases is linked to changes in genetic material. These illnesses—such as cystic fibrosis, Tay-Sachs, and Huntington's Disease—are caused by changes at a single chromosome locus.¹¹⁶ Such monogenic diseases, which affect only a tiny fraction of the population, can now be effectively predicted, although not cured.¹¹⁷ In contrast to these conditions with a unitary genetic cause, however, more widespread diseases are multifactorial in genetic origin.¹¹⁸ For these illnesses, genetics has been able to identify some of the implicated alleles—the form of genetic material at a chromosome locus.¹¹⁹ Narrowing the causes of a disease in this way can help fashion a therapeutic approach by increasing physicians' understanding of the etiology of a specific patient's condition.¹²⁰ A further benefit of genetic science has been the development of recombinant techniques that allow the cloning of DNA.¹²¹ Among the results of this technology has been the manufacture of different kinds of highly beneficial substances, such as human insulin, human growth hormone, and new vaccines.¹²²

Thus, the study of the human genome already has increased mankind's knowledge of the functioning of cellular machinery and the role of genes in disease. These scientific developments are also creating a new kind of

114. *See id.* at 21 (noting that some have predicted the Human Genome Project will lead to "great medical advances"). Genetic information offers a unique promise for scientific breakthroughs not only in biology, but also in solving some of the great puzzles of history. *See* Nigel Williams, *Ancient DNA: The Trials and Tribulations of Cracking the Prehistoric Code*, 269 *SCIENCE* 923, 924 (1995). This promise is heightened by genetic material being able to survive for centuries if the right conditions are present. *See id.* Scientists have studied the genetic material preserved in the remains of Mayan mummies and the tissues of the corpse of a 5000-year-old Alpine wanderer whose body was discovered in a glacier in 1991. *See id.* Scientists are even using ancient DNA to study patterns of human migration over the past 30,000 years. *See id.*

115. The National Institutes of Health provides the latest information about the Human Genome Project on the Internet. *See* National Ctr. for Biotechnology Info., National Inst. of Health, *A Gene Map of the Human Genome* (visited Aug. 20, 1997) <<http://www.ncbi.nlm.nih.gov/SCIENCE96/>>.

116. *See* KITCHER, *supra* note 109, at 56-60.

117. *See id.* at 56-59.

118. *See id.* at 60-62.

119. *See id.*

120. *See id.* at 109-13.

121. *See id.* at 53.

122. *See id.* at 46. The cloning of DNA has also made it possible to create cloned animals. *See* Michael Specter & Gina Kolata, *A New Creation: The Path to Cloning*, *N.Y. TIMES*, Mar. 3, 1997, at A1. This application of technology has led to the creation of the most famous one-year-old sheep in the world, Dolly, who is the genetic twin of a six-year-old sheep. *Id.*

personal information that is used to make predictions as to not only an individual's future health, but even her future behavioral patterns. Genetic data that refer to specific individuals provide a new way of talking about people and making decisions about them.

The value of genetics as a predictive tool is, however, mixed at best. Despite the exciting capabilities of genetics, most investigations of an individual's genetic data do not point to a certain fate, and future developments are unlikely to modify genetic science's potential to predict accurately one's health and behavior.¹²³ These limits will continue for predictions regarding both individuals and groups.¹²⁴ There are a number of reasons for the uncertain nature of genetics as a predictive tool, and this Article will concentrate on three of the most important factors: (1) the heterogenous origins of most diseases, (2) the phenomenon of genetic polymorphism, and (3) the fluid state of current genetic knowledge.

Illnesses generally result from a complex interaction between different genes and environmental influences. As one recent guide to genetics points out, a disruption in health "may be produced by a combination of alleles at one locus, by a single dominant mutation at a second locus, by a combination of mutant alleles at two quite different loci, by many combinations of alleles at three loci."¹²⁵ As for the environmental factors, certain combinations of alleles can either be positive or negative depending upon specific "gene-environment interaction."¹²⁶ Genetic information generally is incapable of telling whether an individual with a given genetic make-up will ever suffer from a given condition or how mild or severe any outbreak of the indicated condition will be.¹²⁷

Just as the heterogenous origins of most diseases set limits on genetic predictions regarding individuals, access to genetic information generally does not tell us anything definitive about the relative medical costs of one group versus another. The role of other factors in determining medical costs is and will continue to be critical.¹²⁸ For example, personal

123. See KITCHER, *supra* note 109, at 60-61; R.C. LEWONTIN, *BIOLOGY AS IDEOLOGY: THE DOCTRINE OF DNA* 66-83 (1991) (noting the unreliability of DNA testing); Paul Billings & Jon Beckwith, *Genetic Testing in the Workplace*, 8 *TRENDS IN GENETICS* 198, 199 (1992) (reporting the limited predictive value of genetic testing).

124. See *infra* text accompanying notes 127-136.

125. See KITCHER, *supra* note 109, at 60.

126. *Id.* at 61.

127. See *id.* at 60-61; LEWONTIN, *supra* note 123, at 66-83; Billings & Beckwith, *supra* note 123, at 199.

This point about the limits of genetics is rarely made within the popular press. See Marilyn Elias, *Half of All Divorces May Be Due to Genes*, USA TODAY, Nov. 23, 1992, at 1A. But see Sharon Begley, *Born Happy?*, NEWSWEEK, Oct. 14, 1996, at 78 (noting that "[g]enes are . . . not destiny").

128. One group of geneticists explains that this particular fallacy is based on "the myth of genetic perfection." Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 480 (1992). The critical assumption is that "the best possible family is the one

behavior tendencies, including eating habits and whether one smokes cigarettes, play a far more important role in deaths caused by cancer than all genetic factors.¹²⁹

The second difficulty regarding predictive claims based on genetic data is that no one other than identical twins has exactly the same genes.¹³⁰ This phenomenon is termed "genetic polymorphism," and it accounts for, among other things, the ability to create the "genetic fingerprints" that are used in criminal trials.¹³¹ No single standard DNA sequence exists; the Human Genome Project is merely attempting to sequence a so-called "standard" sequence.¹³² All of us differ from this sequence in various ways, but the extent to which these deviations indicate anything of importance is uncertain.¹³³ Among the reasons for this uncertainty is the complexity, as already noted, of interactions among different genes and between genes and varying environmental factors.¹³⁴

Finally, the developing nature of genetic knowledge means that at the present time, when genetic science is in its infancy, the genetic component to one condition will be known while the genetic makeup of other, perhaps more significant, illnesses will be entirely uncharted.¹³⁵ Certain groups are now labeled as having a "propensity" for certain kinds of cancers, or even less precisely, as having a "cancer gene," but others will suffer from the same kind of cancer without having this propensity or gene.¹³⁶ Thus, a large element of chance is involved in one group being labelled as genetically fit and another as genetically unfit. To make matters even more complex, some scientists have claimed that individuals with at least one kind of "cancer gene" appear to have a higher survival rate than others who contract the specific cancer in question.¹³⁷

least likely to face medical adversity, the 'perfect' family with a disease-free genome." *Id.* Yet, all humans are at risk for illnesses, whether primarily caused by a genetic condition or other factors, and all humans have some defective genetic material. *See id.* For an insightful criticism of the idea of genetic perfection, see Susan M. Wolf, *Beyond "Genetic Discrimination": Toward a Broad Harm of Geneticism*, 23 J.L. MED. & ETHICS 345, 348 (1995).

129. For a recent study, see Harvard Rep. on Human Cancer, *Causes of Human Cancer*, 7 CANCER CAUSES & CONTROL S. 510, S. 2324 (1996). For an account of this important research project, see Peter J. Howe, *Study Links Lifestyle, Cancer Risk*, BOSTON GLOBE, Nov. 19, 1996, at A1.

130. *See* KITCHER, *supra* note 109, at 157.

131. *Id.* at 157-79 (discussing the forensic uses of DNA).

132. LEWONTIN, *supra* note 123, at 50.

133. *See id.*

134. *See id.*; *supra* notes 125-26 and accompanying text.

135. *See* KITCHER, *supra* note 109, at 67-74.

136. LEWONTIN, *supra* note 123, at 49-54, 71.

137. One current debate among geneticists concerns whether so-called "disease genes" might also have some positive role. *See* Stephen C. Rubin et al., *Clinical and Pathological Features of Ovarian Cancer in Women with Germ-Line Mutations of BRCA1*, 335 NEW ENG. J. MED. 1413, 1414-15 (1996). One aspect of this controversy concerns the breast cancer genes, which have been labelled BRCA1 and BRCA2. *See id.* at 1414-15. Some evidence exists that while women with one of these

Epstein's argument in favor of the ineluctable benefits of open access to personal genetic data ignores these realities of genetic science. We should therefore be skeptical about the promised economic benefits of unrestricted disclosure of genetic data. Neither absolute disclosure nor absolute privacy of these data is likely to be socially optimal; economic efficiency will best be attained by a strategy of information allocation that structures different kinds of access to this and other kinds of personal information. This Article has suggested that Posner and Epstein overstate the benefits from open access to personal data. It now turns to their attack on nondisclosure—that is, on informational privacy.

C. *A Flawed Attack on Privacy*

Beginning with Posner's economics of data privacy, this Article will make two initial criticisms of his theories. These criticisms relate to his constricted notions of transaction costs and information asymmetries. Neither of these issues is as detrimental to the economics of information privacy as Posner suggests. Moreover, Posner and Epstein present an unduly narrow notion of social utility, one that ignores the positive economic role that data privacy plays in many circumstances.¹³⁸

It will be useful to summarize the arguments that will follow in this section. As we have seen, Posner and Epstein alike argue that entrepreneurs and businesses will make economically efficient use of personal information. This section will demonstrate, however, that employers are in fact *not* making such rational use of personal health care and genetic information. Rather, companies utilize these data to make employment-related decisions that, due to critical market imperfections, do not spell economic efficiency for society as a whole.

In addition, wide disclosure of certain kinds of information may distort individual behavior in an inefficient fashion. Fearing loss of employment and social discrimination, people will either lie to their physicians or avoid seeking care that might lead to the creation of sensitive health care or genetic information. These same fears will also harm job market efficiency by causing individuals to remain in current positions rather than risk

mutated genes, BRCA1, may have a heightened chance of getting breast cancer, they also have a higher survival rate than women whose breast cancer is attributable to other causes. *See id.*; *see also* Gina Kolata, *Seeking Reasons for Disease Genes*, N.Y. TIMES, Dec. 3, 1996, at C1 (suggesting that certain genetic mutations such as BRCA1 and BRCA2 may confer advantages to a carrier). *See generally* Jared Diamond, *Outcasts of the Islands*, N.Y. REV. BOOKS, Mar. 6, 1997, at 15-16.

138. To be sure, data privacy can also play a number of other important roles. For a discussion of how informational privacy can help protect a democratic order that is based on individual autonomy, *see* SCHWARTZ & REIDENBERG, *supra* note 2, at 36-43. The goal of this Article is, however, to carry out an *internal* critique of the law and economics perspective, and we will therefore focus on the relationship of data privacy to economic factors.

unemployment or a lack of medical coverage in a new job. These issues will be discussed in more detail below. Part II of this Article concludes by exploring the ways in which widespread access to genetic data will cause distortion in insurance markets.

1. *Transaction Costs and Information Asymmetries.*—We begin by examining Posner's view of transaction costs. Posner argues that the benefits of mandated disclosure will be greater than benefits derived after negotiations regarding the extent of individual preferences for privacy.¹³⁹ Yet, the available evidence suggests that negotiations about certain exploitation rights, such as magazine subscriptions, can easily be structured in an inexpensive fashion.¹⁴⁰ In this regard, technology has the capacity to play an important role in safeguarding, rather than harming, privacy.

Information about individual consumer preferences can now be cheaply processed and combined with other personal data.¹⁴¹ In this fashion, technology has made possible a thriving market for such particularized data.¹⁴² Many enterprises are now involved in two businesses: first, they sell their products or services to one set of clients, and then they offer the associated information about this first exchange to another set of clients.¹⁴³ As a result, many consumer transactions are now exchanges of "goods or services for money *and information*."¹⁴⁴ Yet, technology also has greatly reduced the transaction costs involved in discovering individual preferences regarding the use of personal data.¹⁴⁵

One example of how technology is being employed to minimize transaction costs is supermarkets that provide check writing and other privileges to their customers. The extraordinary data-processing capacity offered by affordable business computers enables these supermarkets and other enterprises to have a straightforward way of involving consumers in decision-making regarding planned future use of their collected personal data. These businesses simply offer written information regarding proposed data

139. See Posner, *supra* note 12, at 398-99.

140. See *infra* text accompanying notes 141-47.

141. See *infra* text accompanying notes 143-45.

142. See SCHWARTZ & REIDENBERG, *supra* note 2, at 310, 312-14, 320; Reidenberg, *supra* note 32, at 516-18 (both discussing the effect of information profiling—made easier by expanding technology—on the direct marketing industry).

143. See JEFFREY ROTHFEDER, *PRIVACY FOR SALE: HOW COMPUTERIZATION HAS MADE EVERYONE'S PRIVATE LIFE AN OPEN SECRET* 89-102 (1992) (discussing particularly egregious examples of companies that have sold personal consumer information).

144. Richard S. Murphy, *Property Rights in Personal Information: An Economic Defense of Privacy*, 84 GEO. L.J. 2381, 2402 (1996) (emphasis in original).

145. Compare BILL GATES, *THE ROAD AHEAD* 120, 158, 157-83 (1995) (discussing how new information technology is "low-friction" regarding information costs regardless of the number of parties involved), with POSNER, *supra* note 76, at 51 (observing that the Coase Theorem holds that "generally the costs of a transaction rise with the number of parties to the transaction—perhaps exponentially").

use on each membership application and provide an opportunity to decline outside use of these data.¹⁴⁶ Thus, the transaction costs for all the parties are minor whether viewed at the moment of *negotiating* the agreement (the ex ante costs) or *complying* with it (the ex post costs).¹⁴⁷

While faulty policy arguments may result from an assumption of frictionless markets, Posner's preference for disclosure offers a skewed policy recommendation due to an inflated concept of transaction costs. In Posner's hands, transaction costs are a kind of trump card that can be employed to prevent the creation of disclosure limitations on certain facts about people.¹⁴⁸ Beyond the issue of transaction costs, Posner's argument regarding information asymmetries also appears overstated. Posner assumes that perfect information is crucial to the functioning of market dynamics. Yet, as a number of economists have pointed out, a wide variety of markets are able to function despite imperfect information.¹⁴⁹ Indeed, to a large extent, information disparities between parties may be more the rule than an exception.¹⁵⁰

The question that matters is not simply whether one party has more information than another. The critical issue is whether this difference will have a negative effect on their negotiations and on the functioning of the marketplace. Oliver Williamson defines such situations as one of "information impactedness," which means that two parties "have knowledge of different and essentially private information and engage in complex contracting."¹⁵¹ In his description of "contractual man,"

146. See SCHWARTZ & REIDENBERG, *supra* note 2, at 330, 330-31 (discussing the example of a supermarket chain that provides customers with complete disclosure and "mechanisms for consent to profiling through precise opt-out rights").

147. For a discussion of these two kinds of transaction costs, see OLIVER E. WILLIAMSON, *THE ECONOMIC INSTITUTIONS OF CAPITALISM* 388 (1985). See generally GATES, *supra* note 145, at 171 (noting the ability of information technology "to sort consumers according to much finer individual distinctions").

148. In a sense, this reliance on transaction costs compounds the inherent circularity of Posner's judgment that the aggregate effect of people's actions will invariably spell efficiency. See Arthur Allen Leff, *Economic Analysis of Law: Some Realism About Nominalism*, 60 VA. L. REV. 452, 458 (1974). In a classic critique of law and economics, Arthur Leff provided this tongue-in-cheek summary: "[W]hat people do is good, and its goodness can be determined by looking at what it is they do." *Id.*

149. See, e.g., Alan Schwartz & Louis L. Wilde, *Intervening in Markets on the Basis of Imperfect Information: A Legal and Economic Analysis*, 127 U. PA. L. REV. 630, 638, 636-40 (1979) (asserting that the presence of some number of informed consumers protects uninformed consumers from overreaching firms if it results in enough competition "to generate optimal prices and terms for all consumers"). The discussion among economic theorists of contract law about information-forcing rules is also based on this view regarding information imperfections. See Ian Ayres & Robert Gertner, *Strategic Contractual Inefficiency and the Optimal Choice of Legal Rules*, 101 YALE L.J. 729, 730-32 (1992); Jason Scott Johnston, *Strategic Bargaining and the Economic Theory of Contract Default Rules*, 100 YALE L.J. 615, 617-19 (1990).

150. See MICHAEL J. TREBILCOCK, *THE LIMITS OF FREEDOM OF CONTRACT* 103 (1993) ("[T]he issue of imperfect information is pervasive, not exceptional, in the contracting process.").

151. WILLIAMSON, *supra* note 147, at 51.

Williamson explains, "Inasmuch as information may be disclosed strategically rather than candidly upon request, initial information disparities between the parties will not be assuredly overcome by proposals that all relevant information be pooled. Instead, initial information asymmetries persist. Indeed, additional asymmetries develop as events unfold."¹⁵² In a classic paper first published in 1945, Frederick Hayek makes a similar point.¹⁵³ Hayek argues that almost all decisions are based on less than complete information and complete understanding of all relevant areas.¹⁵⁴

2. *A Negative Impact on Employment.*—Genetic science does not offer Epstein's treasure trove of information for employers and insurers. Neither transaction costs nor information asymmetries provide a compelling argument against data privacy. Posner and Epstein are no more convincing when they reach for a variety of other grounds in their attack on data privacy. Just as Epstein ignores the complexity of genetic science, he and Posner ignore aspects of human behavior and the market that work against their fervent belief in disclosure as an economic nostrum.

Posner and Epstein establish a contrast between the heroic entrepreneur and the person who wishes secrecy for her personal data to deceive others. Both scholars assume that rational use will be made of personal information.¹⁵⁵ In the place of this heroic assumption, this Article will consider the evidence available, which suggests that virtually unlimited employer access to personal genetic and medical data—permitted by the current, weak legal regulation—has encouraged some patterns of socially inefficient behavior. This Article will also argue that attempts to limit this behavior through scattered employment and antidiscrimination statutes have proven unsuccessful.

Theoretical grounds for this persistent irrational use of personal data will also be found possible. Medical and genetic information have social implications that can make excessive the costs of explanation under a policy of unrestricted access. Even worse, the price of explanation may not be met: the belief in genetic determinism and the social stigma associated with certain diseases have led to persistent inefficient use of certain personal

152. *Id.* at 51.

