

U.S. Health Care Reform and Medical Privacy  
Rights

by

Robert Bryan Atchison

Submitted to the Department of Civil and Environmental  
Engineering

in partial fulfillment of the requirements for the degree of

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at the

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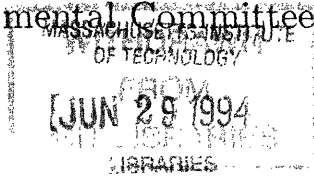
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## Abstract

The purpose of this work is to examine the present structure of the U.S. health care reform debate and how medical privacy rights should be incorporated into it. This work examines the hypothesis, "Present health care reform proposals must be changed in order to protect medical privacy rights adequately." In this work, the term "medical privacy" refers to the interest patients have in restricting disclosure of information gathered about them in the process of their receiving health care. First, we look at three specific motivations behind U.S. health care reform: reducing cost, improving quality, and increasing access to services. The importance of information technology to each of these concerns is examined, and subsequently, medical privacy is discussed as an additional area in which health care reform is needed. The current legal status of medical privacy in the U.S. is also explored. Accordingly, two relevant Federal cases are examined, *Whalen v. Roe* (429 U.S. 589 (U.S. Supreme Court 1977)) and *U.S. v. Westinghouse* (638 F.2d 570 (3rd Cir. 1980)). Medical privacy is discussed as a social good which must be balanced against other considerations, such as the interests of insurance companies, employers, researchers, doctors, hospitals, law enforcement officials, and government agencies. Finally, three health care reform plans presently before Congress are evaluated on how well they plan to protect medical privacy: President Clinton's proposed National Health Security Act (H.R.3600 / S.1757), Rep. Cooper's Managed Competition Act (H.R.3222 / S.1579), and Sen. Nickles's Consumer Choice Health Security Act (H.R.3698 / S.1743). Evaluation criteria include the recommendations of scholars in the field as well as the 1973 Fair Information guidelines given by the U.S. Department of Health, Education, and Welfare. The following four conclusions are made: present legislative action to protect medical privacy is needed, legislative proposals protecting medical privacy should be as specific as possible, an existing agency should have the authority over privacy standards, and vigorous state implementation of medical privacy standards is also necessary.

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# Chapter 1

## Motivations for U.S. Health Care Reform

### 1.1 The Scope of this Work

The purpose of this work is to examine the present structure of the health care reform debate and to discuss how medical privacy ought to be incorporated into it. This work is an examination of the hypothesis: “Present health care reform proposals must be changed in order to protect medical privacy rights adequately.” In this work, the term “medical privacy” refers to the interest patients have in restricting disclosure of information gathered about them in the process of their receiving health care. The work culminates with an evaluation of three health care reform bills currently before Congress on how well they protect medical privacy. In this first chapter, however, the debate over national health care reform in the United States will be discussed in general terms. Three main issues of that debate will be examined: cost, quality, and access. The effect of information technology on each of these issues will be highlighted. Then reasons will be given why medical privacy is an additional important issue in the debate. It will be shown that medical privacy plays an important part in considerations of cost, quality, and access and that these other issues can imply trade-offs against medical privacy. Furthermore, without careful consideration of medical privacy in health care reform, damages to the welfare of the public could result.



## 1.2 Is There a National Health Care Crisis?

The policy debate over the reform of the nation's health care system reform has brought out the question of whether reform is necessary. Is changing the nation's health care system necessary, or is the status quo acceptable? Though this is a question that could be easily forgotten amid enthusiasm over new projects, it is one that ought to be fundamental to the debate. Irwin Stelzer points this out:

Lost in all of this [attention to the details of the various reform plans] has been the large question of whether a massive transformation of our health-care system is in truth either necessary or desirable. And discussion of *that* question has been inhibited, and even for all purposes silenced, by the fact that the main participants in the debate—the politicians—have, for fear of seeming callous, accepted the unexamined assumptions that there is a great “crisis” in health care, and that our system is radically flawed and desperately needs to be overhauled.<sup>1</sup>

This conclusion seems plausible, but whether one agrees with it or not, it is reasonable to examine whether reform is necessary before changing the system. Furthermore, one's view of the status quo—the nature and extent of its failings—directly influences one's views of the best possible solutions. It is not within the scope of the present work to answer the larger question of whether or not reform is necessary. The purpose of this work is to examine the present structure of the health care reform debate and to discuss how medical privacy ought to be incorporated into it. From this standpoint, it is important to understand the motivations behind the push for U.S. health care reform in order to see where medical privacy fits in.

The question of whether reform is necessary has often been framed as “Is there a health care crisis in America?” The word “crisis” can be a vague word which inspires emotion instead of rigorous thought. The term must be defined in order to be analyzed intelligently. Typically, the word “crisis” in the present debate refers to a variety of concerns about the nature of America's health care system. These concerns involve at least the following three issues: the cost of American health care, its quality, and the accessibility of its services. There is also some concern about medical privacy in

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<sup>1</sup>Irwin M. Stelzer, “What Health-Care Crisis?” *Commentary* (Feb. 1994): 19.

the present system. Medical privacy should be included when discussing the other reform issues because, as this chapter will show, medical privacy is involved in each of them. The rest of this chapter will discuss three issues: cost, quality, and access; showing the relation of each to information technology. Then, medical privacy will be considered as an additional issue important to health care reform. Its importance to the full reform debate will be described.

## **1.3 Cost**

### **1.3.1 Total Spending Levels**

One of the major reasons that health care reform is at the top of the American policy agenda is cost. Suzanne Letsch researched health care spending levels through 1991. In 1991, health expenditures in the United States rose to \$751.8 billion. Averaged over the population, this represents \$2,868 per person. This total level was an 11.4 percent increase from the 1990 level, an increase four times the growth rate of the economy in 1991. In 1990, the growth rate of health care spending was similar, 11.7 percent.<sup>2</sup>

### **1.3.2 Rise over Time in GDP Expenditure**

More than the total level of health expenditures, there is concern about health care spending as a percentage of gross domestic product (GDP). The concern is that health care is taking a growing share of national monetary resources which might be better used elsewhere. Health care comprises around one seventh of the nation's economy. The 1991 level was 13.2 percent of America's GDP, up from 12.2 percent in 1991, the largest increase in GDP percentage in over three decades. In 1960, the percentage was only 5.3. The increase each year in national health spending as a share of GDP has been growing since 1988, when it grew 0.2 percentage points. It continued to grow

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<sup>2</sup>Suzanne W. Letsch, "National Health Care Spending in 1991," *Health Affairs* (Spring 1993): 94-95.

by 0.7 points in 1991 and 1.0 points in 1991.<sup>3</sup> In the popular media, the same idea of spending growth is communicated. *Newsweek* reports, “Between 1965 and 1991, health spending rose from 5.9 to 13.2 percent of GDP. If unchecked it could hit 20 percent in a decade.”<sup>4</sup>

### 1.3.3 GDP Expenditure Compared to Other Countries

As of 1991, the United States spent a greater percentage of its GDP on health care than all other industrialized countries.<sup>5</sup> The following table gives a few specific comparisons:<sup>6</sup>

Country	Percentage GDP Spent on Health Care in 1991
United States	13.2
France	9.1
Germany	8.5
United Kingdom	6.6

The concern is that such disparities is rendering the United States less competitive in the global marketplace.

### 1.3.4 Possible Explanations

At least four possible explanations are given for the rise in health care expenditures as a share of GDP. They are the following: weak economic growth, technological advance, consumers’ insulation from responsibility, and waste and bureaucracy.

**Weak Economic Growth** When the share of the GDP taken up by health care spending increases, it means that health care spending is growing faster than the

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<sup>3</sup>Ibid.

<sup>4</sup>Robert J. Samuelson, “How We Got Into This Mess,” *Newsweek*, Oct. 4, 1993, 31.

<sup>5</sup>Ibid., 32.

<sup>6</sup>Ibid.

economy as a whole. According to Letsch, the primary reason for the trend of increases in the percentage of GDP devoted to health care is weak economic growth. The average annual increase in GDP from 1960 to 1990 was 8.2 percent, but in 1991 the GDP grew only 2.8 percent, the slowest growth rate since 1960.<sup>7</sup>

**Technological Advance** Most Americans are satisfied with the quality of the health care they receive. According to Stelzer, 80 percent of Americans report that they are either “very” or “somewhat” satisfied with their own health care in terms of quality and cost.<sup>8</sup> In fact, in some ways American medicine is a victim of its successes. High technology has saved innumerable lives, improved the lives of others, and has given most Americans the quality of health care that they want. However, using this technology can be very expensive, and the way that the present system makes decisions about incurring these costs is now being questioned. In the research of Joseph Newhouse, after accounting for various causes of increases in medical spending, he was left with a large residual. He writes, “To me, the most plausible candidate [for explaining the large residual] is the enhanced capabilities of medicine.”<sup>9</sup> He argues that rises in health care spending have not come primarily from an increase in the number of people utilizing medical services—these have remained relatively stable since 1960—but rather from more spending per person served. Increased technology would explain this increase because, independent of the number of people served, increased technology will lead, on average, to a more expensive patient-day.<sup>10</sup>

**Consumers’ Insulation from Responsibility** According to Letsch, an increasing proportion of health cost is paid for by third parties.<sup>11</sup> This is significant because as the contribution to payment from consumers decreases, they have less incentive to purchase responsibly. She writes:

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<sup>7</sup>Letsch, 94–95.

<sup>8</sup>Stelzer, 19.

<sup>9</sup>Joseph P. Newhouse, “An Inconoclastic View of Health Care Cost Containment,” *Health Affairs* (Supplement 1993): 162.

<sup>10</sup>Ibid.

<sup>11</sup>Letsch, 95–96. See also section 1.3.5 on page 14 below.

When consumers share only modestly in paying for their health care, they become insulated from its true price, thereby compromising the ability of the marketplace to set prices that reflect societal value. Third party payment weakens consumers' incentives to be economical in making health care purchases.<sup>12</sup>

Thus, the lower proportion of cost paid by consumers lessens their ability to consume in a socially responsible way. Moreover, complexity is another cause of insulation from responsibility for health consumption decisions. Letsch writes, "because of the complexity of today's health care system, most consumers lack the knowledge they need to make treatment decisions."<sup>13</sup> This complexity is both administrative and technological. Letsch writes:

Similarly, providers of health care can sometimes increase technology (and therefore costs) without careful consideration of the usefulness of the treatment or procedure when compared with lower priced alternatives.<sup>14</sup>

**Waste and Bureaucracy** Another suspected cause of high health care costs is inefficiency. The concern is that paperwork occupies too much of the time that doctors should be spending with patients. According to *Newsweek*, "There are claim forms for 1,300 insurers and constant feuds over bills."<sup>15</sup> Many believe that the high and uncertain damages paid in malpractice suits lead doctors to practice "defensive medicine"—excessive testing to protect themselves from liability.<sup>16</sup> Malpractice premiums for doctors average about 5 percent of revenues.<sup>17</sup> Likewise, in general, some believe that many procedures are unnecessary. In addition, doctors and pharmaceutical companies are often accused of making excessive profits.<sup>18</sup> Practicing medicine in the traditional way, on a fee-for-service basis, gives doctors an incentive to perform as many procedures as possible. On the other hand, "capitation" is a reimbursement system that rewards doctors based on the number of patients they serve. Capitation

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<sup>12</sup>Ibid., 108.

<sup>13</sup>Ibid., 108–109.

<sup>14</sup>Ibid., 109.

<sup>15</sup>Samuelson, 34.

<sup>16</sup>Ibid.

<sup>17</sup>Ibid.

<sup>18</sup>Ibid.

would give doctors the incentive to reduce the number of procedures they perform, but it also rewards doctors for spending as little time with each patient as possible. Much of the recent activity in health care reform involves Health Maintenance Organizations (HMOs), which receive fees from each customer and then try to save money spent on health care by restricting procedures to those which are necessary. One problem with this is that HMOs have an incentive to cater only to the healthy.

### **1.3.5 Public and Private Reactions to Rising Costs**

According to Letsch, the trend of increases in the share of GDP devoted to health care has typically caused both public and private actions to control spending growth. For example, after rapid growth in this share in 1980 and 1982, Medicare's prospective payer system was implemented along with other reforms of the private insurance industry.<sup>19</sup> Letsch observes that, over the last three decades, the proportion of health care costs paid by public and private third party payers has generally increased. Therefore their concern with rising costs is understandable. Third parties paid for 81 percent of all health care in 1991. The 81 percent figure is an increase from 76 percent in 1980, 66 percent in 1970, and 51 percent in 1960. In 1991, public sources paid 37 percent, and private parties paid 44 percent, while expenditures from the pockets of consumers amounted to a mere 19 percent of health spending.<sup>20</sup>

Different health care payers react differently to increases in health care expenditures. Employers who provide health care to their employees may reevaluate different variables, such as the scope of their benefits, cost sharing, and deductibles. They may consider changing the scope of their retirement benefits, or even eliminating them altogether. Public health care payers consider their options for raising revenues and tightening their regulations. Individuals must reevaluate their priorities and decide if they can still afford insurance. Letsch concludes that "accelerated health spending has resulted in increasing numbers of uninsured and underinsured persons who can-

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<sup>19</sup>Letsch, 94–95.

<sup>20</sup>Ibid., 95–96.

not afford to buy private health insurance yet do not qualify for public programs.”<sup>21</sup> Rising health costs and a perception of a weakened economy have stirred concerns for the plight of those who are vulnerable because of their weak health or economic status.

Letsch also points out that a major contributor to the spending growth in 1991 was Medicaid, which was responsible for nearly one-third of the increase. She attributes this increased contribution to the recent recession in America and attempts by states to increase their identification of poor individuals, and nontraditional financing mechanisms on the part of states.<sup>22</sup>

### **1.3.6 Cost Reduction and Information Technology**

Telecommunication and information technology has been seen as a solution to cost problems in the American health care system. A study by the consulting firm Arthur D. Little concludes that increasing the application of telecommunications technology to health care can reduce annual costs by \$36 billion.<sup>23</sup> Even though the total budget is nearly \$1 trillion, this is a significant savings.<sup>24</sup> In fact, the study holds that this savings figure is both “conservative” and “low” because the study only involves “commercially available” technology and leaves out projections based on technological advance.<sup>25</sup> The study looks at the following four applications:

- “Electronic management and transport of patient information”
- “Electronic submission and processing of health care claims”
- “[E]lectronic inventory management systems”
- “The use of video conferencing for professional training and remote medical consultations.”<sup>26</sup>

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<sup>21</sup>Ibid., 94–95.

<sup>22</sup>Ibid., 97, 100–102.

<sup>23</sup>Arthur D. Little, Inc., “Telecommunications: Can It Help Solve America’s Health Care Problems? (Reference 91810-98),” (Cambridge [MA]: Arthur D. Little, 1992), 2.

<sup>24</sup>See section 1.3.1 on page 10 above.

<sup>25</sup>Arthur D. Little, 12.

<sup>26</sup>Ibid., 13.

But what is the relationship between telecommunications and information technology? The study remarks, “It should also be noted that as we move further into the Information Age the line between telecommunications and information processing begins to blur.”<sup>27</sup> Although these applications which the study surveyed are “largely telecommunications in nature,” they each also contained “an information processing component.”<sup>28</sup>

According to the report, “The United States has not yet linked the telecommunications infrastructure to the health care infrastructure.”<sup>29</sup> It is for this reason that medical privacy should be a present priority in health care reform. Telecommunications and information technology are a source of savings right now. According to the study, technology is not the limiting factor in gaining these savings. Rather, what is lacking is “the vision and momentum to apply it on a broad scale.”<sup>30</sup> There are incentives for its further development and use. Furthermore, another major finding of the study is that “[t]he impact is not limited to cost reductions. Telecommunications applications can have a profound impact on both the quality and accessibility of health care.”<sup>31</sup> Thus, the study confirms one of the positions that this work develops, that information technology will impact all three major health care concerns: cost, quality, and access. Medical privacy should be considered alongside the other concerns, as we do in in chapter 2.

### **1.3.7 Cost Planning and Information Technology**

As pointed out above while discussing the role of third party payment, the American health care system offers both doctors and patients significant power to make decisions on an individual basis, free from planning by the federal government. Similarly, the United States federal government yields important health decisions to state and local governments. Uwe Reinhardt writes:

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<sup>27</sup>Ibid., 12.

<sup>28</sup>Ibid., 11.

<sup>29</sup>Ibid., 10.

<sup>30</sup>Ibid., 33.

<sup>31</sup>Ibid., 2. See also the conclusions on page 33 of the study.



Although American health policy analysts frequently speak of a national health policy, there does not exist in the United States a genuine national health policy of the breadth and coherence characteristic of national health policies in other countries. For example, there is no national policy on the health services to which every American child should be entitled or, for that matter, to which every American should be entitled. The definition of these entitlements has always been viewed as a state and local prerogative.<sup>32</sup>

In order to plan a national health care system in any centralized way, a tremendous amount of information is needed. As information technology increases in its power, a government's ability to keep track of large systems simultaneously increases. Lawrence Gostin et al. illustrate this idea when they write, "[T]he integrity of information is critical to quality patient care, assessment of services, research, and public health."<sup>33</sup> Obviously, if the government is trying to manage a nation's health care resources, it must have information on what treatments are effective and how much they cost so that it can make sure that each dollar spent on health care achieves the maximum health benefits. Likewise, information is needed in order to plan for the future. These are the kind of interests which must be kept in mind while debating health care reform and the medical privacy policy which will emerge from it. The need for information for the purpose of planning must be balanced with the need to protect privacy rights.

