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Cell Wars

Albert R. Jonsen, Ph.D.*

On September 11, our second day of infamy, I was in Davos, Switzerland, delivering a lecture to an international conference. The topic was the ethics of stem cell research. As CNN displayed the horrors of that day, we learned that another kind of cell, the clutch of international terrorists, was our enemy. One war against stem cell research had been waged in the United States; another war against terrorist cells was about to be mounted. The fact that this short word “cell” spanned two issues of moral moment, and the fact that I have spent my career as a professor of ethics, spurred me to reflection on the very nature of morality. Perhaps I have spent years teaching something I really did not understand.

Apart from the word “cell,” meaning in its original Latin “storeroom,” and then a small chamber for a monk or a prisoner, and then the membrane-enclosed cytoplasm out of which all organisms are built, and then, in recent years, a group of revolutionaries and subversives, what might the organic cells about which I was lecturing and the cadre of terrorists who blasted our security have in common as morally meaningful? The organic cell is so tiny as to be invisible to the naked eye; the terrorist cell is also invisible. The organic cell has great power: its complex metabolism can build and sustain an elephant and a human person. The terrorist cell is also powerful: its conspiracy can blast out of existence massive structures and out of balance the equilibrium of a nation. Yet organic cells and terrorist cells are radically different. What joins them in our moral concerns? Why should I be able to speak about the moral issues raised by the stem cell and the moral issues raised by terrorism?

I begin with the horrors of September 11. We saw before our eyes the instant incineration of some 4,000 lives, a sight never seen by any human ever before. Neither Nature’s fickle force nor negligent accident did this, but rather the deliberate intent of human will. We saw that day what the martyred German Lutheran theologian Dietrich Bonhoeffer once called “the depths of evil.” He was referring to the Nazi evils that crushed his own life and that of millions of European Jews and other innocent victims. The

* Albert R. Jonsen is Emeritus Professor of Ethics in Medicine at the University of Washington. He was a Visiting Professor of bioethics at Yale University from 1999-2000.

horrors of that genocide soon came to be known as The Holocaust. The events of September 11 were also a "holocaust," a word that appears in Greek literature and in the Greek Septuagint version of the Hebrew bible to designate a sacrificial offering consumed entirely by fire. Although vastly different in scale, the Nazi Holocaust and this contemporary holocaust both manifest evil so deep that no justification or excuse can free them from utter condemnation. Of course, the Nazis believed that their goal of racial purity justified their destruction; of course, the Islamic terrorists believe that their defeat of the Great Satan renders their destruction praiseworthy. But is not reason revulsed by these rationales? Here the first task of the moral philosopher is engaged: How are we to think about moral relativism? Can we simply glance at the horrors of those two holocausts and say that if Nazis and Taliban think they were good, they must be so? Are there not evils so deep that human moral judgment must condemn them? If there are not, all the work of ethics is relativistic and ultimately meaningless.

Turn to the other cell, the stem cell, infinitesimal origin of our total organism. Microbiologists identify the embryonic stem cell as the chamber of cytoplasm vitalized by a nucleus of chromosomes that exists only for a few days after fertilization or cloning. They are at that point the cells of no particular tissue or organ but are ready to become all tissues and organs once implanted in a womb. Only recently have scientists discerned that these very early cells could be preserved in their primal state and then prepared to become particular tissues and organs that can be transplanted into those whose tissues and organs need repair. In order to do this, however, the evolving embryo will be stopped in its evolution toward a fetus and a baby, and its cells will be diverted to therapeutic use for others. This ending of embryonic life has been called murder, equivalent to the killing of a child or a person. The research promising repair of neural cells, liver cells, and heart cells is a moral evil because it originates with the deliberate murder of a human being. This is a violation of the sanctity of life. Yet is not the salvage of human life from the ravages of damaged neural or islet cells an acknowledgment of the sanctity of life?