153. See F.A. Hayek, *The Use of Knowledge in Society*, 35 AM. ECON. REV. 519, 525 (1945).

154. See *id.*

155. See Epstein, *supra* note 14, at 18 (arguing that both employers and insurers are "rational: If privy to information, employers and insurers will act to advance their own interests and blunt the implicit cross-subsidies that anti-discrimination laws attempt to create"); cf. Posner, *supra* note 12, at 399 n.15 ("No doubt many subscribers to *Christian Motherhood* would be offended to be solicited by *Playboy*, but it is unlikely that *Playboy's* publisher would consider [them] a sufficiently promising source of new *Playboy* subscribers to want to buy the subscription list.").

information.¹⁵⁶ Other explanations for this misapplication will point to the effects of an acquired taste for discrimination and the adaption of preferences and beliefs to the status quo in a fashion that makes change through market ordering hard to achieve. This section suggests that a reflexive dependance on the rationality of employers and others who use personal health information is grounded on no more than wishful thinking.

Understanding this argument requires a foray into health care financing and the ways in which personal health care information can be misunderstood. Most people who receive health benefits in this country obtain it at their place of employment. In the United States approximately 140 million people, or nearly two-thirds of the population under sixty-five, receive medical benefits through their job.¹⁵⁷ Because these benefits are an increasingly costly part of the overall package of compensation, employers have a great incentive to weed out workers with expensive health care needs.¹⁵⁸ Despite any amount of soothing statements about the rationality of employers, the actual use of genetic information and health records in employment decisions is far from efficient.¹⁵⁹

An exuberant and misguided American folklore regarding genetic determinism offers one of the best examples of this misunderstanding of health care information.¹⁶⁰ For the true believers, our DNA controls all of human existence.¹⁶¹ This faith in genetic determinism provides a superb example of why certain kinds of personal information can have incommensurate explanatory costs. Many people expect genetic information to lead to a new understanding of personhood. According to one report, a well-known geneticist has sometimes held out a compact disc in public presentations and told his audience, "This is you."¹⁶² The geneticist's allusion to this popular data storage format is a consequence of the ongoing digitization of the human genome project's results. In the words

156. See *infra* notes 173-87 and accompanying text.

157. See COMMITTEE ON EMPLOYER-BASED HEALTH BENEFITS, INSTITUTE OF MEDICINE, EMPLOYMENT AND HEALTH BENEFITS: A CONNECTION AT RISK 28 (tbl.1.1 (1993) [hereinafter EMPLOYMENT AND HEALTH BENEFITS]).

158. See *id.* at 3.

159. See *infra* notes 170-87 and accompanying text.

160. For an explanation of the term "genetic determinism," see generally KITCHER, *supra* note 109, at 239-69. As Lawrence O. Gostin perceptively summarizes the situation: "Americans seem enamored with the power of genomic information. It is often thought capable of explaining much that is human: personality, intelligence, appearance, behavior, and health. Genetic technologies generated from scientific assessment are commonly believed always to be accurate and highly predictive." Lawrence O. Gostin, *Genetic Privacy*, 23 J.L. MED. & ETHICS 320, 323 (1995) (citations omitted). These kinds of predictive claims have, in fact, contributed to the exalted position of modern genetics and the creation of a folklore of genetics. See *infra* text accompanying notes 166-69.

161. See LEWONTIN, *supra* note 123, at 87.

162. Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L. REV. 313, 319 (1992) (quoting Walter Gilbert, Current State of the H.G.I., Harvard University Dibner Center Lecture (June 15, 1990)).

of this individual, the complete sequencing of the human genome will allow one "to stick one's hand in a pocket, draw out a compact disc, and say, 'Here's a human being.'"¹⁶³

Some have chosen a more lofty metaphor for this endeavor. These individuals compare the study of genetics to the search for the Holy Grail. As two scientists have written, "The search for the biological grail has been going on since the turn of the century, but it has now entered its culminating phase with the recent creation of the human genome project, the ultimate goal of which is the acquisition of all the details of our genome."¹⁶⁴ Achieving this goal will "transform our capacities to predict what we may become."¹⁶⁵ For these scientists, genetics will tell us everything about humans.

This faith has already begun to influence other disciplines and to seep into the wider culture. A folklore of DNA is being created, which appears especially compatible with the orientation of law and economics. For example, in his massive study of sex and legal regulation, Richard Posner writes of "a genetic propensity" in some men for "sticking around" after a woman is impregnated.¹⁶⁶ Such a man is said to have a fortunate "advantage in the struggle of the genes to survive."¹⁶⁷ As for Richard Epstein, he enthusiastically notes the ability of genetic testing to create an "ability to see written in the future what, up to now, has been left to pure chance."¹⁶⁸ On this basis, Epstein makes his argument that genetic science offers employers a critical opportunity to improve their operations by streamlining their labor costs.¹⁶⁹

It is not only legal academics who believe in genetic determinism. Today, companies seeking to maximize their profits are placing actual and potential employees who deviate from a standard genetic model into a pool of those with "genetic defects."¹⁷⁰ These workers are being shunned on

163. Daniel J. Kevles, *Vital Essences and Human Wholeness: The Social Readings of Biological Information*, 65 S. CAL. L. REV. 255, 257 (1991) (quoting Walter Gilbert, Lectures at the California Institute of Technology (Nov. 29, 1989) and at Harvard University (June 16, 1990)).

164. Daniel J. Kevles & Leroy Hood, *Preface* of THE CODE OF CODES at vii, vii (Daniel J. Kevles & Leroy Hood eds., 1992).

165. *Id.*

166. RICHARD A. POSNER, SEX AND REASON 96 (1992).

167. *Id.* For Posner, these and other genetic propensities raise the price for the individual of engaging in sexual behavior that would otherwise be rational. *Id.* Thus, Posner's discussion of such social factors as opportunities, resources, and constraints indicates that he is aware of some level of interplay between genetic and environmental influences. *See id.* Nevertheless, the language with which he discusses genetic factors usually slights these other influences. *See, e.g., id.* at 87, 97, 100, 107.

168. Epstein, *supra* note 14, at 2.

169. *See id.* at 21-22.

170. The evidence regarding the full dimensions of these practices is far from complete, but it is certainly sufficient to refute the assertion that genetic data will invariably be used in a rational fashion. For a sampling of discussions in legal literature regarding such practices, see, for example, Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests* by

a categorical basis. Such employer behavior is motivated by the close link in the United States between the provision of health care benefits and the workplace.¹⁷¹ As genetic knowledge grows and more genetic tests are developed, an increasing number of employers will attempt to reduce their costs in this area by excluding any relationship with workers whose genetic material is found to pose a higher risk.¹⁷² Yet, as noted above, most investigations of an individual's genetic data do not reveal the smoking gun of Epstein's imagination.

The argument against Epstein and Posner's position is greatly strengthened by the generally poor societal record in this area; a considerable historical pattern exists of misapplication of this information. This story begins with the eugenics movement, whose misunderstanding and deformation of genetic science encouraged public policies that included the sterilization of "inferior" members of society.¹⁷³ As for the recent era of modern genetics, the United States has far from a perfect record. Genetic discrimination already takes place in the United States. Studies by scientists at Stanford and Harvard have documented numerous instances of genetic discrimination in the public and private sectors.¹⁷⁴ Another study found a high rate of discrimination in obtaining insurance and employment for people who have a genetic condition or for their family members.¹⁷⁵ Many of these individuals will never suffer from any genetic illness; yet, the testing process itself creates a category of individuals now deemed to be genetically unfit.¹⁷⁶

The screening for sickle cell anemia that took place in the 1970s offers another example of the negative impact of genetics. In the United States,

Employers and Insurers, 17 AM. J.L. & MED. 109, 118-19 (1991) and Jill Gaubing, Note, *Race, Sex, and Genetic Discrimination in Insurance: What's Fair?*, 80 CORNELL L. REV. 1646, 1687 (1995). For discussions in the media, see, for example, Geoffrey Cowley, *Flunk the Gene Test and Lose Your Insurance*, NEWSWEEK, Dec. 23, 1996, at 48; Philip J. Hiltz, *Panel Reports Genetic Screening Has Cost Some Their Health Plans*, N.Y. TIMES, Nov. 5, 1993, at A20; and Gina Kolata, *Advent of Testing for Breast Cancer Genes Leads to Fears of Disclosure and Discrimination*, N.Y. TIMES, Feb. 4, 1997, at C1. For further evidence, see also Billings et al., *supra* note 128, at 478; Billings & Beckwith, *supra* note 123, at 198; and Lisa N. Geller et al., *Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 SCIENCE & ENGINEERING ETHICS 71, 74 (1996).

171. As this Article has noted, nearly two-thirds of all Americans under sixty-five receive health benefits through their place of employment. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 28 tbl.1.1.

172. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 9; see also KITCHER, *supra* note 109, at 138.

173. See Daniel J. Kevles, *Eugenics and the Human Genome Project: Is the Past Prologue?*, in JUSTICE AND THE HUMAN GENOME PROJECT 14, 19 (Timothy F. Murphy & Marc A. Lappé eds., 1994). For an account of the ties between American eugenics and German National Socialists in the period before World War II, see STEFAN KÜHL, THE NAZI CONNECTION: EUGENICS, AMERICAN RACISM, AND GERMAN NATIONAL SOCIALISM 53-96 (1994).

174. See Billings et al., *supra* note 128, at 478; Billings & Beckwith, *supra* note 123, at 198.

175. See Geller et al., *supra* note 170, at 74.

176. See *id.* at 83.

where sickle cell anemia is predominately found in African-Americans, testing for this condition led certain individuals to lose their jobs and health insurance.¹⁷⁷ Indeed, at one point, the United States Air Force even denied African-Americans who tested positive for the sickle cell trait the opportunity to become pilots.¹⁷⁸ This policy resulted from a misunderstanding of the difference between symptomatic individuals and those asymptomatic individuals that carry only a single copy of the sickle cell gene.¹⁷⁹ Representative John Conyers, Jr. points to this and other forms of discriminatory behavior as examples of how genetic information may cause certain members of society to be transformed into a "biological underclass."¹⁸⁰ Moreover, antidiscrimination laws alone have proved unable to stop such behavior.¹⁸¹ Indeed, Representative Conyers argues that the failure of these laws is a reason for Congress to enact a statute that regulates permissible disclosures of personal genetic data.¹⁸²

Like genetic information, health care data are also being used to make employment decisions. According to one empirical study of privacy in the workplace, over one-third of Fortune 500 companies surveyed in 1995 admitted to using the medical records of their personnel in employment-related decisions.¹⁸³ In previous years, this survey found that as many as one-half of these companies admitted to engaging in such behavior.¹⁸⁴ Evidence also indicates that some of this reliance on employees' health data is leading to economically inefficient employment decisions. According to a recent nationwide survey, for example, cancer patients currently lose their jobs at over five times the rate of those who do not have the disease.¹⁸⁵ Considerable ignorance has also been found regarding the

177. See *Domestic and International Data Protection Issues: Hearings Before the Government Information, Justice, & Agriculture Subcomm. of the House Comm. on Government Operations*, 102d Cong. 229 (1991) [hereinafter *Data Protection Hearings*] (statement of Nancy S. Wexler, Chairperson, Joint NIH/DOE Working Group on the Ethical, Legal, and Social Issues of the Human Genome Project).

178. See *id.* at 136 (statement of Rep. Conyers).

179. See *id.* at 229 ("[E]ven the U.S. military misunderstood the consequences of being only a carrier."); NELKIN & TANCREDI, *supra* note 94, at 98-100 (noting the Navy's decision to disqualify pilot recruits with sickle cell traits despite studies which showed no increased risk for these recruits).

180. *Data Protection Hearings*, *supra* note 177, at 135, 135-37 (statement of Rep. Conyers).

181. See Mark A. Rothstein, *The Law of Medical and Genetic Privacy in the Workplace*, in *GENETIC SECRETS* 281, 287-93 (Mark A. Rothstein ed., 1997).

182. See *Data Protection Hearings*, *supra* note 177, at 135-37 (statement of Rep. Conyers).

183. See David F. Linowes, *A Research Survey of Privacy in the Workplace* 4 (Apr. 1996) (unpublished manuscript, on file with the *Texas Law Review*).

184. See DAVID F. LINOWES, *PRIVACY IN AMERICA: IS YOUR PRIVATE LIFE IN THE PUBLIC EYE?* 42 (1989). The change in these figures from the 1989 survey to the more recent one may be without statistical significance. As Linowes notes, "Many of the companies now have policies against responding to surveys." Linowes, *supra* note 183, at 29.

185. See Lauren Chambliss, *The Cancer Reality Gap*, *WORKING WOMAN*, Oct. 1996, at 46; Richard Saltus, *Cancer Patients' Job Losses High*, *BOSTON GLOBE*, Sept. 25, 1996, at A1. The

workplace implications of this disease; another survey found common over-estimation by supervisors of the actual experience of cancer patients regarding fatigue, infections, and nausea during treatment.¹⁸⁶ To consider another socially charged illness, one can point to evidence that greater insurance discrimination is faced by those who are HIV-positive than individuals who suffer from equally serious illnesses with similar costs.¹⁸⁷ Discrimination between employees with different health conditions can be based on social stigma and misunderstandings rather than the relative costs of different workers' medical conditions.

This subsection has pointed to evidence that suggests a more complicated creature than the fully rational employer of Posner's and Epstein's imaginations. Explanations of this behavior are possible. To begin, widespread belief in genetic determinism has resulted in genetic information bearing an excessive "cost of explanation."¹⁸⁸ In other words, the costs associated with placing genetic data in the proper context furnish an argument *against* their disclosure. The individual to whom these data refer faces a high price when attempting to explain the significance or insignificance of the information, and these explanatory costs can exceed the value of unrestricted disclosure to society.¹⁸⁹ Indeed, many parties, including employers, believe that they are *not* ignorant about the full dimensions or implications of certain personal data, and will continue to (mis)apply genetic personal information based simply on their popular beliefs.¹⁹⁰ Thus, achieving economic efficiency necessitates placing certain kinds of limits on access to personal information because of the excessive social costs of placing such data in the proper context under a policy of unrestricted access.

Other explanations for a persistence of inefficient use of personal genetic data are possible. One of the most potent answers to those who expect the market to end all discrimination has been the idea of the taste

Chambliss study also found that 81% of cancer patients said employment helped them to maintain emotional stability while in treatment. *See* Chambliss, *supra*, at 68.

186. *See* Ellen Neuborne, *Illness on Job Adds Insult to Injury*, USA TODAY, Jan. 14, 1997, at 12A.

187. Thus, employers and insurers have attempted to exclude those that might be HIV-positive from health insurance coverage, but not those that might suffer one day from kidney failure and require a kidney transplant. *See* Robert A. Padgug et al., *AIDS and Private Health Insurance: A Crisis of Risk Sharing*, 3 CORNELL J.L. & PUB. POL'Y 55, 57-63 (1993). This distinction between individuals was made despite the somewhat higher costs for a person receiving a kidney transplant. *Id.* at 56-62.

188. *See generally* Murphy, *supra* note 144, at 2400-02 (discussing the cost of counteracting or contextualizing confidential information that has been disclosed).

189. *Id.*

190. Even some physicians have difficulty understanding the meaning of genetic tests. *See* Francis M. Giardiello et al., *The Use and Interpretation of Commercial APC Gene Testing for Familial Adenomatous Polyposis*, 336 NEW ENG. J. MED. 823, 825-26 (1997); Susan Gilbert, *Doctors Often Misread Results of Genetic Tests, Study Finds*, N.Y. TIMES, Mar. 26, 1997, at C8.

for discrimination. A number of scholars have pointed out that some individuals allow their preferences to override their economic self-interest.¹⁹¹ Not only will this taste for discrimination remain uncorrected by the party's self-interest, but the market sometimes will fail to punish the party with the discriminatory preference. As Cass Sunstein has pointed out, this market failure is helped along by the frequent inability of directly affected parties and concerned third parties to create countervailing pressures.¹⁹² Thus, as far as health care data are concerned, the public is generally unaware of the precise informational practices of individual companies and insurers.¹⁹³

3. *Distortion of Individual Behavior.*—As we have seen, employers do not invariably make economically efficient use of personal data. In addition, wide disclosure of personal medical and genetic information will have a negative impact on certain kinds of behavior. First, health care consumers will limit or modify the information they share with those who provide treatment. Second, the possibility of wide disclosure can decrease the extent to which patients seek preventive care and employees search for new jobs. The costs that follow from these distortions of behavior weigh heavily against the economic efficiency of a regime of unrestricted disclosure.

An excessive disclosure norm for certain kinds of information will distort or eliminate the kinds of personal information that health care consumers share in future transactions with physicians. The existence of a multimillion dollar market for self-administered, anonymous AIDS tests already indicates the scope of the desire to keep certain information out of the health care system.¹⁹⁴ Yet, meaningful health care generally depends on full and frank disclosure between doctor and patient.¹⁹⁵ Inadequate safeguards for protecting medical data will make the encounters that take place between physicians and patients less effective because of the likelihood that patients will withhold important information.¹⁹⁶ As the

191. For a discussion of the taste for discrimination in other legal contexts, see John J. Donohue III, *Is Title VII Efficient?*, 134 U. PA. L. REV. 1411, 1415-20 (1986) (employment) and Peter P. Swire, *The Persistent Problem of Lending Discrimination: A Law and Economics Analysis*, 73 TEXAS L. REV. 787, 816-18 (1995) (banking).

192. See CASS SUNSTEIN, *FREE MARKETS AND SOCIAL JUSTICE* 153-55 (1997).

193. For a discussion of this information gap, see *infra* section III(A)(2).

194. Some analysts have estimated that the annual market for home HIV tests will reach at least \$100 million within the next five years. See Dana Canedy, *Seeking Assurance from a \$40 Kit*, N.Y. TIMES, Nov. 21, 1996, at D1. For the Food and Drug Administration's authorization of these confidential AIDS testing kits, see 61 Fed. Reg. 57446, 57446-48 (1996).

195. See Joseph Goldstein, *For Harold Lasswell: Some Reflections on Human Dignity, Entrapment, Informed Consent, and the Plea Bargain*, 84 YALE L.J. 683, 690-94 (1975).

196. For the classic account of the fragility of the communication process between patient and physician, see JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 85-103 (1984).