## 1.4 Quality

### 1.4.1 Minority Health Outcomes

In support of the idea that health care should be a right, some researchers use statistics regarding health outcomes in the U.S. to raise questions about the quality of

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<sup>32</sup>Uwe Reinhardt, "The United States: Breakthroughs and Waste," *Journal of Health Politics, Policy and Law* (Winter 1992): 638.

<sup>33</sup>Lawrence O. Gostin et al., "Privacy and Security of Personal Information in a New Health Care System," *JAMA: Journal of the American Medical Association* (Nov. 24, 1993): 2487. According to the article, Gostin was a member of the President's Task Force on National Health Care Reform. However, the article contains a disclaimer specifying that it is not an official finding of that group.

American health care and the equity of its distribution. Some are concerned that lack of access leads to diminished health quality for minorities and the poor. According Uwe Reinhardt:

Hispanic and black households have a substantially lower median income than white households, and these income differentials translate themselves into differences in life-style, living environment, health insurance status, and access to health care, and hence, into differential health status. In 1987, for example, the average life expectancy at birth for white males was 72.1 years, but only 69.7 years for black males. For white and black females the corresponding figures were 78.8 and 73.8. respectively.<sup>34</sup>

Reinhardt also writes, “In terms of maternal and child health, too, health status for whites is superior to that of non-whites (and both have a higher infant mortality rate than many other nations).”<sup>35</sup>

### 1.4.2 Health Outcomes Compared to Other Countries

In addition, some are concerned that despite its comparatively large health expenditures, when compared to other nations, the U.S. lags in health quality. Diane Duffy gives the following comparative health outcome statistics:<sup>36</sup>

Country	Infant Mortality Rate per 1,000 Live Births	Life Expectancy At Birth (yrs)	Maternal Mortality per 100,000 Births
United States	10.5	75	15.2
Canada	9.1	75	10.8
France	9.0	75	24.0
Norway	7.8	76	3.3
Sweden	7.0	76	2.7
United Kingdom	10.1	73	17.2
West Germany	10.1	74	45.9

<sup>34</sup>U.S. Bureau of the Census 1989, quoted in Reinhardt, 639.

<sup>35</sup>Reinhardt, 639.

<sup>36</sup>Quoted in Diane Duffy, “The Effect of Sweden’s Corporatist Structure on Health Policy and Outcomes,” *Scandinavian Studies* (Spring/Summer 1989): 129.

However, the conclusions drawn from these statistics must be critically examined. Reinhardt warns:

It is, of course, risky to introduce health status indicators of this sort into cross-national comparisons of health systems, because these statistics are driven by a large host of economic, environmental, and behavioral factors. Such differences are not easily eliminated with a medical model of intervention. Therefore one cannot fairly attribute the health status indicators they beget to the functioning of the health system per se.<sup>37</sup>

The same risk is involved in the use of minority health status statistics.

### 1.4.3 Quality and Information Technology

**The Technical Side of Medicine** Regardless of the degree of government intervention in a health care system, that system will need the best possible information in order to treat patients effectively. Illustrating this point, Lawrence Gostin and his colleagues write, “[I]f clinical information is not readily available to health care providers, the best interests of the patients may be significantly compromised.”<sup>38</sup> This is the technical side of medicine. Helminski writes, “Health information is reviewed to ascertain that a certain standard of care has been met.”<sup>39</sup> She also points out that “The most obvious review of this type occurs in a legal liability case.”<sup>40</sup> Meticulous care in keeping medical records is necessary because “[f]ailure to maintain a complete record may lead to an inference of negligence.”<sup>41</sup> It will be interesting to observe whether hospitals will be held liable for malpractice if they do not keep up with a certain standard of technology regarding information technology, just as a tugboat operator was held liable for failing to install a radio in the famous 1932 *T.J. Hooper* case.<sup>42</sup> A less threatening use of medical data, and therefore one that is less useful in

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<sup>37</sup>Reinhardt, 639.

<sup>38</sup>Gostin et al., 2487.

<sup>39</sup>Francis Helminski, “Health and Medical Records,” in George B. Trubow, ed. *Privacy Law and Practice* (New York: Matthew Bender, 1990), ch.7, p.8.

<sup>40</sup>Ibid.

<sup>41</sup>Ibid., ch.7, p.10.

<sup>42</sup>T.J. Hooper, 60 F.2d 737 (2nd Cir. 1932).

asserting the influence of prospective patients, insurance companies, and the government, occurs in “routine peer review and quality assurance meetings, during which health information is studied internally on a regular basis to ensure that the quality of care in the institution meets appropriate standards. . .”<sup>43</sup>

**The Management of Medicine** As organizations increasingly manage health care for cost effectiveness, whether HMOs, insurance companies, or the government, they require more and more information. This is the management side of medicine. Illustrating the need for information in both sides of medicine, Gostin et al. write, “[T]he integrity of information is critical to quality patient care, assessment of services, research, and public health.”<sup>44</sup> Therefore, both access to information and the integrity of that information will improve the quality of medicine. In managing cost, increased quality for the same price is always good. Furthermore, information about health outcomes—what works, what does not— helps health managers plan the allocation of resources more effectively. According to Reinhardt, because of recent studies showing waste in America’s health care system, there is a growing interest in using computer databases in the area of quality assurance in order to prevent the execution of unnecessary procedures:

Spurred on by these studies, and by the ever-mounting national health bill, both the government and the business sector have recently embraced the idea of a wholesale research assault on this issue [of quality assurance]. It is envisaged that, ultimately, there will be a giant, national database that makes it possible to link a patient’s sociodemographic background and medical treatments to his or her life-style one or several years subsequent to the medical intervention.<sup>45</sup>

Reinhardt points out that Congress appropriated \$50 million to research this issue, with expected increases in that budget over time.<sup>46</sup> Finding out what measures are cost-effective is important. Therefore, when developing medical privacy policy, the

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<sup>43</sup>Helminski, ch.7, p.8.

<sup>44</sup>Gostin et al., 2487.

<sup>45</sup>Reinhardt, 662.

<sup>46</sup>Ibid.

need for information in both the management of medicine and its technical execution must be taken in account. However, these monetary concerns must be balanced with the patient's need for privacy, an important, though non-economic, concern. All of these interests must be appropriately balanced. The real question, suggested by Gostin et al., is "[H]ow much privacy does society want?"<sup>47</sup> The question is germane because so many other good things can be bought by trading away privacy. The other important question is "By what process will society decide how much privacy it wants?"<sup>48</sup>

## 1.5 Access to Services

### 1.5.1 Access and the Uninsured

Another major issue in the health care debate is access to services. Important questions include the following: How should the benefits of the American health system be distributed? On what basis? Should health spending be limited, and if so, how should this budget be allocated among the populace? What social mechanism allocates access to health care in a way that is acceptably efficient and just? Is health care a right of citizenship or a gift of charity? Should health care be distributed on the basis of need or ability to pay? Should everyone in America be provided with health insurance or only those who can afford it?<sup>49</sup>

At present, many Americans do not have health insurance. Although figures regarding the number of uninsured in the U.S. are controversial, in 1987 the uninsured population was estimated to be 37 million, or 15.5 percent of people under sixty-five, according to Reinhardt.<sup>50</sup> As noted in section 1.3.5 on page 14 above, the issue of rising health care costs is linked to the issues of access because rising costs reduce the

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<sup>47</sup>Gostin et al., 2487.

<sup>48</sup>Addressing this question is beyond the scope of this thesis. Our focus here is on what legislative initiatives and national and state policies will be required to protect medical privacy in a reformed health care system.

<sup>49</sup>Deborah A. Stone, "The Struggle for the Soul of Health Insurance," *Journal of Health Politics, Policy and Law* (Summer 1993): 291–292.

<sup>50</sup>Reinhardt, 648.

amount of health benefits available to the less fortunate in society. Concern about cost or access based upon theoretical principles is coupled with a practical concern for the needs of those who are not receiving enough health care.

## 1.5.2 The Economics of the Insurance Industry

**The Purpose and Structure of Insurance** The purpose of insurance is protection against risk. With regard to health care, consumers face a risk of paying a high amount of money should they become sick. Consumers of health insurance pay a fixed amount (called a premium) annually in order to receive benefits (called coverage) to pay for health expenditures should they become sick. Upon getting sick, health insurance consumers sometimes pay a fixed amount (called a deductible) and a percentage of the remaining costs (called the co-payment). Premiums, coverage, deductibles, and co-payments differ according to the insurance plan.

**The Necessity of Calculating Risk** Insurance companies collect premiums from all of their customers, and from this pool they draw the money to pay for coverage when claims are made, for overhead, and for profits. Therefore, it is essential for an insurance firm to be able to calculate its likelihood of paying for claims in order to charge rates at which it can make a profit. Two problems that insurance companies face in doing this are moral hazard and adverse selection.

**The Problem of Moral-Hazard** Moral hazard refers to the tendency that people have to alter their behavior opportunistically after taking out an insurance policy in order to bring themselves additional benefits at the expense of the insurance company. For example, insurance policies give customers an incentive either to make false claims on the policy or to engage in behavior more risky than was agreed upon with the insurance company.<sup>51</sup> According to Ruffin and Gregory, "If a moral-hazard problem exists, people cannot buy as much insurance as they would in a world of perfect

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<sup>51</sup>Roy J. Ruffin and Paul R. Gregory, *Principles of Economics* (Glenview [IL]: Scott, Foresman, and Co., 1990), 665–666.

information where their claim could be costlessly checked by insurance companies.”<sup>52</sup> Thus, reducing the moral-hazard problem would benefit consumers who wanted to buy more insurance but could not, because of moral-hazard, and insurance companies who would be able to make greater profits by selling more insurance to these customers. Reducing the moral-hazard problem would also benefit consumers who want the same amount of insurance at a lower price. Decreasing the costs of gathering information about the behavior of insurance customers after taking out policies would reduce the moral hazard problem. Information technology allows this to happen.<sup>53</sup>

**The Problem of Adverse Selection** While moral hazard refers to incentives given after a policy is taken out, adverse selection refers to the incentives faced by insurance customers before taking out a policy. Consumers have the incentive to get as much insurance coverage as they can for the least amount of money. Therefore, if an insurance company lacks the information required to discriminate between high-risk and low-risk buyers, it has two alternatives 1) it can pool all customers into one group, or 2) it can offer policies with premiums that cause high-risk and low-risk consumers to identify themselves simply by which policy they purchase. However, According to Ruffin and Gregory, if an adverse-selection problem exists, one of the following two consequences occur depending on the choice that the company makes:

1. “If all risk groups are pooled, the low-risk group subsidizes the insurance needs of the high-risk group.”
2. “If separate policies are offered to the low-risk and the high-risk groups, the low-risk customers would find that they cannot buy enough insurance.”<sup>54</sup>

Therefore, whichever option the company chooses, it is in the interest of low-risk consumers for the insurance company to have information to reduce the adverse selection problem. It is also in the interest of the insurance company to get such information if selling more insurance to low-risk customers would increase profits.<sup>55</sup>

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<sup>52</sup>Ibid., 666.

<sup>53</sup>Ibid., 665–666.

<sup>54</sup>Ibid., 666–667.

<sup>55</sup>Ibid.

### 1.5.3 Two Competing Views of Justice

According to Deborah Stone, the United States health care system is engaged in a conflict between two views of distributive justice, “actuarial fairness” and the “solidarity principle.”<sup>56</sup> The term “actuarial fairness” refers to the idea that each individual should pay based upon his or her own risk.<sup>57</sup> The term “solidarity principle” refers to the idea that a community should pool its resources in order to help those who need it most.<sup>58</sup> Stone writes: “But the underlying question is whether medical care will be distributed as a right of citizenship or as a market commodity.”<sup>59</sup>

### 1.5.4 Two Visions of Community

In addition, the clash between these two ideas of justice represent a conflict over “competing visions of community.”<sup>60</sup> Stone describes the way insurance creates communities:

Insurance underwriting, far from being a dry statistical exercise, is a political exercise in drawing the boundaries of community membership. That insurers always understood they were creating communities of privilege is very clear.<sup>61</sup>

Stone offers a colorful quote from the 1930 president of New York Life Insurance Company, Darwin Kingsley, to illustrate her point:

This contribution to Life Insurance [the company’s system of numerical rating] has taken an innumerable army of men and women out of the Purgatory of the impaired and put them into the Paradise of the insured.<sup>62</sup>

Actuarial fairness seeks to break people further and further into groups of similar risk. According to Stone, the idea of actuarial fairness breaks “communities into

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<sup>56</sup>Stone, “Struggle,” 287.

<sup>57</sup>Ibid., 290.

<sup>58</sup>Ibid., 291.

<sup>59</sup>Ibid., 288.

<sup>60</sup>Ibid., 289.

<sup>61</sup>Ibid., 299.

<sup>62</sup>Quoted in Ibid.



ever-smaller, more homogeneous groups. . . by fostering in people a sense of their differences, rather than their commonalities, and their responsibility for themselves only.”<sup>63</sup> Stone observes that if this process could be carried to its logical conclusion, the usefulness of insurance would disappear, because each person would be entirely responsible for his or her own risk. The solidarity principle seeks to foster an interdependence between individuals, an interdependence in which those who are not as needy share with those who are needy. Therefore, the solidarity principle defines a community of diverse risk groups, groups larger than the individual or those sharing the same risk level.

Often American advocates of national health insurance see such a proposal as a way to unify various interests in a diverse nation into a community, rather than pitting them selfishly against one another. For example, Uwe Reinhardt writes:

[T]here is no national policy on the health services to which *every American child should be entitled* or, for that matter, to which *every American should be entitled*. The definition of these entitlements has always been viewed as a state and local prerogative. Other nations typically consider the articulation of such entitlements at the national level *fundamental to their sense of nationhood*.<sup>64</sup>

One such nation is Canada, which uses national health insurance as a symbol of its national cohesiveness in the face of the diversity of its population.<sup>65</sup> While describing that system Robert Evans writes:

Canadians are, by and large, satisfied with their health care system. It is for them a symbol of their community and distinguishes them from the United States. Unlike the health care system of that country, it is universal, comprehensive, and accessible, and it costs less as a percentage of GNP to run<sup>66</sup>.

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<sup>63</sup>Ibid., 290.

<sup>64</sup>Reinhardt, 638. Emphasis mine.

<sup>65</sup>Idea from Professors Immergut and Sapolsky's class, "Health Policy." (17.205).

<sup>66</sup>Robert G. Evans, "Canada: The Real Issues," *Journal of Health Politics, Policy and Law* (Winter 1992): 739.

He also notes:

Far more than just an administrative mechanism for paying medical bills, it is widely regarded as an important symbol of community, a concrete representation of mutual support and concern. In a nation subject to strong divisive forces rooted in both geography and history, the health insurance system is an important unifying idea as well as an institution. It expresses the fundamental equality of Canadian citizens in the face of disease and death and a commitment that the rest of the community, through the public system, will help each individual with these problems as far as it can.<sup>67</sup>

The diversity in America brings similar, and possibly greater, forces which threaten to tear the country apart. Consider the 1992 riots in Los Angeles and other instances of violence between various ethnic and racial groups within American cities. National health insurance with universal coverage can be seen as a way to heal ethnic and class tension by having the government unify these groups in a community and provide for their needs.

The solidarity principle is good in that it reminds the rich and the poor as well as the sick and the healthy that they are interdependent upon each other in society. The principle tries to prevent people from mistreating other people because of the station in life to which they were born. However, one problem in the solidarity principle as applied to health care is that it also subsidizes various behaviors. The Clinton plan is an example of applying the solidarity principle to health insurance because it uses an insurance rule called "community rating." In a critique of the Clinton plan, Elizabeth McCaughey writes:

Another rule, "community rating," requires insurers to offer the same basic package to everyone in the region for the same price. Smokers and non-smokers, drug abusers and nonusers pay the same. Community rating means that the sick are not thrown overboard, but it makes those who adopt healthy behavior subsidize those who do not...<sup>68</sup>

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<sup>67</sup>Ibid., 740. It is important to remember that, although it is supported with funding from the national government, Canada's public health insurance system is based upon the plans of each separate province. Evans points out this fact (742). As a result, differences between the plans in each province are possible.

<sup>68</sup>Elizabeth McCaughey "Health Plan's Devilish Details," *Wall Street Journal*, Sep. 30, 1993, 18. Citations omitted.