Pastor Bonhoeffer's words about the depths of evil come from a sentence that opens one of the most eloquent passages of the martyred theologian's writings:

One is distressed by the failure of reasonable people to perceive either the depths of evil or the depths of the holy. With the best of intentions they believe that a little reason will suffice them to clamp together the parting timbers of the building. They are so blind that in their desire to see justice done to both sides they are crushed between the clashing

forces. Bitterly disappointed at the unreasonableness of the world, they see that their efforts must remain fruitless and they withdraw resignedly from the scene or yield unresistingly to the stronger party.¹

"The depths of evil or the depths of the holy." These are the words that have lingered in my mind for decades as I attempted to study and teach ethics. Bonhoeffer is speaking, in this passage, not of ordinary people, to whom it might well apply, but rather of "ethicists," those philosophers and theologians who make it their life's vocation to instruct ordinary people about the good and the right, or if not to instruct, at least to clarify what right and good might mean in a confusing world.

Western philosophical and theological thought has given much attention to ethics, from Socrates to the Stoics, from Jesus to Augustine and Aquinas, from Moses to Maimonides, from Hume and Locke, Kant and Hegel, to James, Dewey, and Rawls. How much deep thought about the meaning and value of human life in society! Yet, when we put down the words of these deep thinkers and turn to practical life, we improvise an ethic to fit the needs of persons in particular times and places. This improvisation is the work of reason, seeking to understand how to stay alive and flourish in humane conditions.

Ethics is an improvisation, much like the improvisation allowed to the pianist or violinist in the classical sonata. "Improvisation," says a dictionary of music, "is the invention of music at the time it is being performed...on the spot, without being written down."² This is, of course, the way most music has been made through human history and it is the way much of the best jazz is made today. In the seventeenth and eighteenth centuries, as composers perfected the concerto form for orchestra and solo instrument, they often allowed the soloist an opportunity to show technical skill by departing from the composer's notation and playing freely for some time. These "cadenzas" usually came just before the end of the first movement, following the statement of themes and their recapitulation, so that the pianist might pick up the melodies already established in the notated score and modify them in harmony, rhythm, modulation of key, and phrasing. The pianist now becomes an improvisationist, allowed to depart from the notation of the composer's score, but still restrained within certain limits as he or she creates music extemporaneously.

Melodies, while varied, are still heard; keys are modulated but not forgotten. The sounds of the improvisation must, in some definite way, echo the sounds of the score. Haydn, it is said, was once so dismayed by a soloist's liberties that he loudly remarked at the end of the cadenza, "welcome home, Mr. Dubourg." Improvisation allows the virtuoso to stray, wander, and explore, but not too far from home. It departs from the

composition and must return to it and, indeed, even as it flows from the artist's virtuosity, it must remain at least remotely true to the composer's inspiration. Improvisation is, I am told, a difficult art and, while Mozart and the other great composers left cadenzas to their performers, they also wrote them themselves, and today most pianists play the composer's cadenza rather than improvise.

I think that practical ethics is very much like musical improvisation. In a realm of practical life, whether it is medicine, familial or sexual association, commerce, or politics, certain great themes, articulated by the great thinkers and felt by the populace, are heard: Medicine must care for the sick, families must nourish children, business must be honest, politics must seek peace and the common welfare. But once these themes are heard, a multitude of practical problems must be faced, for which the themes, while inspiring, are insufficient. Those problems must be solved by careful study and creative responses to the particular shape of the problems. While the improvisations have taken different forms over the centuries, they stay remarkably close to the themes that can be heard from morality outside medicine: put most succinctly by the Roman Jurisprudents, "live honestly, hurt no one and give to each what is due." It is unquestionably true that some improvisations have been more successful than others.

Yet these improvisations are, in Bonhoeffer's phrase, "the work of little reason." They are devised by reason working on the problem; they are implemented by reason recognizing the situations in which restraint is required. They work well when the building, again to recall Bonhoeffer's image, is in good condition: little reason holds the timbers together effectively enough. Yet, when the timbers are parting, under storm or in earthquake, little reason begins to fail. The improvisations are created for ordinary times; they manage the difficulties that disrupt the tenor of ordinary times. But when ordinary times are torn asunder, little reason, which seeks to do justice to all parties, can no longer hold the building together. The ethics of ordinary times, the improvisations of little reason, are insufficient. As is often the case with reason, it does not break totally, but becomes twisted. The same terms that in ordinary times provide sensible advice for the management of problems take on meanings that justify outrageous departures from that sensible advice. People who espouse principles find themselves proclaiming the same principles to do the opposite things they did in ordinary times. And, of course, they say that these are not ordinary times.