Congressional Office of Technology Assessment noted, the "absence of a clear law" protecting the confidentiality of medical records "could well lead to patients withholding information critical to their care, thus jeopardizing their own health as well as denying the health care system (including physicians, nurses, hospitals, third party payers, and researchers) information they may legitimately want and need, and that society has already deemed appropriate to give them."¹⁹⁷

The Supreme Court has recently sought to prevent one kind of access to medical information leading to the creation of an excessive disclosure norm.¹⁹⁸ It did so by placing strong limits on litigants' use of discovery in federal lawsuits to gain access to psychotherapy records.¹⁹⁹ In its opinion in *Jaffee v. Redmond*,²⁰⁰ the Supreme Court stated: "Effective psychotherapy . . . depends upon an atmosphere of confidence and trust in which the patient is willing to make a frank and complete disclosure of facts, emotions, memories, and fears."²⁰¹ Other kinds of medical treatment also depend upon such "confidence and trust" between patient and physician.²⁰²

A lack of privacy safeguards will both harm patient-physician relations and make individuals less willing to seek help.²⁰³ In this fashion, inadequate privacy protection not only distorts future information exchanges between physician and patient, but endangers one popular aspect of health care reform: its emphasis on preventive medicine. Requiring people to see their health care provider early and often decreases the costs of treating any given illness or health condition.²⁰⁴ Put another way, preventive medicine provides greater health benefits for society for any given level of resources spent.²⁰⁵ Yet, without adequate limitations on the

197. OTA, COMPUTERIZED MEDICAL INFORMATION, *supra* note 33, at 48.

198. See *Jaffee v. Redmond*, 116 S. Ct. 1923 (1996).

199. See *id.* at 1928-32.

200. 116 S. Ct. 1923 (1996).

201. *Id.* at 1928.

202. For this very reason, the core idea of medical data confidentiality has been present within the medical profession since the Hippocratic Oath, which was written in the fourth century B.C. See Roger Doughty, *The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic*, 82 CAL. L. REV. 111, 116 (1994). On the failure of these ethical provisions and other measures of professional codes of ethics to provide meaningful guidance for health care professionals, see Robert M. Gellman, *Prescribing Privacy: The Uncertain Role of the Physician in the Protection of Patient Privacy*, 62 N.C. L. REV. 255, 261-71, 274-77 (1984).

203. See *Jaffee*, 116 S. Ct. at 1929-30 (noting that a psychotherapist-patient privilege serves the public interest by "facilitating the provision of appropriate treatment" to those that suffer from mental or emotional problems).

204. See VICTOR R. FUCHS, *THE FUTURE OF HEALTH POLICY* 31 (1993) (contrasting "programs to treat the seriously ill at high cost per death" with "preventive programs that avert deaths at lower costs").

205. See PAUL STARR, *THE LOGIC OF HEALTH CARE REFORM* 80-81 (1994). For a more skeptical view, however, see Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1449,

dissemination of health care data, individuals will think twice about visits to physicians in non-emergency situations.²⁰⁶

Open access to health care or genetic information has a final negative effect on individual behavior. It ties individuals to current jobs out of the fear that they will be denied new employment or health insurance.²⁰⁷ In a recent study, the Institute of Medicine concluded that "many U.S. workers feel locked into jobs they would rather leave."²⁰⁸ Even more precisely, a telephone poll conducted by the New York Times and CBS News found more than thirty percent of adults stated that either they personally or a family member "had taken one job rather than another or remained in a job they wanted to leave because of health benefits."²⁰⁹ These workers were afraid that their health history or that of family members would lead a new insurer to reject or limit their coverage.²¹⁰ As this Article has indicated, such fears are far from baseless. The resulting phenomenon, which has been termed "job lock," introduces significant distortions in the labor market. As health care economist Victor Fuchs notes, "[L]abor market efficiency suffers" when health insurance considerations affect workers' choices of jobs and decisions about job change.²¹¹

4. *An Increase in Health Care Costs.*—An additional flaw in Posner's and Epstein's analysis is found in their failure to discount from any economic merits of disclosure the social costs associated with workers being fired due to access to their genetic and health care data. In particular, many of these cast-off individuals will receive at least some medical care, but at costs that may be higher for society as a whole. To the extent that these externalities exist, they must be included in assessing the social utility of open access to personal information.

Understanding the negative impact of open access to data requires a brief consideration of the financing of health care insurance in the United States. Health care is currently financed in this country through private

1482 (1994) ("[I]t is doubtful that more preventive care would save the government money. It may decrease the expected costs of those illnesses that are prevented, but it also means that individuals will survive to develop new illnesses that may be even more costly to treat.").

206. Evidence exists of attempts by patients to avoid certain tests or to undergo them only if physicians agree not to enter the results into their records. See, e.g., Cowley, *supra* note 170, at 49; Kolata, *supra* note 170. As more general awareness spreads of the poor state of affairs regarding the protection of personal medical information, the public will become more likely to avoid care for certain physical and mental health conditions to protect job prospects and other life opportunities.

207. See FUCHS, *supra* note 204, at 12-13 (stating that health insurance impacts decisions regarding the choice of employment and retirement).

208. EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 32.

209. Tamar Lewin, *The Spreading Insecurity*, in SOLVING AMERICA'S HEALTH-CARE CRISIS 3, 9 (Erik Eckholm ed., 1993).

210. See *id.*

211. FUCHS, *supra* note 204, at 12.

and public insurance markets.²¹² Most individuals who are covered by health care insurance are located within the employment-based part of the *private* market.²¹³ This sector is, however, subject to considerable *public* support. When employers purchase group health care insurance, they receive considerable public assistance by being allowed to deduct as a business expense the cost of their contributions.²¹⁴ Employment-based health insurance is also favorable to workers because these noncash benefits are cheaper when obtained through an employer than when purchased in after-tax dollars.²¹⁵ The effect of the deduction for private health care insurance can be seen as amounting to "the third largest federal spending program."²¹⁶

Thus, employers and employees already enjoy highly beneficial subsidies. When the law allows individuals to be set outside of this private insurance market based on the contents of their health records or genetic profiles, it creates a further benefit for this insurance sector. Such behavior may well be inefficient, however, for the market as a whole. American society has made the determination that medical services are to be provided—if incompletely and with some procedural hurdles—to these individuals. These services are provided through public programs, such as Medicaid²¹⁷ and the Emergency Medical Treatment and Active Labor Act (EMTALA), which is an important federal provision that guarantees emergency medical treatment.²¹⁸ Some care is also provided through private

212. See PHILIP JACOBS, *THE ECONOMICS OF HEALTH AND MEDICAL CARE* 37-47 (3d ed. 1991).

213. See *EMPLOYMENT AND HEALTH BENEFITS*, *supra* note 157, at 1.

214. See JACOBS, *supra* note 212, at 40-42.

215. See *id.* at 40.

216. Peter Jakubowicz, *Andrews Aide Pushes for Limit on Health Insurance Deductions*, 59 TAX NOTES 943, 943 (1993). According to one estimate, if tax law merely reduced the extent of the current 100% deduction of the costs of health insurance to employees, it could save as much as \$60 billion a year. See *id.* For an analysis of the costs of tax subsidies relating to health care and various policy options, see U.S. DEP'T OF TREASURY, REPORT TO THE PRESIDENT AND TO THE CONGRESS, FINANCING HEALTH AND LONG-TERM CARE 81-86 (1990).

217. Medicaid is a federal program that provides medical assistance for low-income persons that are aged, blind, or disabled, or for members of low-income families with dependent children. See 42 U.S.C. § 1396 (1994). Each state administers its own Medicaid program under federal guidelines. See *id.* For an introduction, see JACOBS, *supra* note 212, at 43.

218. The federal law guaranteeing emergency medical treatment is EMTALA, which forms part of the Comprehensive Budget Reconciliation Act of 1986. See 42 U.S.C. § 1395dd (1994). EMTALA places a participating hospital under certain obligations, enforceable by civil liability, to a patient presenting herself to staff in a hospital's emergency room. See *id.* § 1395dd(a) & (b). The most important of these obligations requires the participating hospital to provide a "medical screening examination" and "such treatment as may be required to stabilize the medical condition" for a patient with an "emergency medical condition." *Id.* § 1395dd(a)-(b)(1)(A). With EMTALA, Congress intended to stop hospitals from refusing emergency treatment because of a patient's indigence or lack of insurance. See *Power v. Arlington Hosp. Ass'n*, 42 F.3d 851, 856 (4th Cir. 1994); Diane S. Mackey, *The Emergency Medical Treatment and Active Labor Act: An Act Undergoing Judicial Development*, 19 U. ARK. LITTLE ROCK L.J. 465, 465 (1997) ("The legislative history makes it clear that the dumping of indigent patients and those without health insurance was the focus of EMTALA.").

charity.²¹⁹ To the extent that public programs and charity become the major source of care for individuals who have been systematically exiled from the private health care market, these services change from a minor and useful safety valve to a force that increases overall costs for society. This result is due to a number of factors.

First, the provision of health care to those outside the employment-based market through the kinds of public programs listed above tends to reduce preventive care and increase the extent to which treatment is not given to patients until their condition becomes acute.²²⁰ These programs, which focus on serious illnesses and emergency situations, are becoming the only way that many Americans can receive access to health care services.²²¹ The costs of these programs have increased dramatically over the last decade and placed great strain on the public purse.²²²

Second, as for charity, which is Epstein's favored prescription for responding to those with genetic defects,²²³ it, too, is not without costs. Traditionally, charity medical care in the United States has been provided by either mainstream providers, which attempt to pass on the costs to those with health care insurance, or by nonprofit clinics and teaching hospitals.²²⁴ This cross-subsidy is inefficient because it provides less care overall to patients, who are also generally sicker when they seek medical services.²²⁵ For example, the uninsured are twice as likely to be

219. Indeed, American hospitals have roots in an "almshouse tradition," which has been declining as hospitals are increasingly viewed as being a business like any other. See ROSEMARY STEVENS, *IN SICKNESS AND IN WEALTH: AMERICAN HOSPITALS IN THE TWENTIETH CENTURY* 310-16 (1989).

220. See Steven A. Schroeder, *The Medically Uninsured—Will They Always Be With Us?*, 334 *NEW ENG. J. MED.* 1130, 1131 (1996) (stating that the uninsured are more likely than others to be hospitalized for conditions that could have been prevented earlier with outpatient care).

221. For an estimation of the future number of uninsured Americans, see *id.* at 1130; see also CHARLES J. DOUGHERTY, *BACK TO REFORM: VALUES, MARKETS, AND THE HEALTH CARE SYSTEM* 8 (1996) (noting that providing care in an emergency room is to utilize "one of the most expensive providers in the entire health care system").

222. The steep ongoing rise in public health care costs has led to funding crises in many states. See generally LAWRENCE A. FROLIK & ALISON PATRUCCO BARNES, *ELDER LAW* 335-79 (1992). Part of the response to these funding difficulties has been cuts in services, which, at least under the Medicaid program, have largely been left to the discretion of the concerned state. See, e.g., *Benton v. Rhodes*, 586 F.2d 1, 3 (6th Cir. 1978) (explaining that a state decision to terminate optional Medicaid benefits is a matter of state law or policy). The funding problem has also been met by additional taxes, which are sometimes both regressive and levied on an ad hoc basis. See, e.g., Arkansas Soft Drink Tax Act, *ARK. CODE ANN.* §§ 26-57-901 to 26-57-909 (Michie Supp. 1995) (enacting a state tax on soft drinks to overcome difficulties funding Medicaid).

223. See Epstein, *supra* note 14, at 20 (lauding the "enormous" charitable efforts made on behalf of the handicapped as the best method of assistance).

224. See Schroeder, *supra* note 220, at 1132-33 (suggesting that these providers of charitable care will increasingly be unable to meet the need for such care).

225. See DOUGHERTY, *supra* note 221, at 8 (stating that the cost of emergency charity care is not entirely "uncompensated" but will be shifted, when possible, "to other patients and their payers"); Schroeder, *supra* note 220, at 1132-33.

hospitalized for conditions that timely outpatient care could have averted.²²⁶ As a result, charity care is more intense in its use of technology and other resources and more costly for a given level of benefits provided.²²⁷ It is also likely that in the new era of increased competition among providers of health care, the ability to provide charity care will be greatly diminished.²²⁸

Finally, when disclosure of health care data causes a shifting of individuals out of the private market for health insurance and into a fragmented series of public programs, layers of administration will be utilized to process diffuse claims.²²⁹ This added bureaucracy further compromises the efficiency of health care in the United States. According to all calculations, the United States leads the world in the amount of each health care dollar spent on administration.²³⁰ A more accurate measurement of the relative benefits of privacy and disclosure must include the effects of disclosure that serve to increase the overall cost of health care.

5. *Distortion of Insurance Markets.*—To summarize our argument thus far, employers are not making purely rational use of medical and genetic data. Rather, this information provides an excuse for the exercise of social stigma and misunderstandings of science. Open access to these data also distorts individual behavior by encouraging patients to share incomplete data with physicians and by causing employees to be locked in jobs that they would otherwise leave. Moreover, open disclosure permits certain workers to be cast off into an increasingly strained public insurance market. This process has contributed to an increase in aggregate health care costs.

This Article's final set of criticisms of Posner and Epstein concerns the negative impact on applicable insurance markets of open access to personal health care data. Specifically, unrestricted disclosure of personal information will cause harmful risk segmentation in these markets. Risk segmentation refers to the placement of individuals clustered at higher and

226. See Schroeder, *supra* note 220, at 1132-33.

227. See *id.* at 1131 (“[A]s compared with people with private insurance, the uninsured have less access to care, use less care, . . . are twice as likely to be hospitalized for conditions that can be averted by outpatient care (such as acute asthma attacks), and have a higher risk of death when they go into the hospital.”).

228. See *id.* at 1132 (asserting that the uninsured's difficulty in obtaining proper health care will be a continuing trend absent intervention); David Wessel, *Firms Cut Health Costs, Cover Fewer Workers*, WALL ST. J., Nov. 11, 1996, at A1 (suggesting that in the current competitive market, employers disfavor health care cost-shifting for the sake of the uninsured).

229. For criticisms of bureaucratic profligacy in the U.S. health care system due to its administrative fragmentation, see Woolhandler & Himmelstein, *supra* note 90, at 1253, 1259-67.

230. See *id.* at 1253. Unless the rate of increase in administrative costs slows, spending on administration will represent one-third of health care costs by the year 2003 and one-half of the health care budget by 2020. See *id.* at 1257.

lower risks in different insurance plans or insurance pools.²³¹ By causing lower rates for certain policyholders in the employer-based part of the health care market, this phenomenon (temporarily) helps both employers and employees. Yet, it also drives up the overall social costs of health care and even threatens the public's access to a functioning health insurance market.

This result follows from aspects of the actual marketplace and from certain policy commitments in the United States. A law and economics analysis in the spirit of Posner and Epstein focuses on the individual employer and insurer and how they might use personal data to lower their share of health care costs.²³² From this perspective, open access to personal data permits an efficient "cherry-picking" of those that are likely to have lower costs. This perspective is based, however, on a fantasy market and not the actual marketplace for health care insurance. The nature of the actual market, as the preceding section has indicated, includes a heavy public subsidy to the private insurance market through a tax deduction for employer-provided health care. At the same time as the private market is interwoven in this fashion with the public market, the United States has a firm commitment to the provision of at least some health care to those outside this private market through federal and state programs, such as Medicaid and the EMTALA. A further element of the mixed public-private insurance market consists of nonprofit insurers, including Blue Cross and Blue Shield.²³³ When one keeps in mind these aspects of the actual mixed market for health insurance, excessive risk segmentation in the private insurance market benefits some at the price of raising *collective* costs.

Let us explain this argument more fully. Successful insurance markets depend on risk-spreading that draws on wide risk pools.²³⁴ When employers use health care data to make employment decisions, however, the result is shrinking coverage for an ever larger proportion of the population.²³⁵ As individuals who are deemed to be worse off are placed

231. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 168.

232. See Epstein, *supra* note 14, at 18 ("Individual employers driven by concerns of profit and loss are much more likely to rationally anticipate and control adverse consequences than government bureaucrats who cannot capture any portion of the gain from useful decisions, nor be made to suffer any portion of the loss from silly or mischievous ones."); Posner, *supra* note 12, at 399 (suggesting that it is inefficient for the law to allow an employee to conceal her health problems from an employer).

233. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 68 (recognizing the growth of Blue Cross plans); RAND E. ROSENBLATT ET AL., LAW AND THE AMERICAN HEALTH CARE SYSTEM 132-34 (1997); Paul B. Ginsburg, *The Dynamics of Market-Level Change*, 22 J. HEALTH POL. POL'Y & L. 363, 377 (1997).

234. See Padgug et al., *supra* note 187, at 63-67. See generally JACOBS, *supra* note 212, at 27 (noting that "average loss to the insurer becomes quite predictable" when the "insurer accepts a large number of risks").

235. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 197-201.

outside of the employment-based market for health care insurance, this already disfavored group shares more and more risk and is obligated to pay a higher and higher insurance premium (or make greater demands upon taxpayer-funded or nonprofit programs). This kind of risk selection also distorts competition by encouraging insurers and employers to seek out individuals who are likely to have lower needs than their premiums.²³⁶ Such biased selection has been found to pose a threat to the optimal functioning of health care markets by creating an incentive for employers and insurance providers to strive for lower than average risk groups rather than competing to provide health care services in the most efficient fashion.²³⁷ In addition, when risk pools are defined in a particularly narrow way, insurance markets for these groups can become unaffordable and even collapse.²³⁸

The impact of risk segmentation due to inadequate data protection is already being felt. For example, the most important nonprofit health care insurers, the Blue Cross and Blue Shield companies, are undergoing great turmoil due to their state-assigned role as insurers of last resort. Some of these companies have suffered large losses and even considered declaring bankruptcy.²³⁹ Others have chosen to become for-profit insurers, which allows them to avoid their former obligation for widespread group coverage.²⁴⁰ To the greatest extent possible, insurers have tried to avoid taking care of the higher risk population and the government's assumption

236. See PAUL J. FELDSTEIN, *HEALTH CARE ECONOMICS* 332 (4th ed. 1993); *EMPLOYMENT AND HEALTH BENEFITS*, *supra* note 157, at 199-200 (providing a general discussion of pre-employment and post-employment management of high-risk individuals). This incentive will be heightened for insurers, employers, and plan administrators because premiums and other financial incentives will frequently be negotiated on an annual basis. See *Doe v. Southeastern Pa. Transp. Auth. (SEPTA)*, 72 F.3d 1133, 1135-36 (3d Cir. 1995), *cert. denied*, 117 S. Ct. 51 (1996).

237. See FELDSTEIN, *supra* note 236, at 332 (suggesting that programs will seek to maximize profits by insuring only people who will be likely to demand fewer services rather than striving to provide those services to everyone more cost-effectively).