This criticism assumes a value judgment on behavior, and in a diverse, pluralistic society such as America, it is very difficult for society to agree enough on value judgments to embody them in the law. However, national health insurance will have to make value judgments on a national level because insurance requires that these kinds of value judgments be made. As Deborah Stone writes:

Insurance is a social endeavor . . . and insurability is a collective decision about membership, not a natural trait of individuals. A person is insurable if a group (fraternal organization, mutual benefit society, insurance company, government program) *decides* it will extend mutual aid to him or her.<sup>69</sup>

National health insurance is an attempt to make a nation into one large mutual aid community. In that case, a nation must decide its values in the same way that an insurance company must. It must decide which behaviors or conditions warrant aid and which do not. The assessment of risk often consists of a mixture of objective and subjective criteria. Stone illustrates this when writing about numerical rating, a method by which insurance companies implement the principle of actuarial justice to insurance. Stone writes:

The numerical rating system, and the underwriting guides and rating manuals it spawned, have all the trappings of scientific objectivity—medical terminology, elaborate matrices of diseases and point values, and numbers—but they often seem to be based as much on social prejudices and stereotypes as on empirical knowledge.<sup>70</sup>

Therefore, because insurance is a social activity, not merely a scientific one, national health insurance implies agreement on a national value system. Because of America's pluralism, this is a very difficult thing to construct in America today. As an example of the sensitivity of the issue of national health insurance, consider the relationship of AIDS to behavior.<sup>71</sup> Under community rating, those who do not approve of the homosexual lifestyle will help subsidize the health care costs associated with it. Or

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<sup>69</sup>Stone, "Struggle," 298.

<sup>70</sup>Ibid.

<sup>71</sup>Marian Wallace, "Reform or Ruin? National Health Care," *Family Voice*, Jan. 1994, 5.

consider abortion. Will national health insurance subsidize abortions or leave them without subsidy? Either choice implies a position on abortion. The issue of national health insurance forces the United States to address its most divisive issues. This degree of conflict will not build community in America, given its present state of its political struggles. Instead, it will merely show the present lack of community in the United States.

Furthermore, according to McCaughey, the solidarity principle as embodied in the Clinton plan's health alliances will work to destroy community even on factors which are not related to behavior but birth (such as race) and other factors (such as geography). In President Clinton's plan, a health alliance is a group of insurance consumers unified by the government based on geography in order to negotiate lower premiums. About them, McCaughey writes:

The [Clinton] plan requires states to create health alliance regions—similar to election districts. How those alliance lines are drawn will determine which areas of the state are hit with the highest health care premiums, because they are shouldering the costs of health coverage for the inner city poor. The system promises to pit black against white, poor against rich, city against suburb. . . .

Some alliances will bear especially heavy social burdens, others will not. Everyone will figure out that you get more health care for your dollar or pay lower premiums in an alliance without inner city problems. The plan will be an incentive for employers to abandon cities and relocate.

Considering the number of court battles when states draw election districts, lawsuits over "medical gerrymandering" are inevitable. . . . Home prices and litigation fees will rise and fall depending on which suburbs are sucked into metropolitan areas and which escape.<sup>72</sup>

According to McCaughey, because of its implementation of the solidarity principle, the Clinton plan "will make racial tensions fester and produce mean-spirited political struggles and lawsuits to shirk the cost of medical care for the urban poor."<sup>73</sup>

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<sup>72</sup>McCaughey, "Devilish Details," 18.

<sup>73</sup>Ibid.

### 1.5.5 Actuarial Fairness and Information Technology

**Medical Underwriting** The implementation of the ideal of actuarial fairness requires an process called “medical underwriting.”<sup>74</sup> According to Stone, “[u]nderwriting entails gathering information about applicants to determine their risk status and then selecting the better risks to insure.”<sup>75</sup> Although this can be expressed as fairness to the insurance customer, for the insurer, it is a fundamental business strategy.<sup>76</sup>

[T]ailoring prices to finely differentiated risks is the keystone of insurers’ competitive marketing strategy. They seek to gain a larger share of the market for various types of insurance by offering the lowest prices for coverage. A firm can offer lower prices if it can separate the potentially healthy from the potentially sick and offer insurance only to the healthy.<sup>77</sup>

**The Medical Information Bureau (MIB)** The Medical Information Bureau (MIB) in Westwood, MA is an organization started in 1902 which now links 750 insurance companies.<sup>78</sup> Stone describes MIB as “the [insurance] industry’s central data bank for medical information on insurance applicants and policyholders.”<sup>79</sup> According to MIB, “MIB’s ranks now included virtually every major company issuing individual life, health and disability insurance in the United States and Canada.”<sup>80</sup> In its own words, its purpose is “to detect and deter fraud upon insurers and their policyholders.”<sup>81</sup> MIB has files “on more than 15 million people.”<sup>82</sup> It is the only such data bank in the health insurance industry.<sup>83</sup> Insurance companies can check whether MIB has a record on any applicants, and if so, they can receive the record.<sup>84</sup> MIB

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<sup>74</sup>Stone, “Struggle,” 287.

<sup>75</sup>Ibid., 295.

<sup>76</sup>Ibid., 294.

<sup>77</sup>Ibid.

<sup>78</sup>Medical Information Bureau, Inc. (MIB), “The Consumer’s MIB Fact Sheet,” 1, and “A Consumer’s Guide,” 5. No date for either document. Material available from the Medical Information Bureau, Inc., Westwood, MA.

<sup>79</sup>Stone, “Struggle,” 313.

<sup>80</sup>MIB, “Guide,” 5.

<sup>81</sup>MIB, “Sheet,” 6.

<sup>82</sup>Gary Seidman, “This Is Your Life Mr. Smith. . .,” *New York Times*, Aug. 1, 1993, sec.3, p.7.

<sup>83</sup>Ibid.

<sup>84</sup>MIB, “Guide,” 6.

forbids its member companies from basing insurance decisions entirely on its codes, insisting instead that insurers seek to verify the information themselves.<sup>85</sup> However, Seidman reports a case in which an insurer violated this policy and increased an applicant's disability premium by 25 percent based on mistaken information.<sup>86</sup> MIB's revenue comes entirely from annual dues paid by its insurers and access fees for each inquiry, which combined amount to about \$1.25 to \$1.50 per transaction.<sup>87</sup> Insurers use MIB "more than 80,000 times a day."<sup>88</sup> This comes out to be at least \$100,000 in revenue per day.

MIB relies on insurance companies to send it records.<sup>89</sup> Insurance companies send MIB information on about 15 percent of its applicants, those whose risk seems higher than usual or who seem prone to fraud.<sup>90</sup> According to MIB, it only requires insurance companies to send information "[i]f, and only if, an applicant has a condition significant to health or longevity."<sup>91</sup> The kind of information that MIB monitors are such characteristics as "height, weight, electrocardiogram results, emotional difficulties, suicide attempts," "a criminal record," "a history of dangerous driving," or "a fondness for hazardous sports."<sup>92</sup> In addition, MIB also identifies individuals using "name, birthdate, birthstate, occupation" and the region of the country where they live.<sup>93</sup> According to MIB, "Social Security Numbers are not included in MIB reports, but this may change."<sup>94</sup> MIB reports do not mention claims filed or the decisions made by insurance companies regarding insurability.<sup>95</sup>

MIB policies to protect privacy include documenting all access to its files and maintaining security measures.<sup>96</sup> MIB also allows consumers, at no cost, to find out

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<sup>85</sup>Ibid., 7.

<sup>86</sup>Seidman, 7.

<sup>87</sup>Ibid.

<sup>88</sup>Ibid.

<sup>89</sup>Ibid.

<sup>90</sup>Ibid.

<sup>91</sup>MIB, "Guide," 5.

<sup>92</sup>Seidman, 7.

<sup>93</sup>MIB, "Guide," 6.

<sup>94</sup>Ibid.

<sup>95</sup>Ibid.

<sup>96</sup>Ibid., 8-9.

if MIB has a file on them and receive a copy of the report.<sup>97</sup> Consumers can challenge MIB records by requesting that the insurance company which originally reported the information reinvestigate that information.<sup>98</sup> MIB also allows consumers to file a dispute about the reinvestigation so that their record states which fact is in dispute.<sup>99</sup> In an interview with Seidman, the president of MIB, Neil Day, said that, in the previous year, 10,000 people asked to see their files, and 800 of them raised challenges.<sup>100</sup> According to Day, 400 of these cases led to some correction.<sup>101</sup> Although “patterned after federal law,” MIB’s policies of disclosure and corrections were established voluntarily by MIB in 1971.<sup>102</sup> Since 1983, the Federal Trade Commission has regulated these procedures.<sup>103</sup>

### **1.5.6 The Solidarity Principle and Information Technology**

However, implementation of the solidarity principle on a national scale in the United States also requires an advanced system of information technology. As mentioned before in section 1.3.7 on page 16, in order for a nation’s central government to be able to ensure universal health care, it must possess information to plan budgets, prevent fraud, monitor quality and cost-effectiveness. This requires a centralized network of telecommunication and information technology. The very fact that the government would possess and manipulate this information under national health insurance necessitates privacy protections for this information. Under the Clinton plan, each American would carry a Health Security Card with a magnetic stripe on the back which would access such a centralized medical information network. In fact, President Clinton has used the card as a symbol of government protection both of the individual and the solidarity idea of community. In his speech introducing his health care plan to Congress he said while holding up the card, “With this card, if you lose

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<sup>97</sup>Ibid., 9-10.

<sup>98</sup>Ibid., 10.

<sup>99</sup>Ibid.

<sup>100</sup>Seidman, 7.

<sup>101</sup>Ibid.

<sup>102</sup>MIB, “Guide,” 11.

<sup>103</sup>Ibid.

your job or you switch jobs, you're covered."<sup>104</sup> The existence of the this medical information by itself in a permanent form necessitates some sort of protection, but in the hands of one central entity, this necessity is even larger.

## 1.6 The Need for Medical Privacy Reform

Although medical privacy is involved in health care reform, it is a separate issue on its own. "The collection and transmission of vast amounts of health information in automated form," according to Lawrence Gostin, et al., "will occur with or without reform of the health care system."<sup>105</sup> This is understandable in light of the savings and other benefits discussed in the Arthur D. Little study.<sup>106</sup> Although privacy protection for medical information is recognized as part of the U.S. Constitution, this protection can vary according to developing Supreme Court interpretations.<sup>107</sup> Also, according to the U.S. Office of Technology Assessment, although statutes define the Federal government's use of information, "no Federal statute defines an individual's specific right to privacy in his or her personal health care information held in the private sector and by State or local governments."<sup>108</sup>

Furthermore, the integration of various state rule systems and the federal regulation is a major problem. A report of the U.S. Office of Technology Assessment (OTA) writes, "There is significant variation in the nature and quality of State laws regarding privacy and health care information."<sup>109</sup> Gostin et al. write, "Legal protection of privacy in the current health care system is highly variable."<sup>110</sup> Noted privacy expert Alan Westin agrees:

State law [on medical privacy] is extraordinarily diverse and, in many

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<sup>104</sup>Robin Toner, "Clinton's Health Plan: News Analysis; Pledging Peace of Mind," *New York Times*, Oct. 28, 1993, sec.A, p.1.

<sup>105</sup>Gostin, et al., 2487.

<sup>106</sup>See section 1.3.6 on page 15 above.

<sup>107</sup>U.S. Congress, Office of Technology Assessment, *Protecting Privacy in Computerized Medical Information* (OTA-TCT-576) (Washington [DC]: U.S. Government Printing Office, 1993), 14. Will be abbreviated in subsequent references as "U.S. OTA."

<sup>108</sup>Ibid.

<sup>109</sup>Ibid., 15.

<sup>110</sup>Gostin, et al., 2489.



cases, antiquated. We're moving toward regional information systems and national exchange of [medical] information, so the time is right to enact broad federal legislation.<sup>111</sup>

According to Helminski, "Although there is some uniformity in the right to privacy concerning health information among the states, the diversity of laws relating to this information renders the formulation of general principles quite difficult."<sup>112</sup> Gostin's group quotes a recent U.S. Department of Health and Human Services report which describes the current medical privacy system as "a morass of erratic law, both statutory and judicial."<sup>113</sup> The U.S. Office of Technology Assessment concurs:

This patchwork of State and Federal laws addressing the question of privacy in medical data is inadequate to guide the health care industry with respect to obligations to protect the privacy of medical information in a computerized environment. It fails to confront the reality that... information will regularly cross State lines and will be therefore be subject to inconsistent legal standards... The law allows development of private sector businesses dealing in computer databases and data exchanges of patient information without regulation, statutory guidance, or recourse for persons who believe they have been wronged by abuse of data.<sup>114</sup>

The solution is a uniform national policy towards medical information. According to Representative Gary Condit (D-CA), "There is too much interstate transfer of patient information to continue to rely on differing state confidentiality laws."<sup>115</sup> Condit is working to pass national privacy legislation along with whatever health reform plan emerges from Congress.<sup>116</sup> The present movement towards national health care reform is the prime opportunity to articulate a national medical privacy policy. According to a poll conducted by Louis Harris and Associates, Inc., and Equifax, Inc., 85 percent of American surveyed "rated privacy protection as one of the most

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<sup>111</sup>Quoted in Mitch Betts, "Computerized Records: An Open Book?" *Computerworld*, Aug. 9, 1993, 14.

<sup>112</sup>Helminski, ch.7, pp.3-4.

<sup>113</sup>Quoted in Gostin, et al., 2489, quoted from Workshop for Electronic Data Interchange. *Report to the Secretary of Health and Human Services* (Washington [DC]: U.S. Government Printing Office, July 1992), appendix 4.

<sup>114</sup>U.S. OTA, 15.

<sup>115</sup>Quoted in Betts, "Open Book?" 14.

<sup>116</sup>Ibid.

essential elements of health care reform.”<sup>117</sup> “The goals of integrity, availability, and privacy can only be achieved,” argue Gostin et al., “by establishing a national privacy and security framework.”<sup>118</sup> Even more emphatic is the opinion of Janlori Goldman, the director of the Privacy and Technology project for the American Civil Liberties Union (ACLU): “[G]etting one day into health reform without privacy safeguards is very dangerous,” because of the Clinton plan’s vision of regional data exchanges between doctors, insurers, and health alliances.<sup>119</sup> Sheri Alpert observes:

Because the health care system is to be reformed on a national scale, conforming to a minimum set of standards, it is crucial that patients’ right to privacy and their confidentiality of their medical records also be standard across the nation. Yet thus far, the fact that the law currently does not provide consistent protection for most medical records has been conspicuously absent from reform discussions.<sup>120</sup>

Therefore, the health care reform debates provide the best context for also reforming American medical privacy law by establishing appropriate nationwide standards. Because privacy is a concern of equal importance to other health care concerns which have received more attention, such as cost, quality, and access, and because it affects each of them, the shape of the reform debate should be modified to give privacy the same degree of attention.

## 1.7 The Relevance of Medical Privacy

Why are privacy concerns important to this debate? While medical privacy is an important subject on its own, in the context of the present health care reform debate, privacy concerns form merely one of the many categories of issues to be considered, along with cost, quality, and access, and other issues. However, there are several reasons why medical privacy deserves special attention in this debate. First of all,

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<sup>117</sup>reported in *Ibid.*, 63.

<sup>118</sup>Gostin et al., 2487.

<sup>119</sup>reported in Betts, “Open Book?” 63.

<sup>120</sup>Sheri Alpert, “Smart Cards, Smarter Policy: Medical Records, Privacy, and Health Care Reform,” *Hastings Center Report* (Nov.–Dec. 1993): 13.

privacy is a public good which can be traded in order to get other public goods. For example, in a crude model, the cost of increasing the number of people who have access to health care is decreased privacy, assuming that no additional safeguards are added. Second, in the terms of the present reform debate, privacy is a much less tangible statistic, as compared to the percentage of GNP spent on health care or the number of Americans who are uninsured. By “tangible,” I mean quantitatively measurable using the methods of the natural or social sciences. Privacy is a very ambiguous concept, difficult for even philosophers to define. Third, possibly as a result of its relative lack of tangibility, privacy has not been discussed as often in the debate as have these more tangible statistics. “The fact that the law currently does not provide consistent protection for most medical records has been conspicuously absent from reform discussions,” according to Alpert.<sup>121</sup> Fourth, there is already a medical privacy problem in the United States because of the diversity of privacy laws throughout the nation. Fifth, privacy is a quality that preserves the dignity of human beings, but it will not be protected naturally. The force of law must protect human dignity against the natural tendency of people to exploit that dignity for their own selfish gain. Sixth, rapid advances in technology make it urgent that the United States act to protect privacy, and protect it in a way that will continue to develop as quickly as technology does. In *The Abolition of Man*, C.S. Lewis argues the dangers of combining technological power with moral relativism. The culmination of his arguments describes the arbitrary use of technological power by the elite to condition others:

I am only making clear what Man’s conquest of Nature really means and especially that final stage in the conflict, which perhaps, is not far off. The final stage is come when Man by eugenics, by pre-natal conditioning, and by an education and propaganda based on a perfect applied psychology, has obtained full control over himself. . . . The battle will indeed be won. But who precisely, will have won it?

For the power of Man to make himself what he pleases means. . . the power of some men to make other men what *they* please.<sup>122</sup>

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<sup>121</sup>Ibid.

<sup>122</sup>C.S. (Clive Staples) Lewis, *The Abolition of Man*, (New York: Collier, 1955), 72.

Technological advance must be accompanied by advances in ethical standards in order that technology will not be used to exploit others. Finally, privacy is a concept strongly connected to one's ideas about the nature of humanity, and the degree to which our country maintains an accurate view of privacy represents the degree to which our country preserves an accurate view of humanity. Our present level of technology combined with our present ways of thinking about the world present society with the temptation to view human beings as merely objects. Many forces in present society seek to represent human beings nothing more than commodities or machines. Health care is the arena which human beings meet technology in the most intimate way. Therefore, it is vital, as technology continues to advance, that our nation develop a legal view of medical privacy that will protect human beings by seeing them as they are, as persons, not objects to be exploited.