So, under stress, the intricate improvisations of a particular ethic, medical, clerical, or political, are twisted and stretched until the building

comes apart. That is, the activity which that ethic preserved no longer looks at all as it should: politics exploits the people, religion enslaves them, and medicine kills them. It is now that Bonhoeffer's principal thesis must appear: The failure of reasonable people to perceive either the depths of evil or the depths of the holy. "The depths of evil or the depths of the holy"—terrifying words at both ends. The depth of evil generates terror before the destruction of all that gives familiar stability to life, the abyss that opens when the ordinary is smashed in every respect. Terror that comes when life is at every moment in peril; when love's bonds are ripped apart. The depth of the holy is the *Mysterium Tremendum*, the words philosopher Rudolf Otto used to describe the Divine Presence: a mystery that makes humans tremble, not in fear, but in exaltation and ecstasy. How peculiar that Bonhoeffer neglects the common metaphor: heights of the holy and depths of evil. Yet, in saying "depths of holy and depths of evil," he emphasizes the most paradoxical of metaphysical and psychological realities: While the holy and the evil may be polar opposites, we humans too often confuse them. In principle, we revere the one and despise the other, yet in our decisions and actions we mix them horribly.

Still, we must perceive them and consistently attempt to keep them distinct. I think that Bonhoeffer wished to tell us that the improvised ethics of little reason, useful as it is in ordinary times, has sustaining strength only if surrounded by a vivid perception of what lies beyond the problems of ordinary times. The perception of the depth of evil and the depth of the holy is the external force that supports the interior bindings of the ethics of little reason and sustains it under pressure. Without this perception, the improvised ethics are impotent. Yet, how do we perceive the depths of evil and the depths of the holy? These seem incommensurable. We see depths of evil, or approaches to it, so very often: the killing fields of Cambodia and Bosnia, the slaughters in Rwanda, the starvation in Somalia, the bombings in Ulster, Tel Aviv, and Oklahoma City, and now the tragedy of the twin towers; even the smaller horrors of blasting a Birmingham Sunday School, or gunning down fellow high-school students. Are these not visions of the depths of evil? But are there not other depths of evil in the political and economic world that we ignore and which do as much harm to life and the world as these horrors?

We do not often see visions of the depths of the holy. Perhaps we saw those depths in the courage of the New York police and firefighters at Ground Zero, in the superhuman efforts to save lives, in the tiny panegyric paragraphs about the victims that appear daily in the *New York Times*. When we do glimpse the depth of the holy, in the face of a saint or the courage of a savior of the imperiled, it seems so quickly erased by the magnitude of

evil around it. And, as I noted, our inability to keep distinct the depths of evil and the holy makes recognition of the true lineaments of both perilously difficult.

How can "reasonable people...perceive the depths of the holy and the depths of evil" when we seldom can see either clearly? Might we not excuse ourselves due to our congenital blindness or myopia? I think not. It is, I believe, in the very improvisations of little reason at which we are so competent that we can glimpse, if we are alert, the forces of the holy and of evil. While in ordinary times, we may debate with great seriousness the adequacy of these improvisations, an alert ethicist will constantly glimpse behind these arguments the possibility of evil and holiness. We rarely converse directly about such things and rarely press our debates to those further fields. Indeed, when we do, someone is likely to accuse us of extremism. Still, even without explicit exploration, we must be constantly alert to the drift of our improvisations. They may move, almost imperceptibly, away from the themes that inspire them and, almost without our noticing, become parodies of what they had been created for. The themes that ultimately must inspire our morality are the constant work of reason and sensibility to counter human impetuosity, lethargy, and selfishness. Evil will always be with us, but it must be repudiated without compounding evil and thus must be fought with reason and sensibility. The sanctity of life will draw us, but it must be embraced without fanaticism, irrationality, and insensitivity.