238. See *EMPLOYMENT AND HEALTH BENEFITS*, *supra* note 157, at 169.

239. For example, after Blue Cross/Blue Shield of Massachusetts lost \$200 million over the last decade in its health insurance program for seniors, it felt obliged to take out a full page ad in the *Boston Globe* to assure the public that it was *not* facing bankruptcy. See *Relax. We're Not Going Anywhere*, *BOSTON GLOBE*, Jan. 16, 1997, at A17. Less than a month later, Blue Cross/Blue Shield of Massachusetts explained its plan to split into four different companies. See Alex Pham, *Insurer Plans Breakup: In Bid to Stem Losses, Blue Cross Says It Will Divide into Four Firms*, *BOSTON GLOBE*, Feb. 6, 1997, at C1; see also HEALTH, EDUC. & HUMAN SERVS. DIV., GENERAL ACCOUNTING OFFICE, REPORT NO. GAO/HEHS-94-71, *BLUE CROSS AND BLUE SHIELD: EXPERIENCES OF WEAK PLANS UNDERSCORE THE ROLE OF EFFECTIVE STATE OVERSIGHT 5* (1994), available in 1994 WL 833178, at 6 (noting the financial difficulties of some "Blue plans that are required to serve as insurer of last resort").

240. See Keith H. Hammonds et al., *Blue Cross at a Crossroads*, *BUS. WK.*, June 24, 1996, at 62B; Greg Jaffe & Monica Langley, *Acute Reaction: Fledgling Charities Get Billions from the Sales of Nonprofit Hospitals*, *WALL ST. J.*, Nov. 6, 1996, at A1; Monica Langley & Anita Sharpe, *As Big Hospital Chains Take Over Nonprofits, A Backlash Is Growing*, *WALL ST. J.*, Oct. 18, 1996, at A1.

of this task has contributed to the cost explosion in publicly funded health care.²⁴¹

The legal trend has increasingly been to use antidiscrimination law to prevent this kind of risk segmentation through use of medical information in employment and health insurance.²⁴² Yet, this response, currently incomplete even on its own terms, also requires strengthening through data privacy law. The weaknesses of current antidiscrimination law in this area indicate the need for information privacy law.

Two of the most important antidiscrimination statutes in this context are the Americans with Disabilities Act (ADA)²⁴³ and the Health Insurance Portability and Accountability Act of 1996 (Health Insurance Portability Act).²⁴⁴ The ADA protects disabled individuals from employment discrimination and certain other kinds of disadvantages.²⁴⁵ It does not apply, however, to all health information. The ADA's applicability depends on whether or not an impairing condition falls among this statute's definition of "disability."²⁴⁶ Medical information about the non-disabled is *not* covered by the ADA.²⁴⁷

In the context of health care information, even more critical than this required nexus between the ADA and a defined disability is the Act's failure to create any general limitations on *access* to personal information. The ADA does not prevent an employer from gaining access to data that might lead to forbidden behavior; this law merely prevents discrimination against the disabled based on this information.²⁴⁸ As the Institute of Medicine's Committee on Employer-Based Health Benefits has warned,

241. See generally PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 329-30 (1982). In comparison, areas with long-term support for community rating have had relative success in controlling health care costs. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 218-19.

242. See generally Rothstein, *supra* note 181, at 287-96.

243. 42 U.S.C. §§ 12101-12213 (1994).

244. Pub. L. No. 104-191, 110 Stat. 1936 (1996).

245. See 42 U.S.C. §§ 12112, 12132, 12162, 12182. See generally CHARLES A. SULLIVAN ET AL., *EMPLOYMENT DISCRIMINATION* § 27.6, at 834-39 (2d ed. Supp. 1996) (describing protection for disabled employees against exclusion from employer-sponsored health insurance programs).

246. 42 U.S.C. § 12112(a) ("No covered entity shall discriminate against a qualified individual with a disability because of the disability . . .").

247. See *id.* § 12112(d). For a discussion of the ADA's shortcomings in responding to genetic testing, see Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act*, 46 ADMIN. L. REV. 369 (1994).

248. See Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 HOUS. L. REV. 23, 83-87 (1992). See generally Robert L. Burgdorf Jr., *The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 434-40 (1991); Ellen E. Schultz, *Open Secrets: Medical Data Gathered by Firms Can Prove Less Than Confidential*, WALL ST. J., May 18, 1994, at A1 (exploring ways in which programs touted as beneficial for employees, such as counseling and wellness programs, can provide employers with a ready stock of information to use against an employee regarding disability claims, compensation claims, or survivors' benefits).

"[A]ccess to personal medical information still provides the opportunity and perhaps the stimulus to attempt covert discrimination (e.g., when layoffs are being planned)."²⁴⁹ This Committee has criticized risk segmentation by employers and insurers and called for limits on employer access to certain kinds of information.²⁵⁰ It argues that data privacy is an important element in allowing employment-based health insurance plans to play their traditional role as "a powerful vehicle for spreading risk."²⁵¹

As for the recently enacted Health Insurance Portability Act, it, too, has weaknesses. The Health Insurance Portability Act forbids insurers from failing to renew or discontinuing health insurance coverage in the group or individual markets based on a given individual's preexisting conditions and health status.²⁵² By protecting the continuity of health insurance when employees change jobs, this law seeks to reduce insurers' and employers' desire for access to certain health care information. It also prohibits discrimination towards individual participants in and beneficiaries of group health insurance plans based solely on genetic information.²⁵³ Unfortunately, the law fails to prevent insurers from exorbitant increases in rates designed to drive away individuals with certain genetic or medical conditions.²⁵⁴ This law also permits exclusion of coverage in employer health plans for "any health status-related factor," including cancer and

249. EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 185-86. Regarding genetic information, the ADA offers some assistance and has some limitations. Recently, the EEOC has offered an interpretation of "disabled" that extends this term to "the basis of genetic information relating to illness, disease, or other disorders." 2 EEOC COMPLIANCE MANUAL, Order Nos. 902.8(a)-45, 915.002 (Mar. 14, 1995). For a discussion of this position of the EEOC, see Joseph S. Alper, *Does the ADA Provide Protection Against Discrimination on the Basis of Genotype?*, 23 J.L. MED. & ETHICS 167, 168-71 (1995).

The ADA may also provide some privacy protection by making at least certain employers reluctant to collect and process certain kinds of personal information. See SCHWARTZ & REIDENBERG, *supra* note 2, at 354. Due to fear of litigation, employers may avoid collection of data regarding medical conditions that would place an employee or a qualified job applicant under the ADA's protection. See *id.* Collecting such data might later be harmful to an employer facing a claim of workplace discrimination. See *id.*

But the ADA does *not* prevent employers from using health care information, including genetic data, to exclude pre-existing conditions from a health insurance plan based on underwriting classification risks. See 42 U.S.C. § 12201(c).

250. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 246, 245-46 ("To discourage this form of risk selection, employer access to certain kinds of information collected in connection with employment-based health benefits should be limited through provisions analogous to those contained in the [ADA].").

251. See *id.* at 9.

252. See Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, § 2701, 110 Stat. 1936, 1955-61.

253. See *id.*

254. See *id.* § 2702(b)(1)-(2); CONGRESSIONAL RESEARCH SERV., THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996: GUIDANCE ON FREQUENTLY ASKED QUESTIONS 9 (1996) ("The Act does not restrict the amount of premium that an employer or an insurer can charge.").

AIDS, so long as the exemption pertains to all similarly situated individuals.²⁵⁵

Despite their shortcomings, these statutes and a growing list of state laws reveal the emergence of a non-discrimination approach to the issue of risk segmentation. To be effective, however, this approach needs the assistance of a health information privacy statute. Such a law will prevent certain kinds of use and disclosure of health care data. Because much information may be both harmful and useful in different contexts for different reasons, a socially optimal distribution of information is unlikely to exist at either extreme on the privacy/disclosure continuum. Thus, Posner and Epstein err in opting for a disclosure extreme rather than more carefully evaluating different points on an information allocation continuum that ranges from complete disclosure to complete secrecy.

III. An Economically Efficient Regulation of Personal Health Care Data

Posner and Epstein view disclosure of personal information as invariably favorable to society. This Article has argued, however, that unrestricted disclosure of personal information will not maximize social utility. If the conventional wisdom of law and economics theorists about the virtues of absolute disclosure is wrong, the establishment of rules for an optimal use of personal data remains a difficult undertaking. The creation of such an optimal pattern of knowledge and privacy is a complex task because access to data can be either beneficial or harmful depending on the context. Medical information is a perfect illustration of this phenomenon, and this Article will continue to utilize it as a jurisprudential case study. In this Article's Part III, we move from a critique of existing law and economics theory to a prescription for an economically sound regulation of the treatment of personal health care data.

Because complete disclosure is not always economically efficient, the next step might simply be to let individuals negotiate the level of privacy or disclosure that they desire. This Article finds, however, that various market imperfections have led to a lower level of privacy than most health care consumers would like. Yet, just as the market sometimes *undervalues* privacy, certain social actors and institutions will have a significant need for access to health care information, and a decision to block disclosure under certain of these circumstances would *overvalue* privacy from society's perspective. The market alone cannot be used to generate rules for access to personal medical data.

255. Health Insurance Portability and Accountability Act § 2702(b)(1); CONGRESSIONAL RESEARCH SERV., *supra* note 254, at 9. For criticisms of this law, see Suzy Szasz, 'Portable' Insurance?, N.Y. TIMES, Sept. 4, 1996, at A21.

A. *Health Care Market Failures and Legal Standard Setting*

In the United States, medical services are provided through a series of contracts that involve diverse parties.²⁵⁶ Most health care consumers receive health care financed by their employer, which means that one agreement must take place between employers and employees.²⁵⁷ Employers also carry out a series of negotiations from which their employees are singularly absent. Employers must reach agreement with those parties who provide insurance, manage services, and provide the underlying medical care.²⁵⁸ The agreements between these parties concern two areas: (1) the furnishing of services and (2) the use of the resulting personal information.²⁵⁹ Due to a series of market flaws, the preferences of health care consumers are sometimes underrepresented regarding the use of their personal data.

1. *The Market Failure for Personal Medical Information.*— Considerable evidence exists of a strong consumer desire for health care privacy. For example, significant public support exists both for requiring organizations that handle medical records to have detailed privacy protection policies and for allowing an individual to obtain a copy of her medical record.²⁶⁰ Strong support also exists for the creation of strict rules concerning outside parties that may gain access to medical records and the nature of information that they can obtain.²⁶¹ Finally, seventy-one percent of respondents to a recent survey agreed that individuals had lost control of how companies circulate and apply personal information.²⁶² This survey also found a similarly high percentage of the public to be very or somewhat concerned about threats to personal privacy.²⁶³

Despite a preference for strong data protection, health care consumers have been unable to obtain the kind of practices that they desire. Some examples of the current low level of health care data privacy illustrate this fact. One set of difficulties relates to electronic medical records, which make possible new kinds of access to personal data. One patient recently

256. See ROSENBLATT ET AL., *supra* note 233, at 139-41.

257. *Id.* at 139.

258. See generally STEVEN JONAS, AN INTRODUCTION TO THE U.S. HEALTH CARE SYSTEM 1-2 (3d ed. 1992).

259. Information about planned use of personal information is not, however, generally shared with health care consumers. See text accompanying notes 311-316.

260. See HARRIS-EQUIFAX, HEALTH INFORMATION PRIVACY SURVEY 3, 41, 68 (1993).

261. See *id.* at 42-46.

262. See LOUIS HARRIS & ASSOCS. & ALAN F. WESTIN, EQUIFAX INC., THE EQUIFAX REPORT ON CONSUMERS IN THE INFORMATION AGE 11 (1990).

263. See *id.* at 2 (reporting that seventy-nine percent of those surveyed in 1990 were "very concerned" or "somewhat concerned" with threats to their personal privacy).

went to an internist for a routine treatment only to discover that this health care professional had electronic access to her psychiatrist's complete notes.²⁶⁴ These digital data were available not only to all other physicians, but to everyone, including nurses and clerical staff, working for the large HMO in Boston to which she belonged.²⁶⁵ After a bout of bad publicity, this organization changed its practices.²⁶⁶ Nevertheless, general standards do not currently exist in this area,²⁶⁷ and other HMOs continue to have less than stellar practices regarding access to personal data.²⁶⁸

Another example pertaining to computer-based health care records concerns the increasing use of digital "family trees."²⁶⁹ This term refers to electronic hypertext links that allow immediate access to the records of an individual's family.²⁷⁰ As one primer on health information describes these devices, "Family trees will be incorporated into the data of all patients, with pointers to the computerized records of other family members. Periodically these data sets will be linked and patterns of inherited conditions will be detected and alerts generated for persons found to be at risk."²⁷¹

The practice of creating family trees in medical records has significant privacy implications. By enabling the instantaneous location of data about one's spouse and relatives, electronic health care records with family trees do more than provide new ways for family members to embarrass each another. In some circumstances, patterns of inheritable conditions with a genetic component are already detectable by looking at an individual's or family's records even if a given patient has never submitted to a genetic test.²⁷² The clearest example occurs for monogenic conditions in which the outbreak of the related illness in a child invariably reveals that one or both parents carry the underlying gene.²⁷³ To the extent that electronic

264. See Scarf, *supra* note 37, at 38.

265. See *id.*

266. See *id.* at 39.

267. See *id.* at 40.

268. See *id.* at 38-39 (citing examples of HMOs leaking patients' personal data); see also Noah Robinson, *Rx for Medical Privacy* (visited Sept. 3, 1997) <<http://www.cnn.com/TECH/9709/03/netly.news/>> ("At one of the country's largest HMOs, Kaiser Permanente, any employee can pull up the entire medical history of any patient.").

269. Martin Mendelson, *Future Directions in Clinical Information Management*, in HEALTH INFORMATION, *supra* note 78, at 676, 677.

270. See *id.*

271. *Id.*

272. See Mark A. Rothstein, *Genetic Secrets: A Policy Framework*, in GENETIC SECRETS, *supra* note 181, at 451, 451-52.

273. See KITCHER, *supra* note 109, at 40 (noting the mapping, cloning, and sequencing of the genes for Huntington's disease and cystic fibrosis).

records increase the storage and sharing of family members' data, they will thereby make all kinds of genetic data instantly available. As a result, this digital device will increase the frequency of predictions about an individual's likelihood of suffering from certain genetic conditions.²⁷⁴ The impact on how certain individuals are perceived and treated will be tremendous. Yet, consumers are generally ignorant of the introduction of electronic records and electronic family trees, let alone aware of the different implications of these technologies.²⁷⁵

A final example of a failure in the privacy marketplace is indicated by the decision of employers and insurers to treat health care data as their property over which they have complete, undifferentiated control.²⁷⁶ In contrast, most individuals believe that they deserve fair information practices that structure the terms by which others, including their employers, gain access to these data.²⁷⁷ A recent decision of the United States Court of Appeals for the Third Circuit, *Doe v. Southeastern Pennsylvania Transportation Authority (SEPTA)*,²⁷⁸ illustrates the absence of effective limitations on employers' access to medical data.²⁷⁹

SEPTA began with some good news within one workplace. A state agency, SEPTA, decided to offer drug benefits to its employees.²⁸⁰ It also chose to self-insure, which meant it would assume direct responsibility for payment of these benefits.²⁸¹ SEPTA hired Rite-Aid, a national drug store chain, to be the sole provider of prescription drugs

274. An excellent example of this temptation to engage in genetic predictions is offered by Philip Kitcher, whose otherwise insightful and sober *THE LIVES TO COME*, *supra* note 109, includes uncharacteristic recommendations regarding the taking of genetic profiles of the entire population of the United States, *see id.* at 172-77, and lengthy, starry-eyed musings about the benefits of "utopian eugenics." *Id.* at 217, 217-19, 228-84.

275. The Secretary of the Department of Health and Human Services has commented:

The paper records once kept under the control of physicians [are] giving way to computerized information which is increasingly stored far from its source—the patient and the physician—in forms and even locations of which they may have only imperfect understanding. Even physicians may be frustrated in their traditional role as patient advocates by the complexity of the systems that process their patients' information.

Secretary of Health & Human Services, *Confidentiality of Individually-Identifiable Health Information* (visited Sept. 11, 1997) <<http://aspe.os.hhs.gov/admsimp/PVCREC1.htm>>.

276. *See* John Riley, *When You Can't Keep a Secret: Insurers' Cost-Cutters Demand Your Medical Details*, *NEWSDAY*, Apr. 1, 1996, at A7, A37. For a general survey, *see* ANNE WELLS BRANSCOMB, *WHO OWNS INFORMATION?: FROM PRIVACY TO PUBLIC ACCESS* 54-72 (1994).

277. *See* HARRIS-EQUIFAX, *supra* note 260, at 4. This poll also shows that a large percentage of the public believes consumers have lost control over the circulation of their personal information, and believes computers must be sharply restricted if privacy is to be preserved. *See id.* at 20.

278. 72 F.3d 1133 (3d Cir. 1995), *cert. denied*, 117 S. Ct. 51 (1996).

279. *See id.* at 1136.

280. *See id.* at 1135-37.

281. *See id.* at 1135.

for its employees and to administer all associated paperwork.²⁸² As a self-insurer, SEPTA had a great incentive to limit its employees' use of medications.²⁸³ In this cost-conscious atmosphere, SEPTA's Chief Administrative Officer sought utilization reports from Rite-Aid, which submitted them with the names of individuals filing prescriptions for more than one hundred dollars a month and the specific drugs that these employees received.²⁸⁴

Once in SEPTA's control, these personal data were not ignored. The Chief Administrative Officer and the Director of Benefits looked up unfamiliar medications in a medical reference text and asked a staff physician about drugs not listed in this book.²⁸⁵ As a result of this behavior, the officials learned that one of their employees, John Doe, was receiving AIDS medication.²⁸⁶ In turn, Doe discovered that these officials knew of his infection with AIDS.²⁸⁷ Doe believed that his co-workers began to treat him differently at this time.²⁸⁸ A jury agreed, found for Doe, and awarded him \$125,000 for the invasion of his privacy and his emotional distress.²⁸⁹

The Third Circuit reversed this decision. It found that SEPTA had a strong interest "in containing its costs and expenses by permitting this sort of research by authorized personnel."²⁹⁰ The Third Circuit decided that SEPTA's financial interest outweighed "the minimal intrusion" upon Doe's privacy.²⁹¹ It also found no need under the circumstances of this case for written and binding rules for the use of such sensitive personal data.²⁹² Judge Lewis disagreed with this conclusion and predicted that the decision "will make it far easier in the future for employers to disclose their employees' private medical information . . . and to escape constitutional liability."²⁹³

282. *See id.*

283. Indeed, SEPTA's contract with Rite-Aid provided an additional incentive for the agency to control benefit costs. *See id.* Each year Rite-Aid was to furnish SEPTA with an estimate of the annual costs of all pharmaceutical benefits. *See id.* If the actual costs to Rite-Aid exceeded that estimate by 115%, SEPTA would pay substantial penalties. *See id.* If the actual costs were, however, 90% or less of the estimate, SEPTA would be entitled to a rebate. *See id.*

284. *See id.* at 1135-36.