## **1.8 Survey of Chapters**

This chapter gave an overview of the issues involved in debating U.S. health care reform and how reform relates to the medical privacy rights. Chapter 2 will survey current medical privacy law and relevant court cases. Chapter 2 will also include a look at philosophical considerations of privacy, the legal status of the privacy right in general, and the law concerning medical privacy in particular. The way that current medical privacy law balances the various interests involved will be examined there. The first half of this work, Chapters 1 and 2 relate the problems to be solved at the intersection of health care reform and medical privacy, along with the background necessary to understand these problems. The second half of this thesis, chapters 3 and 4 will look at possible solutions to policy problems involving medical privacy. Chapter 3 will describe important evaluation criteria for any provision to protect medical privacy. Using these criteria, three proposed health care reform plans currently before Congress will be evaluated on their protection of medical privacy and the way that they balance the various interests involved: the Clinton plan, the Cooper plan, and the Nickles plan. Chapter 4, the concluding chapter, will give policy recommendations

for protecting medical privacy rights in a reformed health care system.

# Chapter 2

## Medical Privacy and Current U.S. Law

In this chapter, the current legal structure of medical privacy in the United States will be discussed. First, the philosophical underpinnings of both privacy in general and medical privacy will be given. Then, the structure of general privacy rights in America will be discussed, stemming both from tort law and constitutional law. Two important court cases will then be discussed: *Whalen v. Roe*<sup>1</sup>, the primary Supreme Court decision involving medical privacy; and *U.S. v. Westinghouse*,<sup>2</sup> a Circuit Court of Appeals case, which is important for its policy of deciding when an invasion of privacy has occurred regarding medical records. The implications of these cases for health care reform will then be explored.

### 2.1 Terms

The term “privacy” is difficult to define. Although a more precise discussion of the term will follow below in section 2.2.2 on page 40, one way to define it is “the right of individuals have to exercise their autonomy and to limit the extent of their personal

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<sup>1</sup>*Whalen v. Roe*, 429 U.S. 589 (U.S. Supreme Court 1977).

<sup>2</sup>*U.S. v. Westinghouse*, 638 F.2d 570 (3rd Cir., 1980).

domain to which others have access.”<sup>3</sup> The term “security,” according to Alpert, is “a set of technical and administrative procedures designed to protect or restrict access to information.”<sup>4</sup> In general, privacy is the end to be achieved, while security is the means of achieving it. The term “confidentiality,” according to Alan Westin, refers to the policies of an organization towards the information it collects.<sup>5</sup> The term “medical privacy” refers to the interest patients have in restricting disclosure of information gathered about them in the process of their receiving health care. Helminski defines several other useful terms for the discussion of medical privacy. The term “health information” refers to “the data recorded.”<sup>6</sup> This information is stored on a “record.”<sup>7</sup> Records can be “microfilm, computer data, and any other physical retrievable form the information may assume.”<sup>8</sup> Any person whose data is stored is called the “data subject.”<sup>9</sup> “Second parties” refer to people “who collect and store the information.”<sup>10</sup> “Third parties” refer to anyone else, “anyone without immediate access or right to the health information.”<sup>11</sup>

## 2.2 Philosophical Considerations

### 2.2.1 Ethics

**Descriptive and Normative Statements** In her book *Computer Ethics*, Deborah Johnson points out that there are two kinds of statements about behavior—descriptive and normative: “Descriptive statements are statements about how people *in fact* behave.”<sup>12</sup> She points out that social scientists make descriptive statements when relating their empirical observations of things that happen in the world. An

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<sup>3</sup>Alpert, 19.

<sup>4</sup>Ibid.

<sup>5</sup>Quoted in U.S. OTA, 8–9.

<sup>6</sup>Helminski, ch.7, p.3.

<sup>7</sup>Ibid.

<sup>8</sup>Ibid.

<sup>9</sup>Ibid.

<sup>10</sup>Ibid.

<sup>11</sup>Ibid.

<sup>12</sup>Deborah Johnson, *Computer Ethics*, (Englewood Cliffs [NJ]: Prentice-Hall, 1985), 6.

example from the topic at hand would be, “The United States spent x percent of its GDP on health care last year.” “In contrast, the philosophical study of morality,” Johnson writes, regarding ethics, “is *prescriptive* or *normative*. It is concerned with showing not what people actually do, but rather with what people *ought* to do.”<sup>13</sup> An example from the topic at hand would be, “The United States ought to increase its protection of individual privacy rights.” Johnson reminds us that morality can be studied using either kind of approach.<sup>14</sup>

**Epistemology and Ethics** Epistemology and ethics are two branches of philosophy. Ethics is an endeavor to determine and apply principles that ought to be followed in behavior. It answers the question, “What ought to be done?” Epistemology is the study of knowledge and its justification. It answers the question, “How can what is true be known?” Johnson points out one link between ethics and epistemology: “. . .ethics is not just a matter of applying normative rules. The rules we apply must themselves be justified, or the whole enterprise will be shaky.”<sup>15</sup> In other words, it is not sufficient to apply simply any rules at all, but only rules that have a basis in reality. John Frame points out a second link, in the other direction, between knowing and doing, that knowledge brings an obligation to live consistently with it:

I suggested earlier. . . that epistemology could be understood as a subdivision of ethics. . . . All of our decisions should be reconciled with what we know to be true. We must live in truth, walk in truth, do the truth. . . . To know is to respond *rightly* to the evidence and norms available to us.<sup>16</sup>

## 2.2.2 Privacy in General

Privacy is a sophisticated philosophical topic.<sup>17</sup> Therefore, it is important that the term “privacy” be defined well. In his article “Privacy: Philosophical Dimensions of

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<sup>13</sup>Ibid., 7.

<sup>14</sup>Ibid.

<sup>15</sup>Ibid.

<sup>16</sup>John Frame, *The Doctrine of the Knowledge of God*, (Phillipsburg [NJ]: Presbyterian and Reformed, 1987), 149.

<sup>17</sup>This section draws upon a paper that I wrote for the MIT class “Law, Technology, and Public Policy” (TPP 32J) taught by Nicholas Ashford and Charles Caldart.



the Literature,” Ferdinand Schoeman surveys the issues at stake in the philosophical debate about privacy. According to him, various definitions of privacy include:

1. “[A] *claim, entitlement, or right* of an individual to determine what information about himself (or herself) may be communicated to others.”
2. “[T]he measure of *control* an individual has over... information about himself...”
3. “[T]he measure of *control* an individual has over... intimacies of personal identity...”
4. “[T]he measure of *control* an individual has over... who has sensory access to him.”
5. “[A] *state or condition* of limited access to a person.<sup>18</sup>

The differences among these definitions are subtle but important. Schoeman points out that the trouble with definition 1 is that it assumes that privacy must be protected as an absolute right. That is, it assumes that individuals should have as much privacy as they desire without regard to other considerations. It also fails to specify why privacy is important to this degree.<sup>19</sup> A discussion of why privacy is important follows below. Definitions 2–4 all involve individual control over certain kinds of information. According to Schoeman, these three definitions avoid the problem of the first one, but they do not distinguish between a loss of privacy and a violation of the right to privacy.<sup>20</sup> He gives two examples which illustrate this problem. A person stranded on a deserted island has much privacy—“too much,” as Schoeman observes—but has no control over his or her own information. Also, a person who is able to protect his or her own information perfectly but decides to reveal it all to everyone around has no privacy but great control over information.<sup>21</sup> The last

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<sup>18</sup>Ferdinand David Schoeman, “Privacy: Philosophical Dimensions of the Literature,” in Schoeman, *Philosophical Dimensions of Privacy: An Anthology* (Cambridge [U.K.]: Cambridge, 1984), 2–3.

<sup>19</sup>*Ibid.*, 3.

<sup>20</sup>*Ibid.*

<sup>21</sup>*Ibid.*

definition avoids the difficulties of the others, and it also “leaves open the question of whether privacy is a desirable state.”<sup>22</sup>

Many people have been concerned that the prevalence of computers endangers the privacy of citizens. The first question to ask is, “What is privacy, and why should it be protected, at all?” According to Charles Fried, privacy is a strange sort of social good. Privacy is useful for achieving other, more important things, like friendship, love, trust, respect for others, and self-respect. Privacy builds a “context” in which these activities can grow. Therefore, in one sense privacy is valuable as a means to an end. However, it also seems to have some intrinsic value as an end in itself. Privacy lies somewhere in between a right that should be protected at all costs and a tool that is merely useful for other ends. Privacy is worth protecting because it is linked to extremely valuable human activities, such as love and self-respect. In fact, privacy cannot be separated from these activities.<sup>23</sup>

As Gary Marx and Sanford Sherizen write, “Privacy is an essential component of individual autonomy and dignity.”<sup>24</sup> On the other hand, privacy is not of “ultimate significance” because other qualities, such as these more valuable human activities, override the importance of privacy. This nebulous and paradoxical quality of privacy is what makes debates about privacy complicated.<sup>25</sup> In addition, privacy has different meanings for different people and different meanings depending on the situation. Moreover, the privacy rights of different interests often conflict.<sup>26</sup> One important aspect of privacy, in Fried’s view, is the prerogative of people to reveal what they want about themselves. In other words, it is something more than just secrecy: “Privacy is not simply an absence of information about us in the minds of others; rather, it is the control we have over information about ourselves.”<sup>27</sup> When privacy is strong,

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<sup>22</sup>Ibid., 3–4.

<sup>23</sup>Charles Fried, “Privacy: A Rational Context,” in M. David Ermann, Mary B. Williams, and Claudio Gutierrez, eds., *Computers, Ethics, and Society* (New York: Oxford, 1990), 51 and 53.

<sup>24</sup>Gary T. Marx and Sanford Sherizen, “Monitoring on the Job,” in Tom Forester, ed., *Computers in the Human Context: Information Technology, Productivity, and People* (Cambridge [MA]: MIT, 1989), 398–399.

<sup>25</sup>Fried, in Ermann et al., 51, 53.

<sup>26</sup>Marx and Sherizen, in Forester, 398–399.

<sup>27</sup>Fried, in Ermann et al., eds., 54.

individuals serve as the gatekeepers of their own interiors. The image of a gate is not totally accurate because a gate is binary, either opened or closed. An individual with privacy can choose any point along a spectrum of information to disclose to another. Privacy allows a person not only to control whether a relevant situation is known by others or not but how much detail about that situation is known. Fried gives the example of an illness. When people have been sick, they can usually tell everyone around them the general fact that they were sick. Privacy enables individuals to restrict the people who know the specific nature of the illness. Furthermore, the sight of someone suffering from the symptoms of the illness is even more privileged information. For individuals to be seen suffering the symptoms of a severe illness without their permission is a violation of their privacy. Because privacy implies the discretion of revealing or concealing, privacy cannot exist without the possibility of its invasion.<sup>28</sup> Although the phrase “right to privacy” gives the impression that privacy must be protected at all costs, privacy is not an absolute right. Therefore it must be balanced with other societal interests. Johnson acknowledges this, but she argues that this balance should favor the rights of the individual because organizations exist for the sake of “fulfilling human needs and enhancing human life.”<sup>29</sup> This is a good conclusion.

### **2.2.3 Computers and Privacy**

Why do computers make the situation regarding privacy any different?<sup>30</sup> Of course, privacy was important before computers, and, because of its nature, it was subject to threat. However, the prevalence of computers has enabled the collection of data which gives a much more detailed picture of the everyday activities of citizens. Because today’s computer power is often used to record commercial activity, this kind of data is called “transactional information.”<sup>31</sup> Computers keep track of when telephone

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<sup>28</sup>Ibid.

<sup>29</sup>Johnson, 66–67.

<sup>30</sup>This section draws upon a paper that I wrote for Professors Ashford and Caldart in their MIT class “Law, Technology, and Public Policy” (TPP 32J)

<sup>31</sup>David Burnham, “Data Protection,” in Ermann et al., eds, 94–95.

calls are made and to whom. Banks use computers to record check activity and funds transferred by automatic teller machines (ATMs). Reservations made with airlines or car rental companies are also recorded. Health records are kept on computer by insurance companies through the Medical Information Bureau (MIB).<sup>32</sup> Universities collect personal information in order to determine financial aid. Information that previously might have slipped into oblivion without the intervention of the individuals involved is now preserved and stored by other individuals further removed from the relevant situation.<sup>33</sup> This kind of information can be used in credit evaluations, and insurance and employment decisions.<sup>34</sup> Computers shift the balance of power regarding privacy from the concerned individuals towards others. Computers make it easier for concerned individuals to lose control of a larger quantity of information about themselves.<sup>35</sup> One must keep in mind that the mere presence of computers does not inevitably destroy privacy. Computers create the possibility of diminished privacy, and this is why they are a threat. Moreover, technology tends to change not only the external world but also the way people think. Once a technology is introduced, it often has unintended consequences, and these effects are hard to reverse. The tendency for the power of computers to be abused must be countered actively. Therefore, the existence of computers requires well-thought policies to protect privacy.<sup>36</sup> It must be noted that computerized information also brings benefits to society. A strong policy regarding computers and privacy would balance the rights of society with the rights of the individual.<sup>37</sup>

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<sup>32</sup>Tom Forester, *High-Tech Society: The Story of the Information Technology Revolution* (Cambridge [MA]: MIT, 1987), 268.

<sup>33</sup>Burnham, in Ermann et al., 94.

<sup>34</sup>Abbe Mowshowitz, *The Conquest of Will: Information Processing in Human Affairs* (Reading [MA]: Addison-Wesley, 1976), 167.

<sup>35</sup>Ibid.

<sup>36</sup>Nathan Cobb, "The End of Privacy," *Boston Globe*, Apr. 26, 1992, 17.

<sup>37</sup>Mowshowitz, 179-180.

## 2.2.4 Medical Privacy

The importance of privacy to other relationships, discussed earlier, can be seen in the area of medical privacy. The Hippocratic Oath, written between the Sixth and First Centuries B.C., binds physicians not reveal those things learned in the process of treatment “which should not be published abroad.”<sup>38</sup> The physician’s responsibility for patient confidentiality appears in other codes of professional ethics since then.<sup>39</sup>

Regarding his fears of what loss of privacy will do to the physician-patient relationship, one physician wrote:

Many physicians fear progressive emasculation of the special physician-patient relationship and greater erosion of confidentiality. . . Likewise, physicians fear patients will become less inclined to share needed facts. . . Our once sacred relationship with patients is engaged to marry the technology of the Information Age.<sup>40</sup>

According to Alpert, patients reveal the details necessary for their doctors to treat them because they expect these details to remain confidential. The concern is that the danger of violations of privacy rights will keep patients from trusting their doctors enough to reveal the information necessary for adequate treatment.<sup>41</sup>

## 2.3 General Privacy and U.S. Law

There are three major sources of privacy law in the United States: state common law (tort law), federal and state statutes, and the U.S. Constitution.<sup>42</sup> Two of these sources will be discussed here: tort law and constitutional law.

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<sup>38</sup>Quoted in U.S. OTA, 13–14.

<sup>39</sup>U.S. OTA, 14.

<sup>40</sup>Quoted in Alpert, 17–18.

<sup>41</sup>Alpert, 18.

<sup>42</sup>U.S. OTA, 14–15.

### 2.3.1 The Right of Privacy in Tort Law

In tort law, the right of privacy emerged in the United States in 1890, as the result of an influential law review article by Warren and Brandeis.<sup>43</sup> According to Jeff Meldman of MIT's Sloan School of Management, the tort right of privacy was a distinctly American innovation within a legal system largely borrowed from Great Britain. According to the Warren and Brandeis argument of the right of privacy in tort law, the emergence of the right of privacy represented another step in the logical progression in Anglo-American tort law over time from concrete to abstract rights. Just as property tort claims progressed from trespass, to nuisance, to trade secrets and intellectual property, so too did personal tort claims progress from battery (actually hitting someone), to assault (merely threatening to hit), to defamation and invasion of privacy.<sup>44</sup> In addition to the evolution of legal doctrine, the evolution of technology led to the emergence of a right to privacy in tort law. At the time of the Warren and Brandeis article, 1890, the combination of the recent developments of photography and newspaper technology had led to the power to take personal information from individuals without their permission and gave a market for its profitable sale.<sup>45</sup>

In tort law, there are the following four possible varieties of invasion of privacy:

1. "Unreasonable intrusion upon the seclusion of another"
2. "Appropriation of the other's name or likeness"
3. "Unreasonable publicity given to the other's private life"
4. "Publicity that places the other in a false light before the public"<sup>46</sup>

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<sup>43</sup>This section draws from Prof. Jeff Meldman's MIT class "The American Legal System" (15.611).

<sup>44</sup>Samuel D. Warren and Louis D. Brandeis, *Harvard Law Review* (Dec. 15, 1890): 193–195.

<sup>45</sup>*Ibid.*, 195–197.

<sup>46</sup>62A Am Jur 2d, Privacy §38. Footnotes omitted. This is the abbreviation for the legal encyclopedia *American Jurisprudence*. See the bibliography for more details.