Our war against terrorist cells will engage evil and the holy. We will be forced to ask how we can repel evil and still sustain the holiness of freedom and humaneness. Our war about the stem cells must recognize that we deal with the beginnings of human life, and thus the sanctity or holiness of all human life, and our moral ingenuity will be stressed to effect the good of healing without doing evil. The two cell wars are not, in essence, very different.

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Human Rights and the Ethic of Care: A Framework for Health Research and Practice

Philip Alcabes, Ph.D., M.P.H.* and Ann B. Williams, R.N., Ed.D.†

Wide gaps in health status, access to health care, quality of care, and provision of health-related services are increasingly evident in the context of globalization. In the face of glaring disparities between the health status of the "Haves" and that of the "Have Nots," health professionals in wealthier countries must consider the impact of such disparities on the ethical conduct of health research. Unfortunately, currently established codes of moral conduct fail to provide adequate guidance for ethical decision-making in health research. Formal codes include the U.S. Department of Health and Human Services (DHHS) regulations for protection of human subjects, the Nuremberg Code, the Helsinki Declaration, and the guidelines of the Council for International Organizations of Medical Sciences.¹ Taken together, these documents constitute a body of important standards for protecting research subjects from harm and regulating the balance between potential risks to subjects and potential benefits. Yet, these standards fail to resolve ethical conflicts between upholding human rights and producing more information for medical benefit. Such conflicts are increasingly apparent as economic globalization reveals the depth of international disparities in resources and knowledge.

In this Article, we examine how an ethics based on caring and responsibility can guide clinical research in a manner that is consistent with human rights and justice in the face of global disparities. We review two paradigms for moral reasoning—the morality of rights and the morality of care—with respect to applying the principles of human rights to health. The morality of rights relies on the abstract concept of justice to guide behavior. The morality of care, as the name suggests, seeks to guide decision-making in a way that *takes care of* others, examining real-world conflicts and contexts to resolve moral dilemmas. As such, it can

* Philip Alcabes is an Associate Professor in the Program in Urban Public Health at Hunter College School of Health Sciences at City University of New York.

† Ann B. Williams is the Helen Porter Jayne and Martha Prosser Jayne Professor at Yale University School of Nursing.

supplement the abstractions of justice, protection, and benefit to provide ethical guidance in a wide variety of circumstances. We examine how the two moral paradigms play out in a contemporary bioethical challenge—the case of research related to Human Immunodeficiency Virus (HIV) and AIDS in the developing world. Finally, we propose an approach to ethical decision-making for clinical research that we apply to the HIV/AIDS experience, but which we believe has wider applicability.

We suggest that incorporation of a morality of care into the approach to health research can deepen the ethical discussion, produce more nuanced strategies for research planning, and identify and reinforce a professional stance that is more responsive to both health disparities and changing needs. A more versatile and caring ethical framework will offer better guidance to researchers and health care providers when faced with complex situations and ever-present disparities in an era of globalized health research.

I. HUMAN RIGHTS AND HEALTH

The recognition that protection of human research subjects is a proper public concern and the modern human rights movement are both relatively young ideas. Medical experiments conducted in concentration camps during World War II prompted military judges to promulgate the standard of informed consent.² The Nuremberg decisions framed medical research as a social-justice issue, as Robert Levine has noted.³ Wording in the recent revision of the Helsinki Declaration on ethical principles for human-subjects research captures social-justice concerns both explicitly, with language about “appropriate caution...in the conduct of research which may affect the environment,”⁴ and implicitly, in a controversial standard regarding controlled trials.⁵

Beginning with the formation of the United Nations (U.N.) in 1945, the principles of human rights have been codified in a series of international declarations and treaties. The U.N. Charter was followed by the International Bill of Human Rights (1948),⁶ the International Covenant on Civil and Political Rights (1966, revised 1994),⁷ the International Covenant on Economic, Social, and Cultural Rights (1966),⁸ the Convention on the Elimination of All Forms of Discrimination Against Women (1981),⁹ and the Convention on the Rights of the Child (1989).¹⁰

Human rights, as set out in these declarations, are primarily individual rights in relation to governments. The human rights framework insists that there are some things governments should not do, such as promote slavery or allow torture, and there are other things governments should do, such as protect freedom of expression and religion.¹¹ The goal of the human

rights movement is to ensure that people around the world survive and have the opportunity to achieve their full potential. Clean water, adequate nutrition, education, health care, and basic freedoms are prerequisites for individuals and communities to flourish. Health care providers and other health professionals should be involved in securing these benefits as rights.