285. *See id.* at 1136.

286. *See id.*

287. *See id.*

288. *See id.* at 1136-37.

289. *See id.* at 1135. For the lower court decision upholding this jury verdict, see *Doe v. Southeastern Pennsylvania Transportation Authority (SEPTA)*, 63 U.S.L.W. 2775 (E.D. Pa. 1995), *rev'd*, 72 F.3d 1113 (3d Cir. 1995), *cert. denied*, 117 S. Ct. 51 (1996).

290. *SEPTA*, 72 F.3d at 1140.

291. *Id.*

292. *See id.* at 1140-43.

293. *Id.* at 1147 (Lewis, J., concurring and dissenting).

The *SEPTA* decision stands for a number of propositions,²⁹⁴ but, for our purposes, one of the most critical aspects of this opinion concerns something that is absent from it. In this decision, the Third Circuit does not discuss any privacy statute or regulation that SEPTA might or might not have violated when its officials eagerly pored over its workers' prescription records and explored the health implications of these data.²⁹⁵ A reason exists for this judicial silence: in the United States, no comprehensive regulation applies to the use of health care information, and no law currently forbids the underlying behavior in *SEPTA*.²⁹⁶ This employer acted as if the files developed by the health care plan it sponsored were its property, over which the employer had a complete right of access.²⁹⁷

SEPTA is also important for its implications about self-insurance and privacy. Due to this agency's direct payment of its employees' medical bills, SEPTA viewed itself as having a special need to scrutinize patient information.²⁹⁸ The consequences of self-insurance for health care privacy are even more significant in the private sector because of the Employment Retirement Income Security Act (ERISA), which preempts state regulation of private companies that provide health care benefits through self-insurance.²⁹⁹ Due to weak federal privacy protection,

294. At one level, *SEPTA* is simply a case about the constitutional right of informational privacy. The *SEPTA* court found that the informational privacy right, which extended to an interest in prescription records, did not provide an absolute bar against disclosure of this medical information. *See id.* at 1137-39. The constitutional right in question, which the United States Supreme Court had first identified in 1978 in *Whalen v. Roe*, 429 U.S. 589 (1977), did not forbid "the disclosures present here." *SEPTA*, 72 F.3d at 1140.

In its opinion, the Third Circuit also stressed that SEPTA had at least temporarily abandoned the practice of obtaining reports that linked the names of employees with their medications. *See id.* at 1143. In a murky passage, the court seemed to imply that in the future the Constitution might require better safeguards to be in place than those SEPTA had offered. *See id.* Evidence exists, however, that (1) Rite-Aid continues to deliver detailed prescription information to SEPTA, with the sole exception concerning drugs related to AIDS, and (2) Rite-Aid would also deliver this information about AIDS medicine if SEPTA requested it. *See Riley, supra* note 276, at A37. Yet, whatever the shortcomings or strengths of this constitutional right, it is only available under limited circumstances. *See Schwartz, supra* note 2, at 314-15. Most health care consumers will not be able to avail themselves of this right; the overwhelming majority of medical information in the United States is in the control of private doctors, hospitals, managed care organizations, and insurance companies. *See id.* at 315. Under these circumstances, state action is not likely to exist, and constitutional protections will not be triggered. *See id.*

295. *SEPTA*, 72 F.3d at 1135-39.

296. *See Schwartz, supra* note 2, at 310-11; *cf. Gostin, supra* note 35, at 495.

297. *SEPTA*, 72 F.3d at 1135-36.

298. *See id.*

299. Employment Retirement Income Security Act § 502(a), 29 U.S.C. § 1132 (1994). For the leading Supreme Court cases interpreting the scope of ERISA preemption, see *New York State Conference of Blue Cross & Blue Shield Plans v. Travelers Insurance Co.*, 514 U.S. 645 (1995) and *FMC Corp. v. Holliday*, 498 U.S. 52 (1990). On the difficulties with ERISA preemption of state law, see Mary Anne Bobinski, *Unhealthy Federalism: Barriers to Increasing Health Care Access for the Uninsured*, 24 U.C. DAVIS L. REV. 255, 269-70 (1990).

ERISA has thereby created a considerable loophole for self-insured companies.³⁰⁰ A private company that opts for self-insurance will be subject neither to constitutional requirements for informational privacy (due to the lack of state action) nor to any existing state regulations (due to ERISA preemption).³⁰¹

2. *Explaining the Failure of the Privacy Market.*—If a strong public demand for medical privacy exists, how is one to explain the market's failure to respond to consumers' wishes? The underrepresentation of the American public's privacy preferences can be traced to three factors: (1) the public's lack of knowledge regarding the treatment of personal data; (2) an agency problem; and (3) a collective action problem. We will examine each area in turn as a prelude to an elaboration of the necessary standard setting.

Effective negotiation on behalf of one's interests requires different kinds of knowledge. To be sure, such knowledge is unlikely to be complete, and for this reason Posner's argument regarding the inevitable inefficiency of informational privacy is unconvincing.³⁰² Nevertheless, a more modest claim is possible, which is that certain information shortages can affect the efficiency of some negotiations. For example, "gag rules" on physicians are likely to have a negative impact on agreements about desired health care services. The law appears to share this judgment and is acting to ban such silencing of physicians. This example is highly instructive.

Gag rules are clauses that prevent physicians from telling patients about treatment options for which the HMO does not reimburse.³⁰³ HMOs have been heavily criticized for imposing these requirements on physicians, and several states have enacted laws that ban such clauses.³⁰⁴

300. See Bobinski, *supra* note 299, at 265; Rothstein, *supra* note 248, at 80-81; MASSACHUSETTS MED. SOC'Y, POLICY ON PATIENT PRIVACY AND CONFIDENTIALITY 13 (1996) (on file with the *Texas Law Review*). For a discussion of how ERISA is encouraging selection of this increasingly popular option for health care funding, see EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 312.

301. Indeed, in light of the weaknesses in the current regulation of medical privacy, SEPTA, as a governmental agency, may actually have faced a more difficult privacy obstacle course than most private institutions that process personal health care data.

302. See *supra* text accompanying notes 148-54.

303. See GEORGE ANDERS, HEALTH AGAINST WEALTH: HMOS AND THE BREAKDOWN OF MEDICAL TRUST 80 (1996); Robert Pear, *The Tricky Business of Keeping Doctors Quiet*, N.Y. TIMES, Sept. 22, 1996, § 4 (Magazine), at 7 ("Doctors across the country say H.M.O.'s have limited their ability to talk freely with patients about costly treatment options or H.M.O. payment policies, including the financial incentives for doctors to withhold care.").

304. According to one estimation, 16 states have adopted such laws preventing HMOs from limiting what physicians tell their patients. See Robert Pear, *Laws Won't Let H.M.O.'s Tell Doctors What to Say*, N.Y. TIMES, Sept. 17, 1996, at A12. These states include Indiana, see IND. CODE ANN. § 27-13-15-12 (West Supp. 1996), and Oklahoma, see OKLA. STAT. tit. 63, § 2525.6(h) (1996). New

More recently, President Clinton and the Department of Health and Human Services have acted to prevent HMOs from using gag rules to limit the information about treatment options that physicians share with Medicare and Medicaid patients.³⁰⁵ Congress is now considering legislation to ban the use of these clauses in other government-financed health care programs and in private insurance.³⁰⁶

A gag rule affects a medical service, namely information about treatment options, that plays a special role in health care. As Kenneth Arrow observes, "[I]nformation . . . is precisely what is being bought from most physicians, and, indeed, from most professionals."³⁰⁷ Supply and demand have a peculiar relationship in this area; as a result of the physician's superior knowledge of medical science, in many instances a consumer will know the kind of care that she desires only *after* the health care professional has shared relevant information with her.³⁰⁸

This analysis suggests that gag rules are likely to contribute to a market deficiency regarding the formation of a certain kind of consumer demand. Unless physicians freely share their superior knowledge, health care consumers will not be able to formulate the preferences for which they wish to negotiate. Moreover, because agreements between insurers and physicians are generally confidential, the consumer will not even know if a gag rule is in place. Indeed, some HMOs have vigorously denied that such clauses ever existed or insisted that they were intended only for other purposes.³⁰⁹ Persistent media scrutiny, legislative inquiry, and physician leaks brought this issue into the open.³¹⁰

An informational shortfall also occurs regarding the use of personal health care data. Consumers are generally ignorant of the different kinds of applications of their personal medical data. Indeed, the general public's

Jersey is one of several states currently considering limits on gag rules. See Managed Health Care Consumer Protection Act, Assembly Bill 2668, 1996 N.J.A.B. 2668, §§ 6-7 (1997).

305. See Laurie McGinley, *Clinton to Prohibit Use of "Gag Clause" by HMOs Treating Medicaid Patients*, WALL ST. J., Feb. 20, 1997, at A22 (citing the disapproval of gag rules by the White House, the AMA, and the American Association of Health Plans).

306. See Robert Pear, *U.S. Bans Limits on H.M.O. Advice Within Medicare*, N.Y. TIMES, Dec. 7, 1997, at A1.

307. Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 946 (1963).

308. Arrow dryly notes of the physician, "It is socially expected that his concern for the correct conveying of information will, when appropriate, outweigh his desire to please his customers." *Id.* at 950.

309. See Pear, *supra* note 303, at 7 ("H.M.O.'s insist that the restrictions are rare, that they have been misconstrued and that they are not intended to limit communications between doctor and patient on medical treatment options.").

310. See ANDERS, *supra* note 303, at 80; Pear, *supra* note 303, at 7. Indeed, under this public and governmental pressure, some HMOs have begun to eliminate these controversial clauses from their contracts with physicians. See Ron Winslow, *Humana Lifts Rules Limiting Doctors' Speech*, WALL ST. J., Oct. 29, 1996, at B5.

desire for strong medical data privacy is accompanied by its belief that health care records already receive a high level of protection and that limits have been placed on access to these data.³¹¹ Polls have also shown that insiders—such as physicians, heads of medical societies, health insurers, and hospital CEOs—are aware of the lack of strong safeguards on the use of personal medical data.³¹² Under these circumstances, a monopoly equilibrium exists. As Alan Schwartz and Louis L. Wilde described this condition, “[I]t occurs when firms do not compete to give consumers better terms, but instead are aware of consumer ignorance and actively exploit it to procure for the firms themselves the most favorable terms possible.”³¹³

Regarding the use of health care information, an equilibrium has been reached about the sharing and processing of these personal data; this situation illustrates the adage that ignorance is bliss—at least, for the parties that benefit from the lack of awareness. One of the ways that a monopoly equilibrium is maintained regarding knowledge of the use of health care data is through a shallow consent process. Under this process, consumers of health care frequently are asked to sign broadly drafted release documents, which are then used to justify almost any disclosure of medical data.³¹⁴ Individuals are consenting without an adequate process in place to inform their decisions.³¹⁵ As a result, the current reliance on blanket patient release forms is based on uninformed consent to disclosures of personal data.

Parties that benefit from this informational monopoly equilibrium have scant incentive to do anything other than maintain silence. Put another way, the unregulated privacy market has failed to generate optimal information to guide individual decisionmaking about the use of personal medical data. As Joel Reidenberg has observed of commercial data practices in general, “Companies control the disclosure of their practices and suffer no penalties for refusing to disclose. In fact, companies may suffer harm if they do disclose their inappropriate practices as a result of negative backlashes.”³¹⁶ Companies currently use informed consent forms less to provide essential information to health care consumers than to control and restrict disclosure of their information practices.

311. See *supra* text accompanying notes 255-61. For a discussion regarding the public's belief in the existence of strong protection for medical records, see HARRIS-EQUIFAX, *supra* note 260, at 4.

312. See HARRIS-EQUIFAX, *supra* note 260, at 22.

313. Schwartz & Wilde, *supra* note 149, at 661.

314. See Alpert, *supra* note 1, at 15 (citing an example of a blanket form required by one self-insured company); Schwartz, *supra* note 2, at 339 (“In light of the current abuse of informed consent through the use of blanket disclosure documents, careful new safeguards are required.”).

315. For an analysis of the meaning of informed consent in the informational privacy setting, see Schwartz, *supra* note 2, at 338-39.

316. Reidenberg, *supra* note 32, at 533.

A second reason for the privacy market's failure to address health care consumers' interests is an agency problem. An agency problem arises because employers and employees sometimes have widely divergent interests, but the latter group depends on the former to transmit its wishes to other parties.³¹⁷ One of the most important interests of employers is in reducing health care costs to the lowest possible level.³¹⁸ At the moment when this cost consciousness interferes with the quality of care, however, a direct conflict occurs with employees' interests. As a reporter for *The Wall Street Journal* warns, "Without clear coverage rules, health plans will engage in a race to the bottom, devising audacious ways to avoid treating the sick."³¹⁹ As already noted, a similar disincentive arises regarding the sharing of information about data processing practices.³²⁰

A final factor in consumers' failure to obtain the level of privacy that they desire is due to a collective action problem.³²¹ A shrinking number of firms now provide health care services for larger and larger groups of consumers. A single organization already provides health care for one in every twelve Americans.³²² As another example of this trend of consolidation, HealthSouth, which boasts of its marketing itself as a brand name like McDonald's, recently became the first provider of health care services in all fifty states.³²³ If this trend continues, five or six national firms may one day control all the health care services in the United States.³²⁴

As members of large consumer blocks, individuals may have difficulty finding effective ways to express collectively their relative preferences for privacy. While computer technology provides low cost ways for involving consumers in decisionmaking regarding planned future use of their personal

317. For a general discussion of the agency costs problem in the corporate context, see Posner, *supra* note 12, at 398-99.

318. For a dramatic description of the "businessman's revolt" that is helping to drive the current demand for cost-saving in health care, see ANDERS, *supra* note 303, at 16-18.

319. *Id.* at 246.

320. *See supra* text accompanying notes 311-16.

321. For a perceptive introduction to this cause of market failure, see SUNSTEIN, *supra* note 192, at 59-61.

322. *See* Jill Smolowe, *A Healthy Merger?*, TIME, Apr. 15, 1996, at 77. The HMO in question formed from the 1996 merger of Aetna, a large health insurance company that owned a smaller managed care organization, with U.S. Healthcare, a large and highly profitable managed care company. *See id.* This new entity has no less than 23 million Americans enrolled in its combined managed care plans. *Id.*

323. *See* Anita Sharpe, *Care Incorporated: Medical Entrepreneur Aims to Turn Clinics Into a National Brand*, WALL ST. J., Dec. 4, 1996, at A1.

324. *See* Can HMOs Help Solve the Health-Care Crisis?, CONSUMER REP., Oct. 1996, at 28, 32. Cigna Corporation's recent purchase of Healthsource Inc. offers a further example of this trend of consolidation among health care providers. *See* Milt Freudenheim, *Cigna to Buy Healthsource, Vaulting Ahead in H.M.O.'s*, N.Y. TIMES, Mar. 1, 1997, at 35. This merger has created an HMO that will provide health care for 12.3 million customers spread over 29 states. *See id.*

data, the initial investment in such capacity must be made by HMOs and insurers, who may decide that it is against their interests to provide such means for coordination of consumer preferences.³²⁵ In addition, with a smaller number of firms providing health care insurance and services, competition may not arise regarding disclosure of relevant information. Thus, while solutions to the collective action problem are not unimaginable, they depend upon the parties who currently have a disincentive to provide the required technical assistance.

B. Standard Setting for Personal Medical Information

The response to the market failure regarding the use of personal medical information should be standard setting through law. Here, as is the case regarding gag rules, action is required to correct the market's failure to ensure a fuller representation of consumer preferences. This Article will discuss and develop two groups of concepts in this area: the multifunctionality of computer data and the nature of default and mandatory rules. These ideas provide the necessary conceptual framework for the standards required for efficient use of personal medical information. They suggest that a legislative standard setting for data protection will consist of a mixture of rules that are tied to and follow personal information through various uses.

1. The On-Line Patient, Multifunctional Data, and Standard Setting.—As this Article has noted, personal health care information has become multifunctional due to the capabilities of information technology.³²⁶ Personal data are multifunctional because the computer changes information into a fluid form that makes it applicable at many stages of administration. In the context of health care, the multifunctionality of personal medical information has made it one of the key assets in medicine today.³²⁷ As a result of ever increasing spending on health care management, a state-of-the-art electronic system for patient records has astonishing capabilities, and such systems are already employed throughout the United States.³²⁸ A description of this technology will make clear its significant implications for data protection law—in particular, that

325. Thus, existing competition among HMOs does not extend to competition to provide consumers with information that will permit easy comparison of different HMOs. See MARK GREEN, PUBLIC ADVOCATE FOR THE CITY OF N.Y., WHAT AILS HMOs—A CONSUMER DIAGNOSIS AND RX at 17-18 (1996).

326. See *supra* text accompanying notes 93-99.

327. See INSTITUTE OF MED., *supra* note 77, at 19, 19-21 (“[T]he practice of medicine has been described as being ‘dominated’ by how well information is processed or reprocessed, retrieved, and communicated.” (citation omitted)).

328. See *supra* text accompanying notes 94-99.

electronic health care records restrict the usefulness of any simple rule that would mandate privacy *or* disclosure.

When a health care professional wishes to access patient information in a system that uses electronic dossiers, she begins by accessing a computer screen through a "graphical user interface."³²⁹ Anyone who has used Microsoft Windows software or an Apple computer is familiar with this kind of interface, which relies on commands based on the use of icons and mouse-driven point-and-click functions.³³⁰ A physician using such software begins by clicking on an individualized physician support screen, which lists the names of her current patients, her "on call" schedule, and any urgent messages.³³¹ From this screen, the physician can access data about individual patients by clicking on a specific name.³³² This choice leads to an initial patient screen that lists any news regarding this patient, including recent laboratory results or information added to the file by other health care professionals.³³³ Within this electronic environment, access is also provided to a screen for physician support tools, which allow a physician to regroup data in a patient's chart in a variety of ways, including by body system.³³⁴ In addition, electronic mail is available to increase the ease of communication with colleagues and patients.³³⁵ Beyond such items, the physician can also access the individual's electronic health care record, which provides "longitudinally oriented lifetime patient summaries."³³⁶

329. A robust market currently exists for these products with no fewer than 14 available systems recently compared in one survey. See Steven Ornstein et al., *A Vendor Survey of Computerized Patient Record Systems*, FAM. PRAC. MGMT., Feb. 1996, at 35. This Article's following description of an electronic health care records system will concentrate on the "Ulticare Clinical Workstation," which is a product of Health Data Sciences Corporation. See HDS CORPORATE AND PRODUCT OVERVIEW: APPLICATIONS GUIDE (1995) [hereinafter HDS APPLICATIONS GUIDE] (on file with the *Texas Law Review*). No endorsement of this product is intended; it has been chosen because it is a popular and readily available patient record system.