### 2.3.2 A Note about Tort Law

Among various countries there are two kinds of legal systems: civil law and common law. In this area, “civil law” refers to a system of codified law which specifies the outcomes given certain enumerate fact situations. “Common law” refers to the opposite, law made by a judge on a case by case basis. The use of precedent in common law creates a body of these decisions over time, and future decisions draw on past ones, given allowances for differing fact situations. “Tort law” refers to common law, or case made law.

It is important to remember the history of the United States at this point. The American legal system draws enormously from the legal tradition of Britain. While the American Colonies were under the dominion of Britain, they shared the British legal system. Each colony had its own common law. During the American Revolution, the colonies broke away from British authority, but they kept the same legal system, the same common law. The role of federalism in the American legal system becomes important here. The colonies agreed to form a national government by ratifying the Constitution in 1789. The Constitution defines the powers of the federal government and leaves what is undefined to the authority of the states. Thus, the common law of each state remained intact as long as it did not conflict with the federal statutes. Tort law is state common law.<sup>47</sup>

### 2.3.3 The Right of Privacy and Constitutional Law

There is a great difference between the right of privacy in tort law and the constitutional right of privacy. While tort rights refer to the resolution of cases in state and local court, the Constitution is the supreme law of the United States, by which every act of Congress, state legislatures, state courts, and lower Federal courts, those below the Supreme Court, is judged. The constitutional right of privacy was first established by the Supreme Court in 1965 with the case *Griswold v. Connecticut*.<sup>48</sup> Judge

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<sup>47</sup>These ideas were developed in Jeff Meldman’s MIT class “The American Legal System” (15.611).

<sup>48</sup>*Griswold v. Connecticut*, 381 U.S. 479 (U.S. Supreme Court 1965).

Robert Bork examines the legal idea of a constitutional right of privacy. Bork quotes an opinion by Justice Blackmun's referring to "the most comprehensive of rights and the right most valued by civilized men,' namely, 'the right to be let alone.'"<sup>49</sup> The phrase "to be let alone" occurs in the Warren and Brandeis discussion of the right of privacy in tort law.<sup>50</sup> Bork responds to Blackmun's statement by saying, "There is, of course no general constitutional right to be let alone, or there would be no law."<sup>51</sup> Bork objects to interpreting the Constitution as containing a general right of privacy. It is possible for Bork to oppose the idea of privacy while still advocating both the privacy interests recognized in tort law and government policies that protect privacy. Bork's main problem with the constitutional right of privacy is that for him, it is a misinterpretation of the Constitution. Bork believes that the constitutional right of privacy is a dangerous inclusion because it allows the judiciary to usurp power from the legislatures.

### **2.3.4 Various Interests to Be Balanced**

The issue of medical privacy and its place in health care reform is an issue combining technology and public policy. Many complex interests must be balanced. According to Helminski (1990), "Health information is recorded for diverse reasons: medical, scientific, social, economic, and political."<sup>52</sup> Gostin and his colleagues express the effect of these diverse interests:

Protecting informational privacy poses complex problems of law, technology, and health care provision. One component is public policy; how much privacy does society want? The other component is technical; how much privacy can society realistically ensure, at what cost, and with what effect on the health care system?<sup>53</sup>

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<sup>49</sup>Robert H. Bork, *The Tempting of America: The Political Seduction of the Law*, (New York: Touchstone, 1990), 120.

<sup>50</sup>Warren and Brandeis, 205.

<sup>51</sup>Bork, 120.

<sup>52</sup>Helminski, ch.7, p.3.

<sup>53</sup>Gostin et al., 2487.



To this a third question should be added: "By what process will society decide how much privacy it wants, and by what process will this level be decided and implemented?"

**Consumers** Even though health providers may own a record, "the subject has a legal interest in the record."<sup>54</sup> Consumers have an interest in their own health records, first, in a philosophical and legal sense, because these records are part of the information that they have about themselves. However, these records also affect their tangible interests. The accuracy of and access to their health information affects how much insurance they can buy and how much they have to pay for it. Or if insurance is provided to them through their job, health information can affect how much their employer has to pay for insurance, and thus the consumer's employment prospects. An employer could also use health information to judge an employee's possible performance. Health information also could make consumers subject to unwanted solicitations for buying products. Health information can also affect consumers' reputations and their interpersonal relationships. As a result of the importance of health information, consumers desire knowledge of who has information about them as well as the nature of this information. Consumers also desire the ability to challenge health information if it is incorrect.

**Insurance Companies** As discussed earlier, the ability of insurers to offer competitive prices and to protect themselves from fraud and unknown risks depends on their ability to gather information about their applicants. An organization such as MIB also allows insurers to exchange information among themselves and thus draw from other companies' experience.

**Employers** An employee's health status determines not only his or her job performance, but also how much the employer pays for health insurance, if the employer provides it. Employers might desire this information in order to estimate performance

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<sup>54</sup>Helminski, ch.7, pp.15-16.

and costs.

**Medical Researchers** Medical researchers and those involved with medical education need health information in order to do their work: “Data are the cornerstones of research, and clinical health information is as essential to research projects as it is to medical education.”<sup>55</sup> Furthermore, protection against liability is another reason for maintaining meticulous records during medical research, and a long time may pass before injuries from research appears.<sup>56</sup>

**Providers and Hospitals** Of course, doctors need health information for every aspect of their jobs, for diagnoses and for patient monitoring. Doctors also must keep meticulous records to protect themselves from malpractice suits. In addition, providers or hospitals may own the records. According to Helminski, “There is no controversy that medical records are owned, in a physical sense, by the physician, dentist, or hospital which produced them.”<sup>57</sup> They may even be “transferred to others, like any personal property,” provided that the privacy rights of the subjects are respected.<sup>58</sup> Furthermore, hospitals and HMOs also need health information for both clinical reasons and for management reasons. Hospitals need information for quality control, malpractice protection, cost-effectiveness evaluation, and budget planning.

**Government Agencies and Law Enforcement Officials** Some health information must be given to government agencies for the sake of “public health and welfare.”<sup>59</sup> Such information may include data regarding “birth and death,” “communicable and venereal diseases,” “[i]ndustrial accidents, abortions,” “drug abuse,” “cancer cases,” “gunshot wounds and other violent incidents of maiming,” as well as “child abuse or suspected child abuse.”<sup>60</sup> Furthermore, the more that government

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<sup>55</sup>Ibid., ch.7, p.8.

<sup>56</sup>Ibid., ch.7, p.12.

<sup>57</sup>Ibid.

<sup>58</sup>Ibid.

<sup>59</sup>Ibid., ch.7, p.11.

<sup>60</sup>Ibid.

agencies become involved in the planning and financing of health care, the more they will have an interest in monitoring its quality and cost-effectiveness.

### 2.3.5 The Relevance of Court Cases

By discussing specific landmark federal court decisions on medical information privacy, one can gain a deeper understanding of the issues involved as well as the complex trade-offs required between government information needs and personal the privacy interests of citizens.

### 2.3.6 Court Case #1: *Whalen v. Roe*

*Whalen v. Roe*<sup>61</sup> was a case decided by the Supreme Court in 1977. The decision was unanimous.<sup>62</sup> According to Alpert, *Whalen* is “[t]he major U.S. Supreme Court case addressing medical information privacy.”<sup>63</sup> In 1972, the New York Legislature passed a statute in order to prevent prescription drugs from being unlawfully distributed.<sup>64</sup> This statute tightened the previous controls on prescription drugs.<sup>65</sup> A category called “Schedule II” was created for “the most dangerous of the legitimate drugs.”<sup>66</sup> All prescriptions for these drugs were to be registered on an official form, which included the patient’s name, address and age.<sup>67</sup> A copy of the form was to be sent to the New York State Department of Health, where the data were “recorded on magnetic tapes for processing by computer.”<sup>68</sup> Security measures existed for the health department’s data receiving room, such as “a locked wire fence” and “an alarm system.”<sup>69</sup> In addition, the statute and a health department regulation prohibited public disclosure of the patients’ identities.<sup>70</sup> Penalties for violation of these prohibitions included one

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<sup>61</sup>Whalen v. Roe, 429 U.S. 589 (U.S. Supreme Court 1977).

<sup>62</sup>Ibid., 590.

<sup>63</sup>Alpert, 19.

<sup>64</sup>Whalen, 589.

<sup>65</sup>Ibid., 591–592.

<sup>66</sup>Ibid., 593.

<sup>67</sup>Ibid.

<sup>68</sup>Ibid.

<sup>69</sup>Ibid., 594.

<sup>70</sup>Ibid.

year in prison and a fine of \$2,000.<sup>71</sup>

**Trial Court Decision** A group of patients who used Schedule II drugs and two associations of physicians brought a suit in District Court challenging the statute.<sup>72</sup> The plaintiffs presented evidence that patients needing Schedule II drugs would decline treatment for fear that “misuse of the computerized data will cause them to be stigmatized as ‘drug addicts.’”<sup>73</sup> The holding of the District Court was that “the doctor-patient relationship is one of the zones of privacy accorded constitutional protection,” a protection which the New York statute violated with “a needlessly broad sweep.”<sup>74</sup> The District Court ordered an injunction which suspended of the enforcement of the parts of the statute regarding the individual identification of the patients.<sup>75</sup>

**Issues On Appeal** The appeal of the case raised the following two questions:

- Did New York have to prove the necessity of individually identifiable information before requiring its record?
- Did the New York statute restrict the two constitutionally protected privacy interests of “avoiding disclosure in personal matters” and “independence in making certain kinds of important decisions,” such as choosing medical treatment.<sup>76</sup>

**Appeals Decision and Its Reasoning** Regarding proof of the necessity of individually identifiable information, the District Court had ruled that New York had not demonstrated the necessity of New York’s requirement that patients be identified.<sup>77</sup> However, the Supreme Court held that this inability in itself did not render the statute unconstitutional, because the statute was “the product of an orderly and rational legislative decision” and because states have “broad latitude in experimenting

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<sup>71</sup>Ibid., 594–595.

<sup>72</sup>Ibid., 595.

<sup>73</sup>Ibid.

<sup>74</sup>Ibid., 596.

<sup>75</sup>Ibid.

<sup>76</sup>Ibid., 599–600. Footnotes omitted.

<sup>77</sup>Ibid., 596.

with possible solutions to problems of vital local concern.”<sup>78</sup> Moreover, “the State’s vital interest in controlling the distribution of dangerous drugs” was sufficient to allow such policy experimentation.<sup>79</sup> The Supreme Court wrote, “It follows that the legislature’s enactment of a patient requirement was a reasonable exercise of New York’s broad police powers.”<sup>80</sup>

Regarding the two constitutionally protected privacy interests of autonomy and avoidance of disclosure, the Supreme Court held that the New York statute “does not, on its face, pose sufficiently grievous threat to either interest to establish a constitutional violation.”<sup>81</sup> The Court identifies two possible privacy concerns relevant to the statute. First, violations of the statute might come about through the actions of the health department employees, who fail to maintain the proper security of the records, either deliberately or through negligence.<sup>82</sup> The court determined that past experience in New York and other states demonstrates that the security provisions of the statute “will be administered properly.”<sup>83</sup> Secondly, the stored data might be revealed in a judicial proceeding involving a patient or doctor.<sup>84</sup> This is relevant because the purpose of the statute was to prevent patients and doctors from using or distributing drugs unlawfully. Privacy violations caused by this situation are in the court’s view a “remote possibility” which is “not a sufficient reason for invalidating the entire patient-identification program.”<sup>85</sup>

But did knowledge of the statute’s use of computers inhibit people from receiving medical care? The Court says no. The Court acknowledges that evidence showed that some people were deterred from seeking Schedule II drugs because of privacy concerns.<sup>86</sup> Even so, the Court concludes that “the statute did not deprive the public of access to the drugs,” because 100,000 people each month were still filing

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<sup>78</sup>Ibid., 597.

<sup>79</sup>Ibid., 598.

<sup>80</sup>Ibid.

<sup>81</sup>Ibid.

<sup>82</sup>Ibid., 600.

<sup>83</sup>Ibid., 601.

<sup>84</sup>Ibid., 600.

<sup>85</sup>Ibid., 601–602.

<sup>86</sup>Ibid., 603.

prescriptions for Schedule II drugs before the District Court injunction.<sup>87</sup> However, the opinion does not specify how many people were deterred by privacy concerns. According to the Court, “[u]nquestionably, some individuals’ concern for their own privacy may lead them to avoid or to postpone needed medical attention.”<sup>88</sup> Yet the Court accepted this degree of lack of service and reasoned that this situation was necessary for health care, along with other “unpleasant invasions of privacy” that occur in “modern medical practice.”<sup>89</sup> Therefore, the Court held that the statute did not violate the privacy rights of these people.

About computers and privacy in general, the Court wrote:

We are not unaware of the threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks or other massive government files. . . . The right to collect and use such data for public purposes is typically accompanied by a concomitant statutory or regulatory duty to avoid unwarranted disclosures.<sup>90</sup>

According to the Court, New York’s statute met this duty under the Court’s interpretation of the Constitution. As a result, the Court declined to discuss either “unwarranted disclosure” once it happened or systems “that did not contain comparable security provisions” to those of New York’s health department.<sup>91</sup> Alpert interprets this suspension of judgment to mean that the “Court did not address whether the compilation of the information was itself a violation of privacy.”<sup>92</sup> However, the Court does address the issue of the compilation of medical information. According to the Court, the disclosures required by the New York statute are not “meaningfully distinguishable from a host of other unpleasant invasions of privacy that are associated with many facets of health care.”<sup>93</sup> The Court accepts invasions of this degree as a necessary part of modern medicine, invasions which do not, in and of themselves, violate constitutional rights:

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<sup>87</sup>Ibid.

<sup>88</sup>Ibid., 602.

<sup>89</sup>Ibid.

<sup>90</sup>Ibid., 605. Footnote omitted.

<sup>91</sup>Ibid., 606.

<sup>92</sup>Alpert, 19.

<sup>93</sup>Whalen, 602.

[D]isclosures of private medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies are often an essential part of modern medical practice even when the disclosures may reflect unfavorably on the character of the patient. Requiring such disclosures to representatives of a State having responsibility for the health of the community, does not automatically amount to an impermissible invasion of privacy.<sup>94</sup>

The Court did not address the issues of information systems with security procedures different from those of the New York Department of Health or what should happen if data were disclosed without good reason.<sup>95</sup> However, the Court concluded that the requirements of the New York statute, and by implication, current medical practices in 1977, did not violate the Constitution.

### **2.3.7 Court Case #2: *U.S. v. Westinghouse***

*U. S. v. Westinghouse Electric Corporation*<sup>96</sup> was a case before the United States Third Circuit Court of Appeals in 1980. It is a case which embodies the way the law has attempted to balance various interests involved in medical privacy. The director of the National Institute for Occupational Safety and Health (NIOSH) tried to subpoena documents from an employer under the Occupational Health and Safety Act (OSHA).<sup>97</sup> NIOSH has authority by statute to “develop and establish recommended occupational safety and health standards”<sup>98</sup> and “to conduct research concerning occupational safety and health”<sup>99</sup> This authorized research includes the ability “to conduct a health hazard evaluation” of a workplace at the request of an employer or employee representative.<sup>100</sup> The director motioned to subpoena the documents to the United States District Court for the Western District of Pennsylvania.<sup>101</sup>

In 1978, a union representative at a Westinghouse plant in Pennsylvania requested

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<sup>94</sup>Ibid. Footnote omitted.

<sup>95</sup>Ibid., 605-606.

<sup>96</sup>*U.S. v. Westinghouse Electric Corporation*, 638 F.2d 570 (3rd Cir. 1980).

<sup>97</sup>*Westinghouse*, 570.

<sup>98</sup>Ibid., 572, quoting 29 U.S.C. §671(c)(1). Language from statute.

<sup>99</sup>Ibid., referring to 29 U.S.C. §671(c)(2), §669. Language from court opinion.

<sup>100</sup>Ibid.

<sup>101</sup>Ibid., 570.

a NIOSH health hazard evaluation concerning alleged “allergic reactions” involved in the manufacture of electric insulators.<sup>102</sup> In the course of the investigation, NIOSH officials “requested access to the company’s medical records of potentially affected employees,”<sup>103</sup> but Westinghouse officials said that they would only turn over the records to NIOSH if the employees who were the subjects of the records gave “written informed consent”<sup>104</sup> and if the United States government gave Westinghouse “written assurance. . . that the contents of these records will not be disclosed to third parties.”<sup>105</sup> NIOSH went to district court to ask the court to subpoena the records without Westinghouse’s conditions.<sup>106</sup>

**Trial Court Decision** At the trial, the United States District Court for the Western District of Pennsylvania “granted NIOSH’s petition and ordered full enforcement of the subpoena.”<sup>107</sup> Relying on *Whalen v. Roe* and another case, the district court held that sufficient public interest in this case overrode the privacy interests of the employees.<sup>108</sup> Westinghouse appealed.<sup>109</sup>

**Issue On Appeal** Upon appeal the following issue arose:

- What factors should be considered when deciding if an invasion of privacy surpasses constitutional limits?

**Appeals Court Decision and Reasoning** The Court of Appeals judge, Sloviter wrote the opinion for a three judge panel.<sup>110</sup> The Third Circuit Court used the *Whalen* definition of constitutionally protected privacy as “two types of privacy interests”<sup>111</sup>: “One is the individual interest in avoiding disclosure of personal matters, and another

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<sup>102</sup>Ibid., 572.