The Universal Declaration of Human Rights (UDHR), adopted by the U.N. General Assembly shortly after the U.N. was formed, established a common standard to which all peoples and nations may aspire.¹² Article 25, the key section on health, states that everyone has the right to a standard of living adequate to the health and well being of himself and his family, including food, clothing, housing, medical care, and necessary social services. The adoption of the UDHR by forty-eight member states reflects the commitment of the international community to a minimal standard of health care for all people. Subsequent, related covenants and treaties underscore the responsibility of governments to provide the social, political, and economic circumstances in which people can flourish. This commitment is echoed in the World Health Organization's (WHO) constitution, which states "the enjoyment of the highest attainable standards of health is one of the fundamental rights of every human being."¹³ Both failing to provide adequate opportunities for health and directly preventing access to health care impede the enjoyment of the highest attainable health standard.

While failing to guarantee universal access to clinical care is the most obvious such defect, barriers to the enjoyment-of-health right more often operate subtly at a social level. Since people are vulnerable to disease through membership in society (for example, the common cold acquired from one's neighbor), health cannot always be achieved by modifying individual behavior. Those who occupy a lower rung of the social ladder face a magnified problem, being both more likely to fall ill and less able to seek help for it.¹⁴ By this token, creating and maintaining social and economic differences that prevent individuals from obtaining basic necessities also makes those people more prone to disease. Preventing people from achieving their healthiest potential denies them a human right. Such abuses of human rights, even though they may occur through the social organization structure and economic potential rather than overt punishment of individuals, demand that health care providers act to support the right to health.

Here, we are asserting that abuses of health rights can be overt, or subtly interwoven into economic structures. It is well established that the role and status of individuals in a society determines their health fate. The strongest predictor of health over the long run is neither heredity nor

individual behavior, but social status.¹⁵ For an examination of disease distribution (who becomes ill) and disease outcome (who most often dies or is disabled), the HIV/AIDS epidemic is revealing. In each country the epidemic initially affects specific groups, depending on how and where the virus enters that society. However, over time it concentrates among those parts of the population who hold the least power and who live on the edges of society.¹⁶

Fifteen to twenty years ago, the highest incidence rates of AIDS were seen in America's large coastal cities. For instance, in the first thirteen months of the AIDS epidemic (i.e., between June 1981 and July 1982), 48% of cases came from New York City (217 of 452).¹⁷ Today, the highest incidences are in the rural South. In 1999, 41% of U.S. AIDS cases were diagnosed in the South, compared to 29% in the Northeast, and even smaller proportions in other regions.¹⁸

The pattern of downward social mobility of epidemic disease is not new; other illnesses have followed a similar pattern. For example, tuberculosis, once the emblem of an elitist and delicate lifestyle in the West,¹⁹ is now almost exclusively a disease of the poor.²⁰ Asthma, an allergy-like condition to which innate susceptibility is probably universal, is now so common among the urban poor that it has become a *cause célèbre* to advocates for improved housing and health care in northeastern cities.²¹

Yet, advances in political and economic rights have not necessarily been accompanied by improvements in health. For instance, the collapse of an oppressive political apparatus in the former Soviet Union was followed by economic disruption and social chaos with major health consequences. Increases in crime and disparities in resources led to serious disease in overcrowded prisons, epidemics in many communities, and a decline in life expectancy. In some Asian countries (e.g., China and Vietnam), economic reforms and the opening of society to Western influence has increased drug abuse and commercial sex, and the diseases that travel with them. The Chinese remind us to consider the potential untoward consequences of beneficial innovations, saying that "it is good to open the window and let in fresh air, but flies may enter as well."