330. See HDS ULTICARE CLINICAL WORKSTATION (1996) (on file with the *Texas Law Review*).

331. See HDS APPLICATIONS GUIDE, *supra* note 329, at 11.

332. See *id.* at 11-13.

333. See *id.*

334. See *id.*; Korpman, *supra* note 80, at 282 ("Each provider [of health care] has his or her own view of the world with a unique set of information processing abilities and needs."). Just as specialists look at different parts of an individual or examine the same part from their own perspective, they will also wish to examine the on-line patient in different ways. See *id.* at 283. Practitioners should therefore be able to establish their own screening criteria for patient information in the software system. See *id.*

335. Cf. HDS APPLICATIONS GUIDE, *supra* note 329, at 12 (describing features allowing physicians access to electronic records from homes or offices).

336. *Id.* at 13. Such records also offer "wellness checks" that remind the health care provider to alert patients when they need a check up, flu shot, or such regular tests as a pap smear. See *id.*

In addition, orders for hospital staff as well as prescriptions can now be written electronically. See *id.* at 15-17. "Custom order sets," which can be stored within the tool function, allow a physician to set up standardized forms for the orders that she most frequently issues. See *id.* at 12.

Although a paper record in a doctor's office may already contain more intimate details than those found in almost any other document, electronic health care records created with different software packages link together records from various physicians and from different periods in a person's life. As one textbook in health information management states, "The record must contain everything about a person's health and the care received regardless of provider, time, place, insurance plan, or health care delivery organization."³³⁷ Or, in the words of a medical software company, the electronic patient record is to be a "complete online lifetime medical record."³³⁸ As this Article has noted, such lifetime records will include a patient's complete medication history and family trees. An electronic health record's dimensions at any given moment depend on how different software applications tie together different databases.

The multifunctional patient record has the potential to heighten the efficiency of the health care business. It also is capable of leading to improvements in medical science. Yet, by stimulating interactions between individuals and information-processing institutions, electronic health records raise a more complex issue than a choice between privacy *or* disclosure. Rather than a single directive, economic efficiency for personal health care data requires multiple rules that are tied to and follow personal information through various uses. The critical question concerns the conditions under which various social actors and institutions should have access to personal health care data. A pattern of optimal social use of health care information can only be constructed through the setting of limits on the databases to be shared, the networks in which databases are linked, and the ends to which the processed data will be put. These limits are necessary because a socially optimal distribution of information is unlikely to exist at either extreme on the privacy/disclosure continuum.

In the computer age, we must evaluate different points on an information allocation scale that ranges from complete disclosure to complete secrecy. An individual cannot have complete control over her medical information because access to these data is essential for the modern provision of health care. In a similar fashion, physicians must be limited in their ability to negotiate with patients for privacy because of the significant need for personal health care information on the part of insurers, hospitals, and government. A physician and patient, or an employer and employee, cannot engage in fully customized negotiations because such bargaining might lead to excessive limits on the access to data of such parties as insurance programs (including publicly financed programs), public health agencies, and law enforcement agencies. A good example of limits on

337. Ruckle, *supra* note 78, at 669.

338. HDS APPLICATIONS GUIDE, *supra* note 329, at 3.

fully customized negotiations concerns the growing problem of fraudulent activities and other misbehavior by physicians and HMOs, which means that the extent of governmental scrutiny of billing and other information cannot be decided solely by physicians and HMOs.³³⁹ Thus, freedom of contract must be limited in the context of medical records by the requirement that some third parties have access to certain data.

Rather than establishing a single rule regarding disclosure or privacy, the law must now engage in more complex kinds of standard setting. It must create fair information practices that are capable of responding to the different contexts in which personal medical data are used. Here, the idea of standard setting through default and mandatory rules will be of assistance. This concept is, in fact, at least implicit in the approach of Posner and Epstein,³⁴⁰ but requires adaption in the computer age.

Default rules are those that parties can negotiate around; in contrast, mandatory rules set immutable norms on parties.³⁴¹ According to the standard view, when a contract is silent with respect to a particular term or condition, the law generally should set default rules according to the wishes of most parties to such agreements.³⁴² By setting a rule in this fashion, fewer parties are forced to negotiate around the law, and transaction costs can be lowered.³⁴³ Moreover, such standard setting is beneficial because parties are unlikely to anticipate all future conditions or express specifications regarding unlikely possibilities in a way that allows resulting gains to exceed costs.³⁴⁴

In contrast to default rules, mandatory rules are utilized to set fundamental background conditions around which parties are not permitted to negotiate.³⁴⁵ An example of a mandatory rule is the UCC's duty to per-

339. Thus, law enforcement officials and various governmental agencies are currently carrying out an investigation of Columbia/HCA Healthcare Corporation, the nation's largest health care corporation. See Martin Gottlieb & Kurt Eichenwald, *Biggest Hospital Operator Attracts Federal Inquiries*, N.Y. TIMES, Mar. 28, 1997, at A1. The scope of this investigation includes the company's dealings with Medicare and the question of whether Columbia/HCA inflated the seriousness of illnesses to receive higher payments. See *id.*

340. See, e.g., Epstein, *supra* note 14, at 10-12; Posner, *supra* note 12, at 403.

341. See Ayres & Gertner, *supra* note 149, at 735-40 (examining the costs parties bear when they contract around default rules). For a further discussion of these concepts, see Jules L. Coleman et al., *A Bargaining Theory Approach to Default Provisions and Disclosure Rules in Contract Law*, 12 HARV. J.L. & PUB. POL'Y 639, 640-42 (1989) (exposing the underlying rationale for default rules).

342. See Ian Ayres & Robert Gertner, *Filling Gaps in Incomplete Contracts: An Economic Theory of Default Rules*, 99 YALE L.J. 87, 93 (1989) ("Lawmakers can minimize the cost of contracting by choosing the default that most parties would have wanted.").

343. See *id.* ("[A]s transaction costs increase, so does the parties' willingness to accept a default that is not exactly what they would have contracted for.").

344. See Coleman et al., *supra* note 341, at 640-41. See generally E. ALLAN FARNSWORTH, CONTRACTS § 1.10, at 33-34 (2d ed. 1990) (noting that most rules of contract law can be varied by partners to an agreement).

345. See, e.g., John C. Coffee, Jr., *The Mandatory/Enabling Balance in Corporate Law: An Essay on the Judicial Role*, 89 COLUM. L. REV. 1618, 1624 (1989) (explaining that parties are not free to

form contracts in good faith.³⁴⁶ Other examples are found in corporate law's rules for allocating power between directors and shareholders and for governing transactions that will transform the economic structure of a given firm.³⁴⁷

In this light, both Posner and Epstein can be seen as arguing in favor of a disclosure default rule for personal information. In their view, the law generally should have a starting point of non-privacy.³⁴⁸ In a recently published article, *Property Rights in Personal Information: An Economic Defense of Privacy*, Richard Murphy takes another tack.³⁴⁹ Murphy suggests that a disclosure default rule will be inefficient for at least some consumer contracts.³⁵⁰ A default for disclosure of personal data will be difficult to bargain around because merchants may find it difficult to tell which of their customers value data privacy more highly, and consumers will lack knowledge regarding the use of their information and its value.³⁵¹ In contrast, a privacy default rule will encourage more relevant data about a transaction to be revealed because merchants will be forced to share this information as an initial step before affected parties decide whether to negotiate around the nondisclosure norm.³⁵²

This latter approach is suggestive, but, for two reasons that this Article has explored, requires development in the brave new world of computers. First, information technology has made personal data multifunctional. Rather than a single rule, economic efficiency requires multidimensional fair information standards that combine disclosure *and* privacy rules for the same piece of information. These fair information standards will establish normative practices for the processing of personal data. Second, the ability to reach contractual solutions regarding the disclosure of personal information must be limited when an important social need requires third-party access to personal data.³⁵³ The significant need of some third parties for knowledge of certain data sometimes

contract around terms that "prevent fraud and opportunism"); Jeffrey N. Gordon, *The Mandatory Structure of Corporate Law*, 89 COLUM. L. REV. 1549, 1555-85 (1989) (describing the role that mandatory rules play in a contractual system).

346. See U.C.C. § 1-203 (1994) ("Every contract or duty within this Act imposes an obligation of good faith in its performance or enforcement.").

347. See Gordon, *supra* note 345, at 1592.

348. See Epstein, *supra* note 14, at 23 (arguing that prying is educational and permits individuals to protect themselves from deceptive transactions); Posner, *supra* note 12, at 395 (arguing that prying into another person's private life permits the prying party to protect itself by forming a more accurate picture of the other person).

349. Murphy, *supra* note 144, at 2383 ("The purpose of this article is to show that, with respect to privacy in personal information, the skepticism in the economic literature is overstated.").

350. See *id.* at 2412-16 & 2416 n.173.

351. See *id.* at 2413-15.

352. See *id.* at 2413-16.

353. See *infra* text accompanying notes 361-68.

requires immutable limits to be placed on freedom of contract in this context. Based on these concepts, this Article will now discuss the contents of the standards of an American medical data privacy law.

2. *The Necessary Standards.*—Statutory law should establish four requirements: (1) defined obligations that limit the use of personal health care data; (2) transparent processing systems; (3) limited procedural and substantive rights; and (4) government oversight. These fair information practices will form the essential basis for an optimal use of personal health care information.

One important benefit of an embodiment of these four standards in a federal law would be to close the ERISA loophole for companies that choose to self-insure. Although currently exempt from state regulations, these institutions would be bound by a federal health care privacy law.³⁵⁴ A federal law would also better reflect the current realities of the medical marketplace, which is not organized along state lines. Not only do patients travel across state lines for care, but their personal information may be collected in one state and transported to another state for the processing of insurance claims.³⁵⁵ Only a federal medical privacy law would establish uniform standards for concerned parties who are located in different states.³⁵⁶

Different legislative proposals now before Congress express these four standards to different degrees and provide evidence of at least some agreement regarding the merits of a legal setting of multidimensional norms of fair information practice.³⁵⁷ The contribution of this Article is to identify the core principles essential to such legislation and to provide an explicit economic argument in favor of such a statutory system. Moreover, despite the considerable need for a federal medical privacy law, any single statute may prove unable to resolve all issues concerning the use of all health data.³⁵⁸ More specific laws targeted at especially sensitive or complex

354. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 317.

355. As an IBM health care official stated in congressional testimony, "The health care system of today is composed of natural medical marketplaces not bound by State borders. This reality gives rise to the need for Federal uniformity in the governing of health information." *Health Privacy Hearings*, *supra* note 9, at 316 (statement of Richard Barker, President, Health Care Industries, IBM Corp.).

356. See Schwartz, *supra* note 2, at 322-23.

357. For examples of such proposals, see, for example, Fair Health Information Practices Act of 1997, H.R. 52, 105th Cong.; Genetic Information Nondiscrimination in Health Insurance Act of 1997, H.R. 306, 105th Cong.; and Genetic Information Nondiscrimination in Health Insurance Act of 1997, S. 89, 105th Cong.

358. For examples of voices in the current debate over generic versus more specific legislation in this area, see Rothstein, *supra* note 272, at 457-59 (supporting health care privacy legislation consisting of broad, general categories such as tests, conditions, and medical information, rather than separate statutes for the genetic components of each field); Paul M. Schwartz, *European Data Protection Law and Medical Privacy*, in GENETIC SECRETS, *supra* note 181, at 392-93 (noting the European approach

areas of data use may be necessary to supplement a generic federal law for personal medical data, and this Article's proposed approach provides an essential framework for both generic and specific legislation. We will now examine the necessary elements of such regulation.

a. Creation of a statutory fabric of defined obligations.—The first essential rule concerns the establishment of responsibilities for those that process personal medical information. In the computer age, health care data pass through an increasing number of professional settings and institutions. As a result, the legal regulation of medical privacy cannot focus on the initial relationship in which personal medical data are generated or the first site at which information is processed or stored. From this perspective, a critical problem with the current legal regulation of medical information is that it is centered around discrete relationships rather than the nature of the health care data. Health care information, which may be subject to some protection in the hands of one entity, such as a physician or hospital, may be largely free from legal controls once transferred to another actor, such as an insurance company.³⁵⁹

To be effective, a statutory scheme of controls for medical data must be tied to and follow data through their different applications. Once identifiable health care information is created during the process of medical treatment or payment, it should remain protected health information that is subject to fair information practices which are binding on all those who process it. The law should consider those who handle the information as "health information trustees" with defined responsibilities.³⁶⁰

A health information trustee should have appropriate limitations placed on her initial use and future disclosure of health care data. The law should structure these limits through the use of a general standard, which will be used as a default rule, and by a small group of mandatory disclosure requirements. Let us begin by considering the interplay of the default rule and the mandatory category for the processing of personal health care information.

The law should limit freedom of contract only to the extent that a significant social need exists for access to health care records.³⁶¹ A statute

of enacting targeted statutes that concern specific areas of data use); Secretary of Health & Human Services, *supra* note 275, at I(E) (arguing that the "Administration and Congress must continue to examine the hazards to privacy when health information is held" by institutions other than providers and payers).

359. See Lawrence O. Gostin et al., *Privacy and Security of Personal Information in a New Health System*, 270 JAMA 2487, 2489-90 (1993).

360. For a similar approach in a recent legislative proposal, see Fair Health Information Practices Act §§ 101-102.

361. For a discussion of such limits in the context of corporate law, see Coffee, *supra* note 345, at 1689-90.

will express these limits in mandatory categories. Health care consumers will receive notice of these categories and their standards, but will not be able to bargain out of them. Recourse to the legislative arena will be possible, of course, and consumers, HMOs, and insurers can turn to this forum to alter the terms of mandatory authorizations. Moreover, the judiciary will play an important role in interpreting and developing these norms as well as the amount and kind of information processed under them. In a similar fashion, courts have fulfilled an essential function in monitoring the utilization of corporate law's mandatory terms.³⁶²

The most critical mandatory categories should be for (1) payment; (2) quality control (including physician monitoring); (3) sharing certain information with spouses, life partners, or next of kin (when such disclosure is consistent with accepted medical practice); (4) public health reporting; (5) health research; and (6) law enforcement.³⁶³ To the greatest extent possible, these categories should reflect the same general principles as in the default rule, which, as we shall see, limits the utilization of health care data to: (1) the minimum amount necessary; (2) based on a need to know; and (3) for purposes that are compatible with the original collection.³⁶⁴

Careful drafting will be necessary so that these standards contain some measure of flexibility without creating loopholes that permit abuse of privacy.³⁶⁵ Thus, the mandatory category for health research should require projects that plan to use personal data to be certified by the appropriate institutional review board.³⁶⁶ These boards should determine whether the health research project is of sufficient importance to outweigh

362. See *id.* at 1621 (arguing that courts need to step in at times because "long term relational contracting is necessarily incomplete," creating opportunities for one side to take advantage of another).

363. Considerable legislative effort will be necessary, however, to set the precise boundaries of some of these mandatory categories. For the debate regarding disclosure of positive HIV-status to partners, see Doughty, *supra* note 202, at 163-75; Richard C. Turkington, *Confidentiality Policy for HIV-Related Information: An Analytical Framework for Sorting Out Hard and Easy Cases*, 34 VILL. L. REV. 871, 902-07 (1989).

364. See *infra* text accompanying notes 370-76.

365. Perhaps the single most difficult drafting issue in recent congressional attempts to create a health information privacy bill concerns the law enforcement exception. See Fair Health Information Practices Act §§ 119-120 (providing that a "health information trustee may disclose protected health information to a law enforcement agency" for use in certain limited circumstances); Medical Records Confidentiality Act, S. 1360, 104th Cong. § 212 (1995) (providing that a "health information trustee" shall disclose protected information if required by a proper subpoena). For a criticism of this aspect of the Medical Records Confidentiality Act, see John Riley, *Will Bill Cure Ills?: Legislation on Access to Medical Data Sparks Debate*, NEWSDAY, Apr. 3, 1996, at A19. For criticisms of this aspect of a recent Clinton Administration medical privacy proposal, see Robert Pear, *Clinton Would Broaden Access of the Police to Medical Records*, N.Y. TIMES, Sept. 10, 1997, at A1.

366. For a general account of how these institutional boards review health research projects, see Kathryn Kelly & Sara Jones, *Tort Liability, Immunities and Defenses*, in HEALTHCARE FACILITIES LAW 257, 368-77 (Anne M. Dellinger ed., 1991).

the impact on the privacy of the concerned individuals.³⁶⁷ In addition, this category should call for the removal of all information that would identify an individual. This information should be deleted at the earliest opportunity consistent with the health research project's goals.³⁶⁸

Beyond the mandatory category, a general default rule should be created that both minimizes the cost of contracting and forces the party with superior knowledge to disgorge it. Drawing on the contracts jurisprudence of Ian Ayres and Robert Gertner, one might sketch the contours of such an efficient default rule. Ayres and Gertner have argued that "[s]etting a default rule that least favors the better informed parties creates an incentive for the informed party to bring up the relative contingency in negotiations."³⁶⁹ Because the health information trustee is likely to be better informed regarding the use and disclosure of personal data, the necessary default rule should set strict limits on the conditions under which she can utilize information.

The necessary default standard permits data use and disclosure only (1) to the minimum amount necessary; (2) based on a need to know; and (3) for purposes that are compatible with the original collection. Each of these three factors can be explained. The idea of compatibility calls for a significant degree of convergence between the purpose for which the information was gathered and its subsequent use.³⁷⁰ As for the idea of minimization of information on the basis of the need to know, it requires the release of only the least amount of data necessary to accomplish the purpose for which the information is to be used or disclosed.³⁷¹ This default rule seeks to maximize both the efficient use of information that is already collected and the necessary negotiations between concerned parties regarding use of these data.

In the case that neither a mandatory authorization nor the default standard can be fulfilled, someone who wishes to use or disclose health care data will be obliged to obtain the consent of the individual to whom the information pertains.³⁷² In this fashion, these rules have an information-

367. For a discussion of institutional review boards in a health reform bill proposed in 1994, see Health Security Act, Mitchell Amendment No. 2560, S. 2351, 103d Cong. § 5218(c)(2) (1994) (providing for the certification of institutional review boards).

368. See *id.* § 5218(d) (providing for the destruction of any information that could be used to identify an individual).

369. Ayres & Gertner, *supra* note 149, at 761.

370. In the context of the Privacy Act, the Third Circuit has carried out an insightful discussion of "compatibility." See *Britt v. Naval Investigative Serv.*, 886 F.2d 544, 550 (3d Cir. 1989).