<sup>103</sup>Ibid.

<sup>104</sup>Ibid., 573. Westinghouse’s words.

<sup>105</sup>Ibid. Westinghouse’s words.

<sup>106</sup>Ibid.

<sup>107</sup>Ibid. Citations omitted.

<sup>108</sup>Ibid.

<sup>109</sup>Ibid.

<sup>110</sup>Ibid., 570, 572.

<sup>111</sup>Ibid., 577.



is the interest in independence in making certain kinds of important decisions.”<sup>112</sup> Regarding medical records in particular, the court holds that “There can be no question that an employees medical records, which may contain intimate facts of a personal nature are well within the ambit of materials entitled to privacy protection.”<sup>113</sup> Furthermore, in this case, the medical information sought by NIOSH was “more extensive” and possibly “more revealing of intimate details” than the drug use information involved in *Whalen*.<sup>114</sup> However, the court holds that even information that is protected under the Constitution “must be produced or disclosed upon a showing of proper government interest.”<sup>115</sup> The court quotes the following text, cited earlier, from *Whalen*:

[D]isclosures of private medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies are often an essential part of modern medical practice even when the disclosure may reflect unfavorably on the character of the patient. Requiring such disclosures to representatives of the State having responsibility for the health of the community, does not automatically amount to an impermissible invasion of privacy.<sup>116</sup>

Thus the court recognizes that “the right of an individual to control his or her medical history is not absolute.”<sup>117</sup> Rather, it is limited by the need of the government to protect public health or other important interests.<sup>118</sup>

**Privacy Criteria** In view of the contingent nature of medical privacy rights, trade-offs involving these rights become very important to examine. What criteria should be used to determine how much invasion of medical privacy is to be tolerated. The *Westinghouse* court attempts to answer this question. Regarding trade-offs among different interests the court writes: “In this case, we attempt to reconcile the privacy interests of employees in their medical records with the significant public interest in

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<sup>112</sup>Whalen 599–600. Quoted in *Westinghouse*, 577.

<sup>113</sup>Westinghouse, 577. Footnote omitted.

<sup>114</sup>Ibid.

<sup>115</sup>Ibid.

<sup>116</sup>Whalen, 602. Quoted in *Westinghouse*, 578.

<sup>117</sup>Westinghouse, 578.

<sup>118</sup>Ibid.

research designed to improve occupational safety and health.”<sup>119</sup> “Thus, as in most other areas of the law,” the court also comments, “we must engage in the delicate task of weighing competing interests.”<sup>120</sup> The court then gives its criteria for judging medical privacy cases, “The factors which should be considered in deciding whether an intrusion into an individual’s privacy is justified are” the following:

- “the type of record requested,”
- “the information it does or might contain,”
- “the potential for harm in any subsequent nonconsensual disclosure,”
- “the injury from disclosure to the relationship in which the record was generated,”
- “the adequacy of safeguards to prevent unauthorized disclosure,”
- “the degree of need for access,”
- “and whether there is an express statutory mandate, articulated public policy, or other recognizable public interest militating toward access.”<sup>121</sup>

As it applied these factors to the case, the court first reasoned that the Occupational Health and Safety Act served the “comprehensive statutory scheme” which established NIOSH for the purpose of protecting worker health.<sup>122</sup> This congressional mandate to protect worker health, according to the court, “ranks with the other public interests which have been found to justify intrusion into records normally considered private.”<sup>123</sup> Second, NIOSH was able to prove its need for the records it requested, both in terms of its “authority”<sup>124</sup> to collect the information under NIOSH regulations and in terms of the “relevance”<sup>125</sup> of the information to its investigation.<sup>126</sup> Third, with respect to the relationship between Westinghouse employees to the

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<sup>119</sup>Ibid., 572.

<sup>120</sup>Ibid., 578.

<sup>121</sup>Ibid.

<sup>122</sup>Ibid.

<sup>123</sup>Ibid., 579.

<sup>124</sup>Ibid., 575.

<sup>125</sup>Ibid.

<sup>126</sup>Ibid., 575, 579.

firm's doctors, the court reasons that Westinghouse did not sufficiently prove that disclosure of the data in the records was sensitive enough to cause the employees to suffer or cause them to not to receive future required examinations.<sup>127</sup> We notice that the court, in accord with philosophical examinations of privacy, considered possible "injury... to the relationship in which the record was generated."<sup>128</sup> Fourth, following *Whalen*, which took into account the administration of "security provisions,"<sup>129</sup> this court considered NIOSH's ability to maintain security, and agreed with the trial court that this ability was sufficient.<sup>130</sup> Therefore, the court allowed NIOSH to receive Westinghouse's employee records without any of Westinghouse's conditions.

Once it balanced the competing interests, the court took several measures to protect the privacy of the workers who were the data subjects of the files.<sup>131</sup> Despite its judgment on the issue, the court admitted the possibility that some data in the files might be so sensitive that they ought not be revealed to NIOSH:

We cannot assume that an employee's claim of privacy as to particular sensitive data in that employee's file will always be outweighed by NIOSH's need for such material.<sup>132</sup>

As a result, the court required NIOSH to notify the affected employees and to permit them to "raise a personal claim of privacy, if they desire."<sup>133</sup> Although the court granted NIOSH standing to assert the privacy of its workers in this case,<sup>134</sup> upon deciding the case, it placed upon each individual worker the responsibility for asserting his or her privacy rights.<sup>135</sup> The court disposes of the collective claim and sets the stage for the later judgments by the district court, using these criteria for balancing interests at the individual level.<sup>136</sup>

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<sup>127</sup>Ibid., 579.

<sup>128</sup>Ibid., 578.

<sup>129</sup>*Whalen*, 589.

<sup>130</sup>*Westinghouse*, 579-580.

<sup>131</sup>Ibid., 580-581.

<sup>132</sup>Ibid., 581.

<sup>133</sup>Ibid.

<sup>134</sup>Ibid., 574.

<sup>135</sup>Ibid., 581.

<sup>136</sup>Ibid., 581-582.

### 2.3.8 Implications of These Cases: Balance of Powers and Balance of Interests

Notice that the *Westinghouse* court makes allowances for privacy interests to be traded off against an “express statutory mandate,” “articulated public policy,” or “other recognizable public interest.”<sup>137</sup> This is not to say that the court unnecessarily compromised privacy interests. It did not. However, it must be recognized that the court properly recognized the limits of its own authority. This federal court did not have the power to settle privacy issues for once and for all. In America, there is rarely a final word in public policy, instead, there is continual dialogue in general, and dialogue of particular authority and importance between courts and legislatures.<sup>138</sup> The court recognizes that it cannot set the nation’s priorities regarding privacy protection and thus leaves that decision in the hands of Congress. Of course, Congress is limited by the Constitution as the federal courts interpret it. The role of Congress is to set national priorities through the political process of negotiation, and the role of the federal courts is, from outside of that process, to interpret the expressions of those priorities as embodied in law and apply them to situations as they arise. Should Congress disagree with either the courts’ interpretations or its applications of its will, Congress can reenter the political process of negotiation and issue a statute that is either more explicit or different. This way of describing the two roles is an ideal, and in practical terms, it is evident that there are gray areas where the two roles overlap. In fact, Congress has some authority, under the Constitution, to structure the federal court system and even to dictate the jurisdiction of federal courts.<sup>139</sup> The Circuit Court yielded to the requests of NIOSH because Congress had expressed a mandate for occupational health, according to the Circuit Court’s interpretation of the Occupational Safety and Health Act (OSHA). The Circuit Court interpreted the will of Congress in that document to be that the health of workers was an important

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<sup>137</sup>Ibid., 578.

<sup>138</sup>Many of the ideas in this paragraph, this one in particular, draw from Martha Derthick’s MIT class, “The Policy Making Process” (TPP 22).

<sup>139</sup>*Constitution*, art. III, secs. 1–2.

national priority, and thus the court included it in its balancing of interests. Regarding health care, the importance of Congress becomes clear. If Congress establishes aspects of the health care reform issue as national priorities, the federal courts using the *Westinghouse* factors will consider them as an “express statutory mandate,” “articulated public policy,” or “other recognizable public interest”<sup>140</sup> and balance them with privacy considerations. Such priorities could include any of those discussed in chapter 1: cost control, quality control, universal access (the solidarity principle), or actuarial fairness. Moreover, just as Congress created NIOSH under OSHA to execute its will to protect occupational health, so may it also create executive agencies to ensure various priorities in health care. These will be subject to the authority of the President and the Executive Branch in matters of daily operation while bound by the statutory mandate on more general issues. OSHA was the statutory mandate of NIOSH, and it is possible that a new health care plan will serve as the statutory mandate of new agencies, such as the National Health Board and other agencies envisioned under the Clinton health plan.

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<sup>140</sup>Westinghouse, 578.

## Chapter 3

# Medical Privacy and Three Health Care Reform Proposals

This work contends that present health care reform proposals must be modified in order to protect medical privacy rights adequately. This chapter will examine this hypothesis by looking at three health care reform bills proposed to Congress: first, the plan created by the Clinton Administration and sponsored in the House by Rep. Richard Gephardt (D-MO) and in the Senate by Sen. Mitchell (D-ME), called the National Health Security Act (HSA);<sup>1</sup> second, the Managed Competition Act (MCA),<sup>2</sup> sponsored in the House by Rep. Jim Cooper (D-TN) and in the Senate by Sen. Breaux (D-LA); and third, the Consumer Choice Health Security Act,<sup>3</sup> sponsored in the House by Rep. Stearns (R-FL) and in the Senate by Sen. Don Nickles (R-OK).<sup>4</sup> The criteria used to evaluate the proposals will be discussed. Then, a summary of each proposed plan will be given, along with the privacy provisions in each plan and a discussion of them. In the concluding chapter, chapter 4, the plans will be compared

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<sup>1</sup>U.S. Congress, House, *Health Security Act*, 103rd Cong., 1st sess., H.R.3600, (1993). In the Senate, S.1757. It has 100 co-sponsors in the House and 31 in the Senate.

<sup>2</sup>U.S. Congress, House, *Managed Competition Act of 1993*, 103rd Cong., 2nd sess., H.R.3222, (1994). In the Senate, S.1579. It has 57 co-sponsors in the House and 4 in the Senate.

<sup>3</sup>U.S. Congress, Senate, *Consumer Choice Health Security Act of 1993*, 103rd Cong., 1st sess., S.1743, (1993). In the House, H.R.3698. It has 18 co-sponsors in the House and 25 in the Senate.

<sup>4</sup>Kaiser Foundation on the Future of Medicaid, "Summary of Major Health Care Reform Legislation," Henry J. Kaiser Foundation, (Dec. 22, 1993). Except where noted otherwise, all of the information in this paragraph comes from this source.

for their protection of privacy.

## **3.1 Evaluation Criteria**

### **3.1.1 National Scope**

As discussed in chapter 1, one of the primary motivations for federal action in the area of medical privacy is to create a policy that is national in scope. The major problem in present medical privacy law is its lack of uniformity through the nation. Health care involves a significant portion of the American economy, around one seventh of the Gross Domestic Product. Medicine and insurance are both businesses of at least regional (interstate) scope. Therefore, regulation of these industries should occur at the national level. More than likely, any congressional action, by its nature, will be national in scope. However, at a deeper level, the effectiveness of congressional action depends on how it is implemented. Although congressional action creates national policy in theory, the execution of this policy may differ over various regions. It is important that Congress ensure that its actions regarding medical privacy have adequate funding, especially if states are involved in the administration. State involvement is likely to occur because states are presently involved in Medicare and Medicaid, and their involvement is being discussed in various health plans. This is not unusual. However, because it is also not unusual for states to differ in their economic resources or their administrative mechanisms, Congress must pay attention to the issue of implementation.

### **3.1.2 The “Fair Information Practices”**

In 1973, the Department of Health, Education, and Welfare’s Advisory Committee on Automated Personal Data Systems released a report on computers and privacy, *Records, Computers, and the Rights of Citizens*. That report outlined a set of “fair information practices” to serve as general federal privacy policy.<sup>5</sup> These principles

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<sup>5</sup>Gostin et al., 2490.

can be applied to medical privacy. The following are the fair information practices:

- “There must be no personal-data record-keeping systems whose very existence is secret.”
- “There must be a way for an individual to find out what information about him is in a record and how it is used.”
- “There must be a way for an individual to prevent information about him obtained for one purpose from being used or made available for other purposes without his consent.”
- “There must be a way for an individual to correct or amend a record of identifiable information about him.”
- “Any organization creating, maintaining, using, or disseminating records of identifiable personal data must assure the reliability of the data for their intended use and must take reasonable precaution to prevent misuse of the data.”<sup>6</sup>

According to Gostin et al., these principles “have enduring importance for the development of a uniform federal privacy.”<sup>7</sup> According to Alpert, these Fair Information Practices were incorporated into the 1974 Privacy Act, which applied them only to the federal government and “state and local government record systems using the Social Security Number,” not to private firms or other local or state agencies.<sup>8</sup>

### **3.1.3 The Gostin Group’s Five Recommendations**

Lawrence Gostin, editor of the “Law and Medicine” section of the *Journal of the American Medical Association* and a member of the President’s Task Force on National Health Care Reform, worked together with five other leaders in the area of medical privacy rights, including scholars from Georgetown University and The Johns Hopkins School of Hygiene and Public Health, and officials from the U.S. Department of Health and Human Services (HHS) and the National Institute of Standards and Technology (NIST), to produce an article on that subject for the *Journal of the*

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<sup>6</sup>U.S. Department of Health, Education, and Welfare, *Records, Computers, and the Rights of Citizens* (Washington [DC]: U.S. Government Printing Office, 1973), 41.

<sup>7</sup>Gostin et al., 2490.

<sup>8</sup>Alpert, 19–20.



*American Medical Association.* Lawrence Gostin and his colleagues developed the following five recommendations for health information privacy in a reformed health care system:

1. “Establish, Through Preemptive Federal Legislation, National Privacy Safeguards Based on Fair Information Practices.”
2. “Establish a System of Universal Identifiers for the Health Care System.”
3. “Issue Effective Security Standards and Guidance for Health Care Information.”
4. “Establish a Data Protection and Security Panel(s) as Part of the National Health Board for Overseeing Privacy and Security.”
5. “Establish a Comprehensive Program Fostering Privacy and Security Education and Awareness.”<sup>9</sup>

All of these recommendations are useful in increasing medical privacy protection at the national level. Although all of these recommendations are valid and important, for the purpose of evaluating the three health care bills, recommendations 1, 2, and 4 are the most important. The first one is especially important because the diverse state laws on medical privacy have become outmoded.<sup>10</sup> A unified approach is necessary. In addition to using these criteria for evaluating the bills, I will also use the degree of specificity of the implementation measures suggested in both the Gostin group’s article, as well as the measures described in Sheri Alpert’s article.

### **3.1.4 The Gostin Group’s Three Goals**

According to Gostin and his colleagues, the information policies in a new health care system should have three goals: data integrity, data availability, and privacy of data.<sup>11</sup>

1. It should “ensure... the integrity of health care data so that information is accurate, complete, and trustworthy.”<sup>12</sup>

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<sup>9</sup>Gostin et al., 2492.

<sup>10</sup>Ibid.

<sup>11</sup>Ibid., 2487.

<sup>12</sup>Ibid.

2. It should “ensure . . . the availability of health data so that authorized persons who need the information for legitimate health purposes have ready access to the data.”<sup>13</sup>
3. It should “ensure . . . the privacy of patients so that they can be assured that personal information remains private and will not be disclosed without their knowledge and permission.”<sup>14</sup>

These criteria balance some of the interests discussed earlier. Integrity helps all interests. It makes sure that patients receive proper care. It helps doctors do their job well and avoid malpractice suits. It helps researchers develop sound conclusions. Integrity also helps health care providers, insurance companies, and government agencies in determining both quality and cost-effectiveness. Availability helps health care providers, insurance companies, and government agencies in a similar way by making their jobs proceed more efficiently. Privacy, as discussed earlier, mainly helps consumers protect their own interests.

These three criteria are valuable because they place privacy in the context of the factors against which it must be balanced. Privacy is very important, and it must be protected. However, because it is so important it is easy to make the mistake of viewing privacy as an absolute right, one that can never be compromised to any degree. A more realistic view of privacy insists upon a strong degree of privacy protection with some degree of allowances given to other legitimate interests. The Gostin group’s criteria maintain such a realistic view. Once it is determined that privacy must be protected while leaving other interests intact to some degree, the difficult question is: “How much?” or rather, “To what degree should privacy be protected?” The Gostin group’s criteria do not directly specify an answer to this, nor does the present work fully answer that question. However, this is a question that can probably only be settled by negotiation among the affected parties. Even so, both Gostin’s criteria and the judgments of the present work hope to move toward such a resolution.

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<sup>13</sup>Ibid.

<sup>14</sup>Ibid.

## 3.2 Democrats, Reform, and Privacy

Two of the health care reform proposals we will examine are sponsored by Democrats. Health care reform was a major issue in President Clinton's 1992 presidential campaign.<sup>15</sup> Privacy and health care reform will be interesting to look at through Democratic eyes because, at first glance, it would seem that this issue would cause the collision of two Democratic values: individual autonomy and government assistance.