The human rights framework highlights the dynamic nature of the relationship between fundamental human rights and health. It provides language to describe the common experience of oppression among people around the world and facilitates communication across disciplines, including health care workers, politicians, lawyers, community activists, and others. The nature of the work they do requires that health professionals practice in relationship with others, either individuals or populations. Human rights abuses—including lack of resources—obstruct

professional practice in that they compromise these relationships through limiting the ability to provide care. The difference between care that is unaffordable or inaccessible, and care that is inadequate or intermittent, is no real difference at all. Health professionals who care for those on both sides of the divide—the impoverished and the privileged—are thus held hostage by such abuses.

While health professionals might be unable to change political systems or engrained economic structures in ways that grossly eliminate underlying disparities and impediments to health, their sense of professionalism or humanitarian responsibility moves them, and often leads them to feel obligated to take action against such abuses. It is in this way that the actions of individual professionals who provide health service or conduct research are linked to human rights.

II. SPECIFIC ISSUES

We begin our consideration of the link between human rights and health-research ethics by turning to specific issues. The following six themes arise often when patients and health care providers make decisions about research participation. Naturally, we are especially interested in the choices available when research is done in the context of health disparities and/or where complex motivations obscure definitions of right and wrong.

A. Medical Progress

The desire to acquire more information motivates virtually every clinical trial (along with all health research in general). Researchers and supporters of research hope that ways of improving health can be devised if better information is available. Clearly, the health care provider's desire to gain more knowledge that could help patients aligns with the researcher's motivation to advance medical science and contribute to progress.

But progress for whom? "Medical progress" is for the common good; it has no meaning at the individual level, and we should not pretend that it does. If a research protocol helps one person, but only one, to survive, it has benefited that person, even if it fails to further medical knowledge, and even if it fails to help large numbers of people. Will a research protocol that is beneficial to one or a small number of individuals be abandoned because it fails to rise to the "progress" standard?

Researchers, potential research participants, and health care providers must recognize the disjunction between contributing to collective progress and alleviating an individual's suffering. The researcher seeks to benefit

humankind, an abstract notion of good. The individual participant experiences direct effects of research participation, and finds empirically that his or her decision to participate was either good or bad. It is the health care provider who is most directly challenged by the disjunction between collective and individual benefit. Allied with the researcher by discipline and training, the health care provider values the abstract benefit of research, but at the same time is allied with the patient by predisposition and consent to offer services. Therefore, the provider must also attend to the individual effects of participating in the research. Which choice between the two is right is likely to be uncertain. Which choice supports caring is clearer.

A deeper problem emerges when there is a material disparity in resources between where the research is devised and funded, and where it is carried out. Progress is highly valued in the technology-heavy economies of the western industrialized nations; here, the potential for progress is an accepted rationale for running the risks of research. In the developing world, progress is different—more pressing wants, differing world views, and less dependence on technical advance give progress in the abstract a more equivocal valuation. The fact that progress arising from the fruits of medical research is more likely to benefit the people of the country that funds the research than those of the country where it is carried out magnifies the divergent weighing of “progress.” Researchers from wealthy nations cannot assume that medical progress is a good reason for any individual to participate in research, and even less so when the individual lives in a developing country.

B. Altruism

Linked to the multiple disparities that energize “medical progress” as an ethical problem is altruism. We suggest that altruism is largely constructed by researchers or research funders who seek to justify plans that are at best paternalistic.

The word altruism itself reveals the purely positivist roots of the concept. “Altruism” was introduced into English in the mid-1800s by the translators of Comte, who gave it its present meaning.²² To believe in altruism implies a belief that social good is measurable, and preferable to good for the individual. When researchers suggest that an individual will enroll in their study for what they term “altruistic reasons,” they are saying that while participating in research could be harmful to the individual, the study could be beneficial to people in general. The ethical choice has been made by the researchers. To them, it is a choice between abstractions. By deciding to go forward with research, however, they pile moral freight onto

the decision of prospective participants.

To the individuals who must decide to participate or not, the choice is different. The prospective participants must choose between choices. First, they have to decide at the level of their own comfort and security whether to enter the personally non-ideal state of research participation. Next, they must decide on the basis of their own beliefs whether to consider the potential benefit of the research to the community at large. The fact that the research has been approved by some recognized authority and is going forward—that is, that the decision has been made by the researchers—alters the valence of the prospective participant's decision-making. Being told that the research might benefit everyone, the prospective participant's decision to enter a study or not becomes a question of selfishness or selflessness. The individual's moral equipoise is lost. The situation is liable to become even further determined if the health care provider, particularly a trusted health care provider, endorses the research.