371. A similar recommendation was made in 1977 by the blue-ribbon Privacy Protection Study Commission, which urged that medical records be made "available only to authorized recipients and on a need-to-know basis." PRIVACY PROTECTION STUDY COMM'N, PERSONAL PRIVACY IN AN INFORMATION SOCIETY 304 (1977). For further recommendations of this kind, see CODE OF MEDICAL ETHICS, § 5.07(4) (AMA Council on Ethical and Judicial Affairs 1994) (suggesting that access to confidential medical data be limited to individuals or agencies with a bona fide use for the data).

372. The safeguards on consent will be described *infra* subsection III(B)(2)(c).

forcing result. They will lead to a signaling to the uninformed party about important contingencies and cause negotiations that will improve the efficiency of the privacy marketplace by allowing parties to replace default terms with more detailed, explicit terms that better reflect their wishes.

The use and disclosure of information for *treatment purposes* provides an illustration of the functioning of the information-forcing default rule. A health information trustee's disclosure of health information for treatment purposes will be permitted only if the individual to whom the data refers has not previously objected. This approach creates an opt-out to a default standard.³⁷³ When read in tandem with the proposed requirement for sharing information about data processing practices, this requirement is likely to heighten efficiency by causing parties who so desire to enter into negotiations to replace "off the rack" terms with explicit standards.³⁷⁴

This statutory setting of mandatory and default rules seeks to avoid both inefficient distortions of individual behavior (a result of an excessive disclosure norm) and costly harm to social life (a result of an excessive privacy norm). It does so by allowing the minimal compatible use of health care information by the appropriate party. Anything beyond this result will require the party with the superior knowledge to disgorge information about the use of medical data and seek formal agreement from the other party.

One result of this regime will be to permit HMOs and other service providers a chance to differentiate their product by offering different kinds of data protection. Moreover, to the extent that these obligations replace incomplete and sometimes confusing regulations found in different measures of federal and state law, they have the potential to simplify the business of health care. The medical marketplace is, after all, increasingly organized on interstate lines. For this reason, part of the current alliance that favors the establishment of new privacy standards for health care information is acting under the banner of administrative simplification for the health care industry.³⁷⁵ As the congressional findings that accompany one proposed health care privacy bill stated, "Uniform rules governing the use, maintenance, and disclosure of health information . . . can reduce the cost of providing health services by making the necessary transfer of health information more efficient."³⁷⁶

373. See generally Ayres & Gertner, *supra* note 149, at 761-62 (discussing the use of negotiated contingencies to override a default rule).

374. *Id.* (discussing the improvements in efficiency caused by explicit negotiations over contingencies). I am using "off the rack" as Ayres and Gertner do—as a synonym for "default."

375. See, e.g., H.R. REP. NO. 103-601, pt. 5, at 12 (1994) (setting out proposed statutory provisions for "Administrative Simplification and Fair Health Information Practices").

376. Fair Health Information Practices Act of 1997, H.R. 52, 105th Cong. § 2(a)(5).

b. The maintenance of transparent processing systems.—The second element of an economically efficient regulation for the use of health care data requires a structuring of this process to make it open and understandable to individuals. The transparency standard requires the sharing of information regarding the use of personal medical data. Expression of this standard should be made through notice of information practices that is given to all health care consumers.

A legal insistence on transparent processing of personal information will increase the efficiency of the privacy market. This Article has noted the existence of a monopoly equilibrium regarding knowledge of personal information processing by the health care industry.³⁷⁷ The privacy market can move toward a competitive equilibrium through disclosure legislation that requires notice of information use. In a similar fashion, Alan Schwartz and Louis L. Wilde have argued that consumers of more traditional products will benefit from the creation of statutes that make relevant information readily available.³⁷⁸ Such statutes seek to provide these consumers with comparative price and term information. In this fashion, Mark Green, the Public Advocate for the City of New York, has argued that increased disclosure of health care plan provisions would enhance competition among HMOs.³⁷⁹ Although New York state law already requires HMOs to distribute an annual shopping guide that describes plan provisions, Green found the resulting information to be superficial and to suffer from other inadequacies.³⁸⁰ In the area of data use, notice of how health care insurers and HMOs utilize the personal information of their clients should also be required.

Established data protection law in the United States has already made some use of the idea of notice under the Privacy Act,³⁸¹ which is the statute that represents the most comprehensive attempt to regulate the information processing of federal agencies. Similar to the Privacy Act's notice provisions,³⁸² a health care notice requirement should be considered a mandatory rule. To end health care providers' exploitation of individual ignorance regarding data processing practices, the law should ensure that consumers are provided with all relevant information.

In particular, a health care data protection act should establish a notice requirement with four elements. The first two components concern information regarding the individual's rights, and the last two address the

377. See *supra* text accompanying notes 311-316.

378. See Schwartz & Wilde, *supra* note 149, at 670 (arguing that "the state should therefore make obvious efforts to increase market participation by reducing search costs").

379. See GREEN, *supra* note 325, at 17.

380. See *id.*

381. 5 U.S.C. § 552a (1994).

382. See *id.* § 552a(e)(3).

purposes for which data are collected. This careful structuring of notice is necessary in light of shortcomings both with the Privacy Act's current notice provisions and with the trend of uninformed consent to medical data use.³⁸³ These two examples indicate that the individual pursuit of personal privacy interests can only be successful when the law carefully creates the necessary preconditions for effective negotiations.

The notice document will first describe the individual's rights, including the extent of access provided to her records, the capacity to correct them, and the ability to find out which parties have gained access to them.³⁸⁴ Second, the notice of information practices should explain the procedures under which these rights can be exercised. Beyond the health care consumer's right to inspect her medical information and receive a copy of it, she should be allowed to seek correction of any health information that is inaccurate or incomplete.³⁸⁵

One of these initial rights deserves some further description. Technology has made possible not only the invasion of privacy, but its protection. Specialized software permits the creation of audit trails of those who have looked at a given health care record, and consumers should be given the opportunity to find out who has examined their health care records.³⁸⁶ This access to audit trails will create a strong deterrence to violations of institutional standards by health care providers. Indeed, a study by a Special Committee on Privacy of the National Academy of Science's National Research Council has found that health care institutions are already using computer screens to inform data users of the possibility of audit review.³⁸⁷ This study recommends, however, that more follow-up be made of these audit trails and that more serious consequences follow when this scrutiny reveals violations.³⁸⁸ The Committee's report states, "[A]lthough there is some benefit in users thinking that an audit trail is being kept and analyzed, such trails are truly effective only if their

383. Regarding the trend of uninformed consent, see *supra* text accompanying notes 314-15. For criticism of "broad language that fails to convey a precise statement of the planned uses of . . . data" under the Privacy Act's notice provisions, see SCHWARTZ & REIDENBERG, *supra* note 2, at 106, 105-07 and see also PRIVACY PROTECTION STUDY COMM'N, *supra* note 371, at 89 (suggesting ways to improve the Privacy Act's notice provisions).

384. For a discussion of the failure of many state laws to provide such rights, see Barrows & Clayton, *supra* note 79, at 143.

385. A similar right of correction exists under the Privacy Act. See 5 U.S.C. § 552a(d)(2) (allowing individuals to request amendments to their records).

386. For a discussion of the importance of audit trails, see Barrows & Clayton, *supra* note 79, at 142.

387. See COMMITTEE ON MAINTAINING PRIVACY & SEC. IN HEALTH CARE APPLICATIONS OF THE NAT'L INFO. INFRASTRUCTURE, NATIONAL RES. COUNCIL, FOR THE RECORD: PROTECTING ELECTRONIC HEALTH INFORMATION 98-99 (1997) [hereinafter NRC, PRIVACY COMMITTEE]. The author of this Article served as Special Advisor to this Committee.

388. See *id.* at 97-99.

information is actually reviewed and analyzed.”³⁸⁹ One reason to give health care consumers concrete knowledge of the parties that have accessed their records is to encourage the concerned institutions to utilize audit trails on a prophylactic basis—that is, before their outraged customers bring violations to their attention.

The third and fourth elements of the notice of information practices relate to a specification of the purposes for collection. The third element requires an explanation of the purposes for collection of personal medical data. The health care consumer should know how this information will be applied in decisionmaking and in administration, including who will be using it. Finally, the notice document should specify the extent of legal authorization for disclosure of the collected data. This part of the document should explain the nature of the law’s authorization of mandatory use and disclosure of personal health information and its substantive limits on additional, unrelated disclosure or use of the information.³⁹⁰ Such knowledge encourages the individual to participate in policing the processing of her data by health care providers and to enter into necessary negotiations when a default standard is applicable.

c. Assignment of limited procedural and substantive rights.—The third element of an economically efficient American data protection law for health care information requires the assignment of limited procedural and substantive rights to the individual. As this Article has observed, an individual’s control over medical or other personal information cannot be absolute. Thus, personal rights must be shaped to reflect a balance between individual and societal interests in medical data. Procedural interests of the individual in personal medical information include: (1) being informed whether one is required to supply medical information; (2) being granted a mechanism by which one can inspect and correct data and find out which parties have gained access to one’s records; and (3) being able to grant or refuse informed consent to proposed uses of medical data that are not mandatory. This assignment of rights also requires shaping effective remedies when data processors fail to follow the defined obligations set out in subsection III(B)(2)(a), above.

Such procedural and substantive rights will serve to heighten the efficiency of the privacy market. These interests will provide health care consumers with knowledge regarding the extent to which their privacy preferences are fulfilled and the remedial tools to prevent

389. *Id.* at 97-98 (emphasis omitted).

390. For analogous requirements under the Privacy Act, see 5 U.S.C. § 552a(e)(3) (requiring those agencies that maintain records to inform individuals about the agency’s use of their personal information).

underrepresentation of their interests. With this knowledge and these tools, health care consumers will be able to manipulate the incentives of processors of their health care information. Such procedural and substantive rights are particularly important as the United States shifts to a service economy that increasingly depends on transactional data. Indeed, empirical research by Professor Mary Culnan has shown that consumers are more willing to disclose personal information when they are explicitly told that fair information practices are employed.³⁹¹ Culnan's important research has also identified circumstances in which many consumers are ignorant of certain existing fair information practices and of the absence of such practices.³⁹² Culnan argues that this lack of knowledge raises significant ethical concerns because it is concentrated among those "more likely to be disadvantaged due to lower education."³⁹³ The service economy will function better when consumers have a more complete awareness of fair information practices.

The nature of the necessary procedural and substantive rights can be elaborated further. As has been noted,³⁹⁴ health care consumers should be informed whether they are required to supply medical information and should be told of the mechanism by which they can inspect and correct data and find out the parties who have gained access to their records. These important procedural interests are to be carried out through the notice of information processing that this Article has described above.³⁹⁵

As for substantive rights, they begin with an interest in informed consent. The weaknesses of the current regime of uninformed consent have already been noted.³⁹⁶ In the context of data processing, the emphasis of an informed consent doctrine should be on developing objective standards concerning the conduct of the informing authority.³⁹⁷ In establishing this approach, the law must reconsider its current over-reliance on written consent, which has encouraged the creation of vaguely worded consent forms.³⁹⁸ Its goal should be to require formal documentation of informed consent only under nonroutine circumstances. Once a health care provider furnishes the patient with information regarding the planned data

391. See Mary Culnan, *Consumer Awareness of Name Removal Procedures: Implications for Direct Marketing*, 9 J. DIRECT MARKETING 10, 17-18 (1995).

392. See *id.* at 17.

393. *Id.*

394. See *supra* text accompanying note 384.

395. See *supra* text accompanying notes 383-90.

396. See *supra* text accompanying notes 314-16.

397. For a discussion of this particular concept of informed consent, see Goldstein, *supra* note 195, at 690-98; Peter H. Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 902-04 (1994).

398. For a discussion of a well-considered approach to crafting narrow conditions under which authorization release forms will be required, see Fair Health Information Practices Act of 1997, H.R. 52, 105th Cong. §§ 111-112.

use, including an explanation of the notice of fair information practices, the patient need not consent in writing to a mandatory release of health care information.³⁹⁹ In circumstances in which a use or disclosure is sought that is not mandatory and falls outside the default standard, however, formal documentation of consent will be required. This approach will lead individuals to scrutinize closely all consent documents concerning health care information and improve the quality of negotiations in the privacy marketplace.

Finally, the assignment of rights to the individual requires the shaping of effective remedies. The current regime of medical data privacy law does not fully provide such remedies. A modern informational privacy remedy scheme should entail three kinds of protection. First, any individual whose interests under a health care privacy statute have been violated should be permitted to bring a civil action with the availability of monetary penalties.⁴⁰⁰ Second, methods of alternative dispute resolution should be available to encourage affordable relief and timely resolution of claims. This conclusion has also been reached by the Workgroup for Electronic Data Interchange, an important industry committee, which has emphasized the potential economic efficiency of alternative dispute resolution mechanisms in resolving disputes about fair information practices.⁴⁰¹ Lastly, violations of a limited group of fair information practices should be punishable by criminal penalties. Among these violations would be obtaining protected health care information under false pretenses with the intent to apply such information for monetary gain.⁴⁰² This form of theft represents a coercive transfer that should be met by the imposition of criminal penalties.⁴⁰³

d. Establishment of Independent Governmental Oversight.—The fourth and final element of an economically efficient American data protection law is independent governmental oversight of medical information processing. The effective balancing of privacy and disclosure in an age of rapid technological change depends on the assistance of government. It is striking that virtually all Western nations, with the exception of the United States, have already created such an agency.⁴⁰⁴ These institutions take

399. *Id.* § 123.

400. For an analogous provision under the Privacy Act, see 5 U.S.C. § 552a(g)(1) (1994).

401. See WORKGROUP FOR ELECTRONIC DATA INTERCHANGE, 1993 REPORT 3-9, *reprinted in Health Privacy Hearings*, *supra* note 9, at 262, 273.

402. For a bill that has reached a similar conclusion, see Fair Health Information Practices Act, H.R. 52, § 154.

403. For a discussion of the idea of criminalization of coercive transfers, see POSNER, *supra* note 76, at 217-23.

404. Indeed, the European Union's recently enacted Directive on Data Protection requires each Member Nation to have such an independent commission. See Council Directive 95/46/EC of 24

variety of forms, but all of these nations have felt the need for an agency that monitors data processing practices and the functioning of existing regulation.⁴⁰⁵

A United States Data Protection Commission would assist numerous social groups and draw the attention of the legislature and the public to the weaknesses of current laws. By fulfilling these tasks, the data protection agency would keep the legislature, citizens, and the business community aware and active as information technology continues to utilize different kinds of personal information in new ways.⁴⁰⁶ The most fruitful structure for a United States Data Protection Commission would be as an independent advisory body without direct enforcement powers. International experience has shown that the "advisory model" can be more effective than more coercive methods.⁴⁰⁷ This approach has already proven successful in the Federal Republic of Germany and Canada, two otherwise disparate countries.⁴⁰⁸ The data protection commissions in these countries advise the legislature, act as ombudsmen for citizen complaints, and have some authority to audit the federal government's handling of personal information.⁴⁰⁹ They also carry out the important work of informing the public and the media of developments concerning data privacy.⁴¹⁰

Different bills introduced in the United States Senate and House of Representatives in the last two Congresses have sought to create such a privacy agency.⁴¹¹ Unfortunately, any such bill has been kept from enactment by an instinctive American belief in the inefficiency of government and an accompanying hostility to the creation of additional institutions of the State.⁴¹² Despite these beliefs, creation of an American data

October 1995 on the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of Such Data, art. 28, 1995 O.J. (L 281) 31, 47 [hereinafter Data Protection Directive].

405. For a discussion of the ways these agencies differ in terms of their political autonomy, scope of power, expertise, and effectiveness, see FLAHERTY, *supra* note 31, at 385-404.

406. *See id.* at 402-04 (discussing the positive effects of data protection agencies).

407. *See id.* at 394-97 (citing the examples of Germany and Canada). In contrast, the international experience with agencies with more direct enforcement power has been mixed. In particular, agencies with greater *de jure* powers of decision have been more reluctant to take strong stands for fear of offending the government and other powerful interests and have been overwhelmed by the more bureaucratic nature of their responsibilities. *See id.* at 391-97. For a perceptive analysis of the merits of the advisory approach, see EVANGELIA MITROU, *DIE ENTWICKLUNG DER INSTITUTIONELLEN KONTROLLE DES DATENSCHUTZES* 273-79 (1993).

408. *See* FLAHERTY, *supra* note 31, at 40-47, 259-62.

409. *See id.* at 56-62, 265-75 (explaining how data protection commissions perform these functions).

410. *See id.* at 62-65, 275-78. For a discussion of these roles of European data protection commissions, see Paul M. Schwartz, *European Data Protection Law and Restrictions on International Data Flows*, 80 IOWA L. REV. 471, 492-95 (1995).

411. *See* Privacy Protection Act of 1993, S. 1735, 103d Cong.; Individual Privacy Protection Act of 1993, H.R. 135, 103d Cong.

412. *See, e.g.*, Lillian R. BeVier, *Information about Individuals in the Hands of Government*, 4 WM. & MARY BILL RTS. J. 455, 503 (1995) ("In the current deregulatory climate, however, political

protection agency would heighten the efficiency of regulation in this area. With respect to consumer contracts generally, some scholars view government monitoring as an efficient way of resolving information problems.⁴¹³ In a similar fashion, a data protection commission could play a significant role in moving the market to competitive equilibrium by using hearings and the media to bring necessary information to the public's attention. Evidence suggests that the most successful data protection agencies in other countries have emphasized this aspect of their agenda.⁴¹⁴

Beyond providing information and publicizing important trends, the data protection agency would have other roles. In the United States, a strong tradition exists of governmental institutions that assist and protect consumers. This Article has mentioned the effective evaluation of HMOs by Mark Green, the Public Advocate of for the City of New York.⁴¹⁵ The tradition of the ombudsman is also relevant in the context of data privacy. A recent report of the National Research Council's Special Committee on Privacy drew on the idea of the ombudsman in suggesting the creation for consumers of "a visible, centralized point of contact regarding privacy issues."⁴¹⁶ The Committee noted the limited avenues for seeking redress of violations of privacy, the difficulties in understanding existing rights in this area, and the lack of a place "for patients to lodge concerns" about the information processing practices of organizations that are not care providers—such as benefit managers, insurers, and marketing firms.⁴¹⁷

A data protection agency would also help American businesses comprehend and comply with legal requirements in this country and abroad. The European Union's recently enacted Directive on Data Protection not only requires each member state to have an independent data protection commission, but authorizes the European Union's member states to forbid data transfers to nations that lack "adequate levels of data protection."⁴¹⁸ The Directive raises important economic issues for the United States by prohibiting data transfers, including those involving medical information, to countries with insufficient data protection.⁴¹⁹ Similar powers to limit

capital seems unlikely to be available for the creation of another layer of bureaucracy, even one with such a benign and seemingly uncontroversial mission as that of protecting informational privacy.").