## 3.3 The Clinton Plan

The President's health care plan, sponsored by Rep. Gephardt, is officially called the National Health Security Act of 1993.<sup>16</sup>

### 3.3.1 Summary of the Clinton Health Care Plan

**Managed Competition** The central concept behind the Clinton health plan is "managed competition." Managed competition is an experimental attempt to combine the power of governmental regulation with the flexibility of private profit motives. "Managed" means that the government will attempt to use the nation's health resources in a more cost-effective manner. In addition, the government will change the distribution of health benefits in such a way as to provide them to all citizens. "Competition" means that the government will try to build a system where doctors compete to provide medical benefits at the lowest possible cost. Should managed competition fail, the Clinton plan includes provisions for strong government regulation to achieve the same goals.<sup>17</sup>

**Health Alliances** Health alliances will serve as the representatives of consumers in the plan. According to the HSA, "the term 'regional alliance' means a non-profit

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<sup>15</sup>Stone, "Struggle," 303.

<sup>16</sup>U.S. Congress, House, *Health Security Act*, 103rd Cong., 1st sees., HR 3600, (1993). In the Senate, S 1757. From here on I will abbreviate the name of this bill with the acronym "HSA"

<sup>17</sup>Tom Morganthau and Mary Hager, "The Clinton Cure," *Newsweek*, Oct. 4, 1993, 37-39.

organization, an independent state agency, or an agency of the State which” represents the health needs of a large group of citizens.<sup>18</sup> According to *Newsweek*, “The health alliances would be quasi-governmental bodies created by the states—large organizations that would represent consumers in a given region.”<sup>19</sup> The goal of health alliances is to unify a large number of consumers in order to give them “more bargaining power and more expertise in selecting health-care coverage.”<sup>20</sup> In addition, the health alliances would provide a large pool for the spreading of risk. Almost everyone would be in a health alliance because only corporations with over 5,000 employees would be allowed the choice of forming their own groups.<sup>21</sup>

**Health Plans** On the other hand, health plans are groups of providers. The term “health plan” is defined in the Act.<sup>22</sup> Health plans provide the adversary to health alliances in the negotiation process. According to *Newsweek*, “plans could be formed by doctors, hospitals, insurance companies or any combination of the three.”<sup>23</sup> Thus, the Clinton health plan would institutionalize and accelerate the present trend in medicine away from independent practitioners who charge for each service they provide (fee-for-service medicine) toward consolidated groups of doctors, called health-maintenance organizations (HMOs) which provide a complete health package at a fixed price.<sup>24</sup> This systemic change would change the incentives for doctors to provide procedures.<sup>25</sup> Every year, health plans would bargain with health alliances to provide at least the amount of service included in a uniform package of benefits, as defined by the government.<sup>26</sup>

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<sup>18</sup>HSA §1301

<sup>19</sup>Morganthau and Hager, 39.

<sup>20</sup>Ibid.

<sup>21</sup>Ibid.

<sup>22</sup>HSA §1400

<sup>23</sup>Morganthau and Hager, 39.

<sup>24</sup>Ibid.

<sup>25</sup>Ibid.

<sup>26</sup>Ibid., 39, 43.

**Assumption of Waste Elimination** A major assumption of the Clinton health care proposal is that there is enough waste that can be eliminated to pay for universal coverage.<sup>27</sup>

**Regulatory Measures** Should managed competition fail, the Clinton health plan would allow the federal government to intervene in the negotiation between health alliances and health plans. One mechanism for intervention would be setting a national budget for health care with cost controls that become more strict over time.<sup>28</sup>

**National Health Board** The primary body which would be created to administer the Clinton health plan would be the National Health Board.<sup>29</sup> The National Health Board would be “composed of 7 members appointed by the President, by and with the advice and consent of the Senate.”<sup>30</sup> They would serve as full-time officers.<sup>31</sup> Each member serves for a 4-year term with a possible one term renewal.<sup>32</sup> The chair, however, has a term concurrent with the president’s and can serve up to three 4-year terms.<sup>33</sup>

### 3.3.2 Privacy and the Clinton Plan

By its nature, the Clinton health plan entails considerations of privacy. The plan hopes to create a program to provide health care to every citizen. Because the government must keep track of how each citizen uses health benefits, this plan necessitates an increased government role in the lives of citizens. The two sides of the National Health Security Card, an important symbol of President Clinton’s reform effort,<sup>34</sup> shows both sides of this dilemma. On the front of the card will be a person’s name,

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<sup>27</sup>Ibid., 37.

<sup>28</sup>Ibid.

<sup>29</sup>HSA Title 1, Subtitle F, Part 1

<sup>30</sup>HSA §1501(b)

<sup>31</sup>HSA §1502(c)

<sup>32</sup>HSA §1501(d)

<sup>33</sup>HSA §1501(c)

<sup>34</sup>Maureen Dowd, “Clinton’s Health Plan: Reporter’s Notebook; Props and Fuzzy Anecdotes in a Sober, Grown-Up Talk,” *New York Times*, Sep. 23, 1993, sec.A, p.1, and Toner, “Pledging Peace of Mind,” 1.

a “tangible symbol” that he or she will be able to have reliable health care.<sup>35</sup> On the other side of the card will be a magnetic stripe, or possibly some other technology which will enable the government to keep track of the program.<sup>36</sup>

Privacy is specified as a goal of the Act: “The Congress finds as follows . . . (2) Under any reform of the health care system . . . (L) an individual’s medical information should remain confidential and should be protected from unauthorized disclosure and use.”<sup>37</sup>

**Health Information System and Electronic Data Network** President Clinton hopes that his plan will simplify insurance claims processes and reduce medical cost through the use of the Health Security Card and the national medical database: “Freeing the health care providers from these costly and unnecessary paperwork and administrative decisions will save tens of billions of dollars.”<sup>38</sup> Within two years after the passage of the Clinton plan, the National Health Board must “development and implement a health information system by which the Board shall collect, report, and regulate the collection and dissemination of the health care information. . . .”<sup>39</sup> Both the regional alliances and the health plans must comply with privacy regulations promulgated by the National Health Board.<sup>40</sup> The National Health Board is also responsible for establishing an “electronic data network consisting of regional centers that collect, compile, and transmit information” as part of this national information system.<sup>41</sup>

**Privacy Standards** The bill defines individually identifiable information as information easily associated with the enrollee relating to “the past, present, or future

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<sup>35</sup>Robert Pear, “Clinton Medical Plan Calls for ‘Health Security’ Cards,” *New York Times*, Apr. 10, 1993, sec.1, p.7.

<sup>36</sup>Seth Neubardt, “How to Put Single Payer in Clinton Health Plan; Magnetic Medical File,” *New York Times*, Oct. 5, 1993, sec.A, p.26.

<sup>37</sup>HSA §2

<sup>38</sup>President, “Clinton’s Health Plan; Transcript of the President’s Address to Congress on Health Care,” *New York Times*, Sep. 23, 1993, sec.A, p.24. This statement agrees with the \$36 billion of savings projected by Arthur D. Little, Inc. Arthur D. Little, 2. See section 1.3.6 on page 15 above.

<sup>39</sup>HSA §5101(a)

<sup>40</sup>HSA §1327, §1413, §1503(e)

<sup>41</sup>HSA §5103(a)

physical or mental health of the enrollee. . . the provision of health care to the enrollee; or. . . payment for the provision of health care to the enrollee.”<sup>42</sup> An “enrollee” is anyone covered under a health plan. The disclosure of individually identifiable information must be authorized by the data subject, except in the following two cases:

(C) the disclosure is to Federal, State, or local law enforcement agencies for the purpose of enforcing this Act. . .or

(D) the disclosure otherwise is consistent with this Act and specific criteria governing disclosure established by the Board.<sup>43</sup>

Some of these criteria depend on the actions of the future Board, but what does the rest of the bill allow? In order to protect privacy, the Clinton plan offers the following principle:

Minimal disclosure. All disclosures of individually identifiable health information shall be restricted to the minimum amount of information necessary to accomplish the purpose for which the information is being disclosed.<sup>44</sup>

I will call this the “minimal disclosure principle” of the Clinton plan. McCaughey calls this “vagueness” and “double talk.”<sup>45</sup> The problem with this provision is that “the purpose for which the information is being disclosed” could be defined in almost any way. However, the bill explicitly forbids health plans from supplying alliances with individually identifiable information “for the purpose of setting premiums based on risk adjustment factors”<sup>46</sup> or the use of individually identifiable information “in making employment decisions.”<sup>47</sup>

**Consumer Rights** The Clinton plan also offers the following governing principles as the rights of data subjects:

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<sup>42</sup>HSA §5123(3)

<sup>43</sup>HSA §5120(c)(1)

<sup>44</sup>HSA §5120(c)(2)

<sup>45</sup>Elizabeth McCaughey, “She’s Baaack!” *New Republic* (Feb. 21, 1994): sec.A, p.18, and “Price Controls on Health Care,” *Wall Street Journal*, Nov. 22, 1993, sec.A, p.14.

<sup>46</sup>HSA §5120(c)(3)

<sup>47</sup>HSA §5120(c)(9)

- Right to know. An enrollee... has the right to know... whether any individual or entity uses or maintains individually identifiable health information concerning the enrollee; and... for what purposes the information may be used or maintained.”
- Right to access. Subject to appropriate procedures, an enrollee... has the right, with respect to individually identifiable health information concerning the enrollee that is recorded in any form or medium... to see such information... to copy such information... to have a notation made with or in such information requested by the enrollee...
- Right to notice. An enrollee and an enrollee representative have the right to receive a written statement concerning... the purposes for which individually identifiable health information provided to a health care provider, a health plan, a regional alliance, a corporate alliance, or the National Health Board may be used or disclosed by, or disclosed to any individual or entity; [and] the right of access described [above].<sup>48</sup>

The bill also requires the National Health Board to submit a legislative proposal to Congress for “a comprehensive scheme of Federal privacy protection for individually identifiable health information” within three years after the plan’s passage.<sup>49</sup> This proposal must give a “Code of Fair Information Practices” to inform citizens of their rights.<sup>50</sup>

**The National Health Security Card** The health alliances issue the health security card: “A regional alliance is responsible for the issuance of health security cards to regional alliance eligible individuals ...”<sup>51</sup> Both health alliances<sup>52</sup> and health plans<sup>53</sup> face privacy requirements in the Act.

**Smart Cards** “Smart cards” are a new technology which enable a normal identification card to carry much more information than before. A magnetic stripe, like those on the back of credit cards, can hold half of a page of information, but a smart card can hold thirty pages of information by using memory chips and a microprocessor.

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<sup>48</sup>HSA §5120(c)

<sup>49</sup>HSA §5122(a)

<sup>50</sup>HSA §5122(b)

<sup>51</sup>HSA §1324

<sup>52</sup>HSA §1327

<sup>53</sup>HSA §1413



In France, the smart card is already being used for pay phones and bank cards and is beginning to be used in medicine.<sup>54</sup> Furthermore, another current technology is the optical card. By using the same technology as compact disk players, optical cards can hold up to 2,000 pages of information or even a few digital images. Optical card systems are already being installed for libraries in Ontario.<sup>55</sup>

Should a smart card be used as the national health security card? The president cannot guarantee whether or not a smart card will be used once the plan goes to Congress and then, if passed, to administrative agencies. In fact, the legislation of Clinton's plan does not specifically forbid this. The HSA leaves this to the discretion of the National Health Board: "The National Health Board shall establish standards respecting the form of health security cards and the information to be encoded in electronic form on the cards."<sup>56</sup> In the past President Clinton planned to use smart card technology: "During the campaign, candidate Clinton said, 'Everyone will carry a smart card, encoded with his or her personal medical information.'"<sup>57</sup>

The HSA gives discretion to the National Health Board to determine the information kept on the card: "The National Health Board shall establish standards respecting . . . the information to be encoded in electronic form on the cards. Such information shall include [identity of the citizen, that person's health plan and policies] and any other information that the National Health Board determines to be necessary in order for the card to serve the purpose described [earlier in the Act]."<sup>58</sup>

The use of the Health Security card outside of medical contexts is forbidden in the HSA: "A health security card . . . may be used . . . in accordance with the regulations promulgated by the [National Health] Board, only for the purpose of providing or assisting the eligible individual in obtaining an item or service that is covered under [the programs permitted by the Act]."<sup>59</sup>

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<sup>54</sup>William M. Bulkeley, "Technology—Information Age: Get Ready for 'Smart Cards' in Health Care," *Wall Street Journal*, May 3, 1993, sec.B, p.11.

<sup>55</sup>Ibid.

<sup>56</sup>HSA §5105 (b)

<sup>57</sup>Bulkeley, "Get Ready," 11.

<sup>58</sup>HSA §5105(b)

<sup>59</sup>HSA §5105(a)

**Strengths and Weaknesses of the Clinton Plan** The main strengths of the Clinton plan are its specificity. Even so, it still has problems with vagueness both in its minimal disclosure principle and its treatment of the health security card.

### 3.4 The Cooper Plan

The health plan sponsored by Representative Cooper is officially called the “Managed Competition Act of 1993.”<sup>60</sup>

#### 3.4.1 Summary of the Cooper Plan

The Cooper plan makes voluntary coverage available to everyone not under Medicare through group private insurance.<sup>61</sup> The cooperative groups are administered by the states and organized into regional pools, similar to the alliances of the Clinton plan.<sup>62</sup> The Cooper plan gives the title “Health Plan Purchasing Cooperatives,” or “HPPCs,” to these “not-for-profit corporations.”<sup>63</sup> With the exception of possible interstate areas, each state will serve as one HPPC.<sup>64</sup> The health care industry is represented in the plan by “accountable health plans” or “AHPs.”<sup>65</sup> These are providers of health benefits who make agreements with their customers.<sup>66</sup> The Cooper plan is financed by individual contributions and voluntary contributions from employers, along with state and federal subsidies for small businesses and people with low incomes.<sup>67</sup>

**The Health Care Standards Commission** Like the Clinton plan’s National Health Board, the Cooper plan establishes an executive agency called the Health

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<sup>60</sup>U.S. Congress, House, *Managed Competition Act of 1993*, 103rd Cong., 2nd sess., HR 3222, (1994), §1. In the Senate, S.1579. From this point on, I will abbreviate this bill with the acronym “MCA”

<sup>61</sup>Kaiser

<sup>62</sup>Ibid.

<sup>63</sup>MCA §1101(b)(1)

<sup>64</sup>MCA §1101(a)(1)

<sup>65</sup>MCA §1201, §1701(b)(1)

<sup>66</sup>MCA §1701(b)(1), §1701(c)(1)

<sup>67</sup>Kaiser

Care Standards Commission in order to administer the program.<sup>68</sup> Health plans become “accountable” when they register with this organization.<sup>69</sup> The Commission features “5 members appointed by the President by and with advice and consent of the Senate”<sup>70</sup> for terms of seven years.<sup>71</sup> There is a chairman, and all the members serve full-time.<sup>72</sup> This commission is responsible for setting the “Uniform Set of Effective Benefits,” the treatments permitted under the plan.<sup>73</sup> This commission is also responsible for establishing information standards which “protects the confidentiality of individual enrollee.”<sup>74</sup>

### 3.4.2 Privacy and the Cooper Plan

**Cost Savings through Information Technology** According to information from Rep. Cooper’s office, reducing paperwork in the insurance industry could save “[a]t least \$5 billion in annual health care expenditures.”<sup>75</sup> The Cooper plan hopes to achieve these savings through “standard claims forms and electronic transmission of data.”<sup>76</sup> Given the estimates of the Arthur D. Little study—savings of \$36 billion annually<sup>77</sup>— the estimate of the Cooper staff seems to be well within the realm of possibility.

**National Health Data System** The Cooper plan also involves a national data system.<sup>78</sup> The Cooper plan requires the accountable health plans (AHPs) to submit to the Commission and its regional cooperative (HPPC) “such information as the Commission determines to be necessary.”<sup>79</sup> This information must include the

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<sup>68</sup>MCA §1301

<sup>69</sup>MCA §1201(a)

<sup>70</sup>MCA §1301(a)(1)

<sup>71</sup>MCA §1301(a)(3)

<sup>72</sup>MCA §1301(a)

<sup>73</sup>MCA §1302

<sup>74</sup>MCA §1307, §6002

<sup>75</sup>Information from Rep. Cooper’s Office. U.S. Representative, Jim Cooper, Staff Office, “The Managed Competition Act of 1993: A Summary of H.R. 3222,” 5.

<sup>76</sup>Ibid.

<sup>77</sup>Arthur D. Little, 2. See section 1.3.6 on page 15 above.

<sup>78</sup>MCA §1307

<sup>79</sup>MCA §1203(a)(1)

following:

(A) Information on the characteristics of enrollees that may affect their need for or use of health services and the determination of risk adjustment factors for enrollee units.

(B) Information on the types of treatments and outcomes of treatments with respect to the clinical health, functional status, and well being of enrollees.

(C) Information on health care expenditures, volume and prices of procedures. . .<sup>80</sup>

The act makes payment of providers contingent upon their submission of this information, except in the case of emergency services.<sup>81</sup>

**Role of the Commission** Similar to the Clinton plan, the Cooper bill gives the responsibility for medical privacy standards to the Health Care Standards Commission. There are two sets of privacy standards, one for information provided by health plans and one dealing specifically with individually identifiable information.