The term "altruism" is thus a tip-off to an ethical squeeze play. Health care providers who sign on with a research project change the weighting of the choices their patients are faced with. The researcher who proffers altruism as a legitimate reason for people to submit to the imperfect state of research participation ignores the dual-level nature of the actual decision to participate, and subtly injects a moral suasion into that decision. An individual's decision, especially if the research participation has been presented by the individual's own care provider, is complexly freighted, far from simple, and worthy of careful and not rule-bound attention.

C. Equipoise

Equipoise is the state of not knowing which of two claims is true. In the context of health research, equipoise refers to the investigator's honest ignorance as to which of two interventions is more beneficial. Many writers have emphasized the central importance of this state of not knowing in the ethics of health research. If one treatment regimen is clearly more effective than others, subjecting patients to the less-effective approach(es) violates the consensus standard expressed in the Helsinki Declaration—that everyone is entitled to the highest current standard of care. Only if the researcher is genuinely undecided about which approach is better is it justifiable to conduct a clinical trial. Benjamin Freedman rejected individual equipoise on the part of the investigator, the true absence of what he called "treatment preference," as an impediment to carrying out clinical trials. Charles Weijer and others have joined Freedman in advocating community equipoise as a hedge against disingenuous

contentions on the part of researchers that they were truly uncertain of whether there was a difference between treatments A and B. Not just the investigator, but the medical community, these authors claim, must be genuinely uncertain as to whether treatment A is preferable to treatment B, or the reverse.²³ Equipoise, by these claims, makes it permissible to expose some individuals to a new treatment that is (or later turns out to be) less effective than the best treatment.

Levine has argued that equipoise motivates research in two ways.²⁴ Not knowing which approach is better generates a need to find out. The research (with its attendant risks and discomforts) is therefore justifiable if it serves to relieve equipoise in a way that helps to decide which approach is better. If the results suggest that one treatment is better than others, equipoise is lost, and the researcher is obligated to stop the study even if the full protocol has not been completed. Today, standards for stopping are normally incorporated into clinical trial protocols, an acknowledgment of the necessary equipoise principle.

If equipoise is the principle on which ethical enrollment in clinical trials is based, then the point where equipoise vanishes is an ethical fulcrum. Clearly, the exact point at which evidence makes a new treatment look better than placebo can be different for one health care provider than for another. Clinical trials attempt to standardize that point, so that all health professionals will agree that it is not yet proven that treatment is preferable to placebo. The clinical trial thus obviates decision-making on the part of the individual health care provider and researcher and justifies its own continuation—or the inception of another trial. But appeals to the medical community to decide when treatment A is better than B invite the certainty of consensus, but do not necessarily produce truth (that would be true even if the nature of “community” in medicine were not so elusive). Codifying how to draw inferences from clinical trials does not entirely work. Part of the discomfort health care providers experience when enrolling patients into some clinical trials comes from their own sense that the placebo and treatment options are not really equivalent, no matter what the medical community says. The health care provider is again hostage.

Justifying research through consensus or community equipoise—as clinical trials invoke—lifts from the shoulders of both the researcher and health care provider the responsibility to decide whether they believe the study treatments to be equipoised. It also eliminates the prospective participant’s belief from the ethical equation. A more versatile approach would embrace the varied, and potentially conflicting, beliefs of all parties involved. But then equipoise could not be the sole motivation for research,

and relieving equipoise could not be the primary justification for entertaining its risks. Like medical progress, equipoise would have to be demoted from its major role in ethical decision-making if the ethics of health research were based on the complexities of caring for individuals acting individually.

D. Placebo Control

Results of a randomized, placebo-controlled trial are the *sine qua non* of evidence in an increasingly evidence bound, health science establishment. Investigators who seek to find a good prophylactic or treatment regimen are essentially required to mount a placebo-controlled trial. Even if researchers are concerned that patients given placebo are not receiving adequate care, they might find no alternative to the placebo-controlled trial. If the treatment's efficacy is to be believed and the treatment used so that people can be helped, some people—the participants who are randomized to the placebo arm—will have to receive no treatment at all. Of course, occasionally a treatment is harmful, and placebo recipients are the lucky ones. Still, the randomized, placebo-controlled trial often, albeit not always, stakes adequate care for some patients today against the hope of better care for many patients tomorrow.

That wager presents caring researchers everywhere with a dilemma. But health care providers in resource-poor regions must face this problem on a magnified scale. Where there is too little money to pay for treatment for all, the availability of a placebo-controlled research protocol moves health care providers to a Hobson's choice. They must decide between two situations that compromise care: Either no or inadequate treatment for all of their patients, or potentially effective treatment for some. Those who enter the trial and are randomized to the active-treatment arm will receive treatment that might be effective; those randomized to the placebo arm are certain to receive no treatment.

The World Medical Association chose to address the placebo dilemma directly in the recent revision of its statement on ethical principles for research involving human subjects. It stated unequivocally that new treatments must be tested against the best current treatment, not a placebo.²⁵ Placebo trials are to be undertaken only when there is no proven treatment. Although this seems straightforward, in many real world situations, the ethics of a placebo arm are not immediately obvious. As the case of HIV/AIDS drugs will show, conducting placebo-controlled trials of inexpensive regimens in poor nations when the effectiveness of more expensive regimens has been demonstrated is a Solomon's dilemma. If a trial goes forward, some people will not do as well as others, because some

will receive placebo. If no trial is carried out, nobody will be treated. Thus, no matter which choice is made, research perpetuates inequality in access to health. The morality of care and human rights would recognize that social injustice lies at the root of the dilemma, and then indicate that action to correct larger social disparities be linked to furthering research agendas.

E. Informed Consent

The right to informed consent established a new standard of justice in health research when it was agreed on as part of the Nuremberg Code. However, even informed consent cannot transform offering a treatment regimen that is less than optimally beneficial into good care. Getting people to agree to receive a lesser standard of care does not make offering inadequate care acceptable. In this light, informed consent assists the pursuit of justice in research, but it does not by itself guarantee that the obligations of caring have been discharged.

As practiced in the United States today, research participants have the right not only to be informed about the procedures entailed in research and their potential risks and benefits, but also the right to understand. The current interpretation of informed consent thus closes the gap between researchers' discharging their obligation to inform, and the patients' needs to know and understand what is going to happen—a divide that emerges readily when research procedures are described in technical jargon. By observing the informed-consent standard, justice is done in that all prospective subjects are equally aware and, therefore, equally able to choose.

But is that the only gap? The assertion that awareness creates choice seems problematic. Certainly, lack of awareness of possible risks and benefits diminishes the range of choices available to the subject. But full awareness, as the modern informed consent standard seeks to achieve, might still leave many choices unavailable—precluded by the patient's economic resources, class, sex, or race, or by a desire to please his or her family or health care provider.

Neither is the dilemma of the placebo alleviated by informed consent. That patients know, or are told, that they might receive placebo does satisfy an abstract concept of justice (e.g., that awareness creates choice), but it does not relieve the caring researcher's or the caring provider's burden of choosing between two unwanted situations. Consider the situation in which the person who normally provides care to a patient also acts as collaborator on a professional colleague's research project. As part of informed consent, the provider explains the research project to the

patient, offers all the information required under informed-consent guidelines, and asks for consent to participate. Should health care providers make clear to the patient their opinion about the wisdom of participating? If so, on what criteria should that be based?

The ethical conundrum is highlighted here: If health care providers discuss the choice about participation because of their concern for the patient's personal situation, must the providers acknowledge their own interest in the research project's success—even though that acknowledgment reveals that they are not interested solely in the patient's welfare? If the providers do not discuss their own role, are they offering the patient full enough disclosure about the situation, and in particular about how their own alliance with the researchers might alter their presumed alliance with the patient for whom they care? Informed consent elicits an ethical challenge about care, even as it resolves one about justice.

F. Medical Care for Research Participants

Marcia Angell asserts that when investigators enroll subjects in clinical trials, they assume a responsibility analogous to that of clinicians.²⁶ Are investigators, therefore, responsible