413. See Schwartz & Wilde, *supra* note 149, at 679.

414. See Schwartz, *supra* note 410, at 492-95 (discussing the success that France, Germany, and other European countries have had at stimulating public discussion of data protection issues through their expert knowledge, monitoring of international data regulations, and ability to force a data embargo).

415. See *supra* text accompanying notes 379-80.

416. NRC, PRIVACY COMMITTEE, *supra* note 387, at 184.

417. *Id.*

418. Data Protection Directive, *supra* note 404, art. 25.

419. See Robert G. Boehmer & Todd S. Palmer, *The 1993 EC Data Protection Proposal: An Examination of its Implications for U.S. Business and U.S. Privacy Law*, 31 AM. BUS. L.J. 265, 294-

data exports also exist under the domestic laws of various European nations.⁴²⁰ Because the world's data protection commissioners now meet on a regular basis to discuss these issues, the United States must have a similar institution in order to participate in these international summits.⁴²¹ A Data Protection Commission would not only represent American interests in these debates, but also explain international requirements to American companies facing scrutiny by foreign data privacy authorities.⁴²²

No systematic oversight of data processing in the area of health care currently exists in the United States.⁴²³ Yet, based on past legislative proposals and the extensive, successful international experience with data protection agencies, one can make a final observation about the structure of a United States Data Protection Commission. Rather than an agency restricted to health care issues, this entity should be a generalist privacy protection agency. Informational privacy issues are cross-sectoral in nature; the regulation of health care data, for example, raises issues that also touch on administrative law, civil procedure law, constitutional law, employment law, fair credit law, insurance law, and labor law.⁴²⁴ As a result, a generalist data protection agency has the greatest potential for developing the necessary expertise in all relevant legal areas.

C. *Application of the Standards of Fair Information Practice*

This Article has advocated the passage of a fair information practices law that will set standards for the processing of personal health care data. How will such a law work in practice? Here, we can consider four areas. The first two examples concern the use and disclosure of personal data (1)

96 (1993) (describing restrictions on transfers to third-party countries); Schwartz, *supra* note 410, at 483-88 (discussing the Directive's "adequacy" standard for data transfers from member states to states outside the European Union).

420. See Schwartz, *supra* note 410, at 488, 488-95 ("[A] number of nations have statutory standards that allow the blockage of data exports to countries without equivalent protection.").

421. The most recent annual meeting of the world's data protection commissions, the eighteenth, took place in Ottawa, Canada on September 18-20, 1996. See INTERNATIONAL PRIVACY AND DATA PROTECTION CONFERENCE, PRIVACY BEYOND BORDERS (1996) (on file with the *Texas Law Review*).

422. For a discussion of the high stakes for United States business in light of its poor record at self-regulation, see Reidenberg, *supra* note 32, at 542-46.

423. See BENNETT, *supra* note 31, at 241 ("The American experience demonstrates . . . the enormous problems associated with enforcing data protection standards without a commission or some other agency whose sole responsibility is privacy.").

424. This scope can be shown by considering a selective list of the statutes and cases that this Article has discussed. For statutes, see 5 U.S.C. § 552a (1994) (the Privacy Act); 42 U.S.C. § 1395dd (1994) (emergency medical care); 42 U.S.C. § 1396a (1994) (Medicaid); Americans with Disabilities Act, 42 U.S.C. §§ 12111-12117 (1994); and Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936. For cases, see, for example, *Jaffee v. Redmond*, 116 S. Ct. 1923 (1996) (civil procedure) and *Doe v. Southeastern Pa. Trans. Auth. (SEPTA)*, 72 F.3d 1133, 1139-40 (3d Cir. 1995) (constitutional law).

for public health reporting and (2) for treatment purposes. In its final section, this Article will examine the use and disclosure of such information (3) in employment and (4) for insurance purposes.

1. Public Health Reporting and Medical Treatment.—Disclosure of personal medical data for public health purposes should only be permitted pursuant to an acceptable public health reporting statute. Such a law must contain specific, sufficient limitations on the use and disclosure of health care information. Among these limitations must be a restricted period of time during which these data may be stored in an individually identifiable form. Such standards for public health reporting disclosure would require state legislatures to redraft those public health reporting laws that are currently couched in vague or excessively broad terms. While some legislative attention has been devoted to crafting acceptable HIV reporting laws, reporting laws for child abuse have been less successful.⁴²⁵

A specific problem regarding the public health laws for the reporting of child abuse has been the storage of unsubstantiated reports for unlimited periods of time.⁴²⁶ A vigorous social policy combating child abuse is a necessity. Yet, due to the large number of agencies and private sector institutions that have access to these computerized dossiers, the unlimited maintenance of unsubstantiated reports is likely to have a considerable negative impact on individuals who have never been found guilty of violating the law.⁴²⁷ To indicate the extent of this impact, one need only note that employers are granted access to these reports in some jurisdictions.⁴²⁸

As for processing of medical data for treatment, this purpose represents perhaps the most essential utilization of personal health care information. Yet, in the age of electronic records and integrated service providers, the use of personal health care data for treatment has great

425. For an illustration of public health laws for AIDS reporting, see, for example, N.Y. PUB. HEALTH LAW § 2782 (McKinney 1993 & Supp. 1997); OHIO REV. CODE ANN. § 3701.243 (Banks-Baldwin 1995); and TEX. HEALTH & SAFETY CODE ANN. § 81.041 (Vernon 1992). For criticism of a perceived trend toward more aggressive public health measures regarding HIV-related information, see Doughty, *supra* note 202, at 163-76.

426. For example, Arkansas requires the maintenance of "unsubstantiated" reports of child abuse in its Child Abuse and Neglect Central Registry for three years. See ARK. CODE ANN. § 12-12-505 (Michie 1995). The Arkansas Supreme Court has upheld this requirement. See *Arkansas Dep't of Human Servs. v. Heath*, 848 S.W.2d 927 (Ark. 1993). But a federal appellate court has invalidated parts of a New York law permitting storage of the names of suspected child abusers. See *Valmonte v. Bane*, 18 F.3d 992, 1003 (2d Cir. 1994). The Second Circuit found that an unacceptably high risk of error existed due to the procedures under which this central registry operated. *Id.*

427. See *Valmonte*, 18 F.3d at 1003-04.

428. See Michael R. Phillips, Note, *The Constitutionality of Employer-Accessible Child Abuse Registries: Due Process Implications of Governmental Occupational Blacklisting*, 92 MICH. L. REV. 139, 144-45 (1993) (discussing the way states control access to child abuse registries).

potential for an overdisclosure of information. This Article has discussed the disturbing example of an HMO in Boston that made patient records, including a psychiatrist's complete notes of sessions with patients, available to all physicians, nurses, and clerical staff.⁴²⁹ This Article has also proposed a better approach to this area. A health information trustee's disclosure of health information for the purpose of treatment should be permitted only if the individual to whom the data refers has not previously objected in writing. When combined with the notice of information practices given to health care consumers, this opt-out to the default rule will encourage parties who so desire to replace off the rack standards with explicit terms that better reflect a customized agreement.

One initial area for these negotiations in the restructured privacy marketplace will concern the amount of data that should be accessible on-line. Certain patients may decide that the possible benefits of having full session notes of a psychiatrist on-line may outweigh the risks. The combined force of consumers seeking to "opt out" in this area might lead to a decision by health care service providers to digitize only psychiatric diagnostic codes and to keep psychiatric session notes available in a paper format on a "need to know" basis consistent with the fulfillment of the goals of an individual's psychiatric treatment.⁴³⁰

Negotiations regarding access to data for treatment purposes are also likely to lead to a greater differentiation of access rights for physicians and certain nonphysicians. Some organizations that have already made the transition to computer-based patient records have taken this approach; the lowered transaction costs of electronic records have encouraged this move. These institutions allow physicians access to records of their current patients but require documentation of this access.⁴³¹ Physicians are only to seek information that is relevant to treatment of these patients. Access for nonphysicians is shaped around role-specific privileges. Thus, nurse practitioners are given the same access to information as physicians while clerical staff involved in billing decisions receive only necessary diagnostic codes and relevant billing information.⁴³² In this context, the creation of audit trails will do much to insure that institutional rules are followed.

2. *Employment and Insurance.*—This Article has described a number of problems that currently exist with the use of health care data in

429. See *supra* text accompanying notes 264-68.

430. This proposal is consistent with the current practices of at least some health care organizations. See NRC, PRIVACY COMMITTEE, *supra* note 387, at 131-34.

431. See *id.* at 132 (describing the use of additional prompts and warnings which remind users that audit logs maintain a record of all access to patient records).

432. See *id.* at 133 (discussing some health organizations' approach to protecting information by using well designed authentication procedures and access controls to all patient information).

employment and insurance. To begin with, employers in the public and private sectors sometimes have unrestricted access to medical records. Such control over health care data has not, however, contributed to economic efficiency in employment or insurance. Employers are not making rational use of health care information but are acting on myths and mistaken beliefs.⁴³³ Moreover, evidence exists that in response to this situation, workers will share less than complete information with their physicians, avoid preventative care, and remain in jobs rather than risk unemployment or lack of medical coverage in a new position.⁴³⁴ Finally, open access to personal health care data creates a risk to health care insurance markets in the United States. To the extent that the employment-based market can shunt certain individuals into a public insurance market based on their health care data, this behavior threatens the efficiency of risk spreading through insurance.⁴³⁵

In addition, genetic information, as a special subset of health care data, raises a number of difficulties as it is currently utilized in employment and insurance. These data have encouraged the faith of genetic determinism—a belief that we are no more than the sum of our genetic material.⁴³⁶ Partially as a consequence of the limited value of genetic labels, personal genetic information has not, however, heightened the economic efficiency of the workplace or the insurance market, but has led to genetic discrimination based on social stigma and misconceptions.⁴³⁷

In response, this Article has proposed standards of fair information practices for health care data. This approach will permit employers to utilize employees' health care information for a mandatory purpose, within the parameters of the default rule, or following the employee's consent. Rather than having complete access to all health care information under all circumstances, employers would be obliged to use the minimal amount for a purpose compatible with its collection or to seek their employees' consent.

Applying this approach to the facts in the *SEPTA* litigation, it would *not* be consistent with the proposed standards to send pharmaceutical data in non-anonymous form to parties involved in personnel or management decisions. Full access to pharmaceutical data is necessary for physicians for treatment purposes, but not for management representatives. Ironically, the Third Circuit's opinion reveals that SEPTA did have a Chief Medical Officer, who would have been in an ideal position to serve as the

433. See *supra* section II(C)(2).

434. See *supra* section II(C)(3).

435. See *supra* section II(C)(5).

436. See *supra* section II(B)(2).

437. See *supra* section II(C)(2).

employer's health information trustee and to prevent other parties from gaining inappropriate access to health care information.⁴³⁸

Such a result would be consistent with established principles in the field of occupational health. Thus, the American College of Occupational and Environmental Medicine (ACOEM), the largest international organization of physicians dedicated to the health of workers, has stated that the issue of whether a company owns medical records should not be permitted to resolve issues relating to data privacy.⁴³⁹ ACOEM guidelines also place responsibility on occupational physicians to restrict the disclosure of medical records for nonmedical purposes.⁴⁴⁰ The statutory approach that this Article has suggested would reinforce these guidelines by giving occupational physicians the power to resist overbroad corporate requests for medical records.

As for health care insurance, a mandatory standard for payment will permit disclosure of medical information to the underwriter of a health plan. This information will be restricted, however, to the minimum data used for compatible purposes. Here, one must read into the mandatory standard the emerging antidiscrimination norms that prohibit the utilization of medical or genetic information regarding preexisting conditions or predispositions to deny any individual coverage for group insurance or a basic package of individual insurance.⁴⁴¹ For reasons that this Article has discussed, limiting insurers' access to certain information will encourage health care consumers to share data with their physicians and prevent economically inefficient risk segmentation in insurance.

These limits will be economically efficient for other reasons. Most genetic testing in the future is likely to be for multifactorial conditions concerning one's genetic propensities for developing certain kinds of diseases or engaging in certain types of behavior.⁴⁴² Economically efficient use is unlikely to result from unrestricted access to this kind of genetic information. Use of genetic information will likely cause employers to engage in strategic behavior, that is, an attempt to obtain an outcome in their favor but one which will *not* spell efficiency for the market as a whole. This behavior will take the form of the now familiar concept of

438. See *Doe v. Southeastern Pa. Transp. Auth. (SEPTA)*, 72 F.3d 1133, 1139-40 (3d Cir. 1995).

439. See *ACOEM Position on the Confidentiality of Medical Information in the Workplace*, 37 J. OCCUPATIONAL & ENVTL. MED. 594, 595 (1995) (recommending that corporations that own medical records designate an independent custodian to process internal requests in the same manner as those requests made outside the corporation).

440. See *id.* at 549. For a thoughtful discussion of the potential for occupational physicians to protect the confidentiality of patient data, see Dean M. Hashimoto, *The Future Role of Managed Care and Capitation in Workers' Compensation*, 22 AM. J.L. & MED. 234, 258-60 (1996).

441. See *supra* text accompanying notes 243-55.

442. See Rothstein, *supra* note 272, at 475.

“risk segmentation.”⁴⁴³ When acting strategically to lower the costs of her business, the entrepreneur can have a negative impact on social utility. This absence of effective regulation will prove economically inefficient and encourage devastating kinds of social discrimination.

These limits also make sense for such conditions as Huntington’s Disease, which is an inheritable and incurable disease caused by a single genetic defect.⁴⁴⁴ Once this disease sets in, it causes a serious and irreversible degeneration in physical and mental capacities that inexorably lead to an individual’s death.⁴⁴⁵ Any legal model for the application of genetic information must take into account a situation in which: (1) an individual carries a gene that causes a terminal disease for which she is currently presymptomatic; and (2) a reliable test exists concerning her likelihood of developing this illness. Yet, the creation of legal limits on access to and use of this kind of genetic information also makes economic sense.

Let us consider the social costs of caring for a worker with a potentially fatal genetic condition, such as Huntington’s Disease. One should begin by noting that individuals with this rare condition are likely both to be found throughout all parts of the United States and to be applicants for a wide variety of jobs.⁴⁴⁶ As a result of the close connection between employment and access to health care benefits, the placing of legal limits on the use of genetic information is an economically efficient way to require that employers share in the social cost of caring for individuals who will develop serious illnesses. Otherwise, they will attempt to carry out a “cost-shifting” that is likely to lead to less health care for those with more serious illnesses.⁴⁴⁷ This behavior will, in turn, also lead to serious distortions in labor market efficiency by tying individuals to current jobs due to fear of being denied new employment or health insurance.⁴⁴⁸

The application of mandatory and default standards for health care data will allow genetic data to be used in employer-financed care where they are most likely to be useful: in the individual’s own health care. Limited human resources exist in this area; as of 1995, only 792 board-certified clinical geneticists and 814 board-certified genetic counselors

443. See *supra* section II(C)(5).

444. For a discussion of the genetic causes of Huntington’s Disease, see KITCHER, *supra* note 109, at 242-44.

445. See *id.* at 73.

446. See *id.* at 242-44.

447. See EMPLOYMENT AND HEALTH BENEFITS, *supra* note 157, at 9 (“For some employers as well as insurers, the selection of low-risk workers or enrollees or the use of rules regarding preexisting conditions to exclude high-risk workers from health plans can be more attractive than trying to manage health care utilization or prices.”).

448. See FUCHS, *supra* note 204, at 12-13.

practiced in the United States.⁴⁴⁹ Public health would be best served by using personal genetic information in medical contexts to improve individual health. Beyond the mandatory categories, employers' access to these data should be limited to the conditions of the default rule, which will circumscribe the access to this information. Modern genetic science and trends in data processing provide powerful support for a statutory enactment of the kinds of fair information practices for health information that this Article has described.

IV. Conclusion

This Article has examined the conventional wisdom of the law and economics movement regarding informational privacy. We have seen that Posner's work contains a valuable insight into the weaknesses of an excessively broad right to informational privacy. Yet Posner overstates his case by insisting upon the boundless merits of disclosure. In a similar fashion, Epstein advocates a disclosure-oriented regime for personal genetic information. Yet the use of personal health care and genetic information has been far from efficient. A persistent tradition of misapplication of these data exists in the United States, and ample reasons exist to suspect that open disclosure of personal health care data is unlikely to maximize social utility now or in the future.

Establishing rules for the use of health care information is, however, far from a simple task. The computer's power to process and store data has allowed the collection of more detailed personal information about more people. Society's net for collecting information is now cast both wide and deep. Moreover, in the electronic age, a health "record" per se no longer exists. Rather than a static document, a more fluid kind of dossier is being created based on how different software applications tie together different databases. As a result of information technology, health care data are increasingly utilized within networked systems. These networks already function on a statewide basis and are being extended beyond these boundaries.

This Article has argued that the structure of the existing American health care market—and any market for these services that we are likely to have in the future—makes necessary the creation of limits on the use of personal health care information. In place of a single default rule regarding privacy or disclosure, the law must now engage in more complex kinds of standard setting. Individual preferences regarding the limits to be set on multifunctional health care data will best be addressed by creating a series

449. See Mark A. Rothstein, *Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation*, 71 IND. L.J. 877, 898 (1996).

of multi-dimensional standards. Looking to contract theory, this Article has utilized the concept of default and mandatory rules and adapted it in light of the development of electronic records and health care information networks. Rather than choosing between extremes of privacy or disclosure, this Article has advocated that the law set background rules that take the form of fair information practices. Most of these rules will be background terms around which parties can negotiate; a smaller number will be mandatory rules around which parties are not permitted to negotiate. This Article has articulated four standards that statutory law should establish: (1) defined obligations that limit the use of personal health care data; (2) the maintenance of transparent processing systems; (3) the assignment of limited procedural and substantive rights; and (4) the establishment of government oversight. These standards seek both to minimize the cost of contracting in the privacy marketplace and to force the party with superior knowledge to disgorge it.

As we have seen, multifunctional electronic records encourage the use of personal medical information for a variety of purposes within ever larger systems for providing medical care. There is much that is good about this development. The increased use of data processing technology in health care has the potential to help reduce waste and fraud and to increase the efficiency and quality of administration and treatment. Issues will increasingly arise, however, regarding how our health care data are to be stored, shared, and utilized, and market forces alone will not generate a socially optimal use of such personal information. Just as medical services without personal information are not possible, health care also requires fair information practices that protect our personal data.