The Health Care Standards Commission must promulgate standards for the information from health plans.<sup>82</sup> Regarding the level of privacy in these standards, the Cooper plan states:

The standards shall be established in a manner that protects the confidentiality of individual enrollees, but may provide for the disclosure of information which discloses particular providers within an AHP.”<sup>83</sup>

In addition to these standards, the Commission is responsible to issue and modify specific standards regarding individually identifiable information:

The Health Care Standards Commission shall promulgate, and may modify from time to time, requirements to facilitate and ensure the uniform, confidential treatment of individually identifiable health care information in electronic environments.<sup>84</sup>

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<sup>80</sup>MCA §1203

<sup>81</sup>MCA §1203(b)

<sup>82</sup>MCA §1307

<sup>83</sup>MCA §1307(a)(2)

<sup>84</sup>MCA §6002(a)(1)

The Commission must issue these standards within six months of the passage of the bill.<sup>85</sup> These standards must apply to individually identifiable information at any stage of its existence (its collection, handling, storage, and all disclosures).<sup>86</sup> State and federal public health reporting is exempt from them.<sup>87</sup> Special protections must be given for “highly sensitive data,” such as mental health or drug abuse information).<sup>88</sup> Under the bill, these medical privacy standards must “require publication of the existence of health care data banks”<sup>89</sup> and “provide for the deletion of information that is no longer needed to carry out the purpose for which it was collected.”<sup>90</sup> States with privacy standards already consistent with those of the Commission are exempt from the Commission’s standards.<sup>91</sup> Violations of these privacy standards, under the Cooper plan, will result in civil damages, in accordance with the regulations of the Commission.<sup>92</sup>

**Fair Information Practices** The Commission’s privacy standards must also include “fair information practices that assure a proper balance between required disclosures and use of data.”<sup>93</sup> Criteria for this balance include the following:

- (i) creating a proper balance between what an individual is expected to divulge to a record-keeping organization and what the individual seeks in return,
- (ii) minimizing the extent to which information concerning an individual is itself a source of unfairness in any decision made on the basis of such information, and
- (iii) creating and defining obligations respecting the uses and disclosures that will be made of recorded information about and individual,<sup>94</sup>

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<sup>85</sup>MCA §6002(4)

<sup>86</sup>MCA §6002(2)(B)

<sup>87</sup>MCA §6002(2)(C)

<sup>88</sup>MCA §6002(2)(G)

<sup>89</sup>MCA §6002(F)

<sup>90</sup>MCA §6002(I)

<sup>91</sup>MCA §6002(b)(1)

<sup>92</sup>MCA §6002(d)

<sup>93</sup>MCA §6002(2)(E)

<sup>94</sup>MCA §6002(2)(E)

### 3.5 Republicans, Reform, and Privacy

The Nickles plan will be interesting to examine because it is an example of a large scale reform plan from someone in the Republican party. Many Republicans have denied the existence of a health care “crisis” in order not to give into the assumptions that President Clinton and other Democrats have used in shaping the reform debate.<sup>95</sup> Typically, Republicans oppose large scale bureaucracy and heavy government intervention with the private market. Using superficial stereotypes, it would also seem that Republicans would focus more on the negative effects of government than the Democrats.

According to an article by Ruth Shalit in *The New Republic*, the dominant Republican position on health care reform is that there is no “crisis” and that only minor changes are necessary.<sup>96</sup> She writes:

The line is now monolithic and simple: there is no health crisis; no coverage problems; no cost increase spiral; no need to do anything drastic at all.<sup>97</sup>

This position was inspired by a memo written by William Kristol of Project for the Republican Future, and, according to Shalit, between December 1993, when the memo was written, and February 1994, Republicans moved towards his position.<sup>98</sup>

However, the simplicity of the Republican line that Shalit’s article paints can be questioned. Shalit’s article mentions two Republican Senators who are sponsoring major measures in health care reform. At least two Republican Senators, John Chafee and Don Nickles have sponsored large scale health care reform bills.<sup>99</sup> The Chafee plan, is, in Shalit’s view, “the most comprehensive of the Republican health care plans,”<sup>100</sup> had “some twenty co-sponsors” including Minority Leader Bob Dole, said Chafee in February 1994.<sup>101</sup> The Nickles plan has 25 co-sponsors, also including Dole,

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<sup>95</sup>Ruth Shalit, “The Wimp-Out,” *The New Republic* (Feb. 14, 1994): 19.

<sup>96</sup>Ibid.

<sup>97</sup>Ibid.

<sup>98</sup>Ibid.

<sup>99</sup>Ibid., 22.

<sup>100</sup>Ibid.

<sup>101</sup>Quoted in Shalit, 22.

according to information from Nickles's office.<sup>102</sup>

## 3.6 The Nickles Plan

The official name of the plan that Senator Nickles is sponsoring is the Consumer Choice Health Security Act of 1993.<sup>103</sup>

### 3.6.1 Summary of the Nickles Plan

The Nickles plan is one of the Republican proposals for major health care reform.<sup>104</sup> It uses the Federal Employees Health Benefits Plan as its model.<sup>105</sup> The plan requires those not under Medicare to buy private health insurance.<sup>106</sup> It is financed with general revenues, reductions in Medicaid and Medicare, individual premiums, but subsidies are given to those with low incomes.<sup>107</sup>

### 3.6.2 Privacy and the Nickles Plan

**Cost Savings through Administrative Standardization** According to material from Nickles's office, under the CCHSA "[t]he Secretary of Health and Human Services would have the power to require all health care providers to submit claims to health insurance companies in accordance with the Secretary, if providers are not voluntarily complying with the standards. The Secretary is also directed to adopt standards relating to data elements for use in paper- and electronic-claims processing of health insurance claims, uniform claims forms and uniform electronic transmission of data."<sup>108</sup>

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<sup>102</sup>Information from Sen. Nickles's Office. U.S. Senator, Don Nickles, "Fact Sheet: S.1743: Consumer Choice Health Security Act," (Nov. 20, 1993)

<sup>103</sup>U.S. Congress, Senate, *Consumer Choice Health Security Act of 1993*, 103rd Cong., 1st sess., S 1743, (1993), §1. In the House, HR 3698. The number of the bill in the House is H.R.3698 and in the Senate is S.1743. From this point on, I will abbreviate this bill with the acronym "CCHSA."

<sup>104</sup>Shalit, 22.

<sup>105</sup>U.S. Senator, Don Nickles, "A Health Plan Good Enough for Senators," *Wall Street Journal* (Nov. 16, 1993): sec.A, p.22.

<sup>106</sup>Kaiser

<sup>107</sup>Ibid.

<sup>108</sup>Nickles Staff Office, 6

The CCHSA requires the Secretary of Health and Human Services to adopt two sets of standards regarding electronic medical information. The first set of standards concerns the administrative side of medicine: “claims processing,” “utilization review,” and “management of care.”<sup>109</sup> The other set of standards concern the technical side of medicine.

**Data Standards for Administration** The CCHSA requires the Secretary to “adopt standards relating to . . . Data elements for use in paper and electronic claims processing,” “Uniform claims forms,” and “Uniform electronic transmission of the data elements.”<sup>110</sup> According to the CCHSA, the electronic transmission standards “shall include protections to assure the confidentiality of patient-specific information and to protect against the unauthorized use and disclosure of information.”<sup>111</sup> Though this language is not very specific, the CCHSA requires the HHS Secretary to incorporate the recommendations of recent task forces on the subject, such as the Workgroup on Electronic Data Interchange (WEDI) and the Computer-based Patient Record Institute (CPRI) and to consult American National Standards Institute.<sup>112</sup> These electronic transmission standards must be promulgated within two years after passage of the act, for “hospital and physician services” and later for “transmission of information on other services.”<sup>113</sup>

**Data Standards for Providers** The Nickles plan requires the Secretary of the Department of Health and Human Services to promulgate another set of standards “for hospitals concerning electronic medical data.”<sup>114</sup> This is to occur “Between July 1, 1995 and January 1, 1996.”<sup>115</sup> These standards will define a “set of comprehensive data elements” which includes a standard data set for “quality control peer re-

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<sup>109</sup>CCHSA §401(a)(1)

<sup>110</sup>CCHSA §401(a)(1), Nickles Staff Office 1993: 6

<sup>111</sup>CCHSA §401(a)

<sup>112</sup>CCHSA §401(b)

<sup>113</sup>CCHSA §401(c)(3)

<sup>114</sup>CCHSA §411(a)

<sup>115</sup>CCHSA §411(1)



view organizations.”<sup>116</sup> Regarding the privacy of this data, the CCHSA also requires “Standards for an electronic patient care information system with data obtained at the point of care.”<sup>117</sup> These standards must contain provisions “to protect against the unauthorized use and disclosure of information.”<sup>118</sup> In addition, the Secretary must promulgate standards for the transmission of hospital data and for the “confidentiality of patient-specific information.”<sup>119</sup> Under the CCHSA, the HHS Secretary can, at his discretion, impose standards similar to these “concerning electronic medical data for providers that are not hospitals.”<sup>120</sup> Once the comprehensive data set for hospitals is established, an insurer cannot require any additional data or violate the transmission standards for that data.<sup>121</sup> Civil penalties accompany such violations of the standards.<sup>122</sup>

**Medicare and Veterans Administration Requirements** In order for a hospital to participate in either Medicare or Veterans Administration programs, it must maintain the required data sets on its patients and provide these to the Department of Health and Human Services or organizations with which it has contracted for the purpose of quality control or fiscal management.<sup>123</sup> This requirement can be waived under certain circumstances.<sup>124</sup> In general, when federal agencies receive data from hospitals, the agencies can require the hospitals to meet the same standards that apply in other cases.<sup>125</sup>

**The Purpose of the Following Chapter** The purpose of this chapter was to examine the privacy provisions of the three reform bills. Chapter 4 will offer further evaluations of the bills and recommendations for medical privacy reform.

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<sup>116</sup>CCHSA §411(b)

<sup>117</sup>CCHSA §411(b)(3)

<sup>118</sup>CCHSA §411(b)(3)

<sup>119</sup>CCHSA §411(b)

<sup>120</sup>CCHSA §411(c)

<sup>121</sup>CCHSA §414(a)

<sup>122</sup>CCHSA §414(b)

<sup>123</sup>CCHSA §412

<sup>124</sup>CCHSA §412

<sup>125</sup>CCHSA §413

## Chapter 4

# Conclusions and Recommendations for Medical Privacy Reform

The original hypothesis holds, that although each of the three health care reform proposals takes steps to protect medical privacy, none of them do as much as should be done to protect the medical privacy of citizens. This work recommends four actions to Congress for improving upon the privacy protection provisions of these three bills:

1. Congress should take legislative action now to protect medical privacy, rather than delaying it by leaving it exclusively in the hands of administrative agencies.
2. This legislative action must more directly specify details of policy implementation than the provisions in these three bills.
3. Congress should place the administrative authority for medical privacy regulations in the hands of a presently existing agency in order to speed up the implementation of medical privacy standards.
4. Congress should work to ensure vigorous implementation of its policies through the states.

## **4.1 Recommendation #1: Present Congressional Action Is Needed**

### **4.1.1 Present versus Future Action**

The medical privacy problem is one that already exists. It is best to deal with it right now, at the same time that health care reform is dealt with.

### **4.1.2 Legislative versus Other Types of Action**

Although the Clinton plan delays substantial action for the longest period of time, one strength of the Clinton plan is that it keeps privacy standards tied to Congress. The Clinton plan requires its National Health Board, within three years, to submit comprehensive medical privacy legislation to Congress. This allows approval of medical privacy standards to occur within Congress rather than an administrative agency.

## **4.2 Recommendation #2: Specific Proposals Are Needed**

One problem with the privacy provisions of all three proposals is their vagueness. However, although it has its own problems with vagueness, as mentioned above, the privacy protections of the Clinton plan are the most specific, mainly because of the three consumer rights that it explicitly mentions (right to know, right to access, and right to notice). There are at least two major problems of vagueness in the privacy provisions of the Clinton plan. First, the restrictions of Clinton's plan regarding the health security card are not able to specifically govern whether or not smart cards will be used as the national health security card. The National Health Board has the power to shape information technology in this area. Second, the minimal disclosure principle is so vague to be almost meaningless.

### **4.3 Recommendation #3: An Existing Agency Should Have Authority**

In one sense, the Nickles plan is better than the other two, because it places the authority to create privacy regulations in the hands of an existing administrative agency, the Department of Health and Human Services (HHS). It already has its own policies and standards which have weathered the political process and gained some kind of consensus approval. If a new agency were created, the entire structure of the agency would be developed in the same political environment that created health care reform. This could take a long time because of the present lack of consensus regarding health care reform. Using an existing agency would also require less congressional action. Congress could issue specific details of policy implementation regarding the issues of medical privacy, rather than initiating an entirely new administrative process. On the other hand, it could be objected that newly created agencies could have greater expertise in the emerging field of information technology and privacy as well as a more fair representation of the affected interests. However, an existing agency, like HHS, could hire or contract with experts and also set up negotiation procedures to give a fair voice to all of the relevant interests. On the whole, it is more stable to use an existing agency to create privacy regulations.

### **4.4 Recommendation #4: Vigorous State Implementation Is Necessary**

One of the major problems in the present U.S. policy toward medical privacy is lack of uniformity. Congressional action is one step in solving this problem. However, it is not enough. Congress must ensure the effective implementation of the policies it creates in this area. This involves two things: money and mechanisms. Congress must make sure that the programs it creates have enough money to work vigorously. This is a particular problem if its programs will be administered in any way by the states.

States often execute federal programs with differing degrees of effectiveness because of the differing resources or their differing priorities in the use of those resources. Furthermore, different states have different administrative mechanisms. Congress must ensure that these mechanisms satisfy standards high enough to achieve its policy goals.

## 4.5 Conclusion

This work argues that the following proposition is true: “Present medical privacy proposals must be revised in order to protect medical privacy adequately.” This conclusion is only an inductive one, not a deductive one, because three proposals do not constitute a sample that is statistically valid. Nor are the three proposals an exhaustive set of the existing health reforms in Congress. In fact, in its “Summary of Major Health Care Reform Legislation,” dated December 22, 1993, the Henry J. Kaiser Family Foundation examines six proposals, only three of which this work has discussed.<sup>1</sup> However, these three include the President’s plan, which has received the most attention of any other plan; the Cooper plan, which is a main competitor of the President’s plan; and the Nickles plan, one of the major Republican measures. The argument of this work is that if these three important health care reform proposals do not take measures of adequate strength to protect medical privacy, it is probable that the issue is not receiving enough attention in Congress or even in the public at large. Further work should examine specific initiatives to deal with the issue of medical privacy alone, such as Rep. Gary Condit’s “Fair Health Information Practices Act of 1994” (H.R.4077).<sup>2</sup> It will also be important to observe the ability of measures such as this one to be integrated, as Condit hopes his will be, into the text of whatever health care reform plan emerges from Congress.<sup>3</sup>

On the whole, the privacy provisions of the Clinton plan are superior to those of

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<sup>1</sup>Kaiser

<sup>2</sup>Congress, House, Committee on Government Operations, “Rep. Condit Introduces Fair Health Information Practices Act,” (Mar. 18, 1994). News release written by Bob Gellman.

<sup>3</sup>Ibid.

the Cooper plan. However, all three plans are much too vague when compared to the recommendations of the Gostin group, Sheri Alpert, or even the Fair Information practices written by the Department of Health Education and Welfare in 1973. For example, HEW's practices says, "There must be a way for an individual to prevent information about him obtained for one purpose from being used or made available for other purposes without his consent." None of the three proposals deal with this issue, except for the Clinton plan's prohibition on the use of the health security card for non-health purposes. Likewise, the HEW practices state, "There must be a way for an individual to find out what information about him is in a record and how it is used." Only the Clinton plan mentions this. Of the three proposals, the Clinton plan gives the greatest degree of specificity.

In all fairness, it appears that all three bills are concerned with the issue of privacy. All three bills explicitly deal with the issue. It seems that all three bills depend heavily upon administrative agencies to fill in the details of privacy protection. However, all three rely upon later actions to produce privacy standards rather than including them explicitly in the legislation. It is possible that each plan delayed dealing with privacy more specifically because their authors were more concerned with getting health reform measure passed. This is understandable because privacy policy is generally less controversial than the issues of health care reform in general. However, as chapter 1 showed, the issues of health care reform involve privacy and cannot be separated from it. Therefore privacy decisions should be made at the same time as decisions on more general issues.

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## A Note about the Author

Bryan Atchison was born in 1970 in Birmingham, AL, where he grew up. He attended Vanderbilt University in Nashville, TN, receiving a Bachelor of Science in Physics in 1992. At Vanderbilt, he graduated *summa cum laude*, was inducted into Phi Beta Kappa as a junior, and received the Founder's Medal in the College of Arts and Sciences, awarded to the top graduate in the College. After graduating from MIT, Bryan plans to attend Covenant Theological Seminary in St. Louis for a year, after which he hopes to pursue an academic career studying ethics and public policy through the discipline of either law or philosophy. He is particularly interested in the effect of technology on ethics and public policy. The driving motivation behind Bryan's work is his conviction that the Christian faith is the truth about every part of life. He desires to integrate his faith into his intellectual pursuits in order to demonstrate both the truth of the Christian faith and its relevance to the problems of the modern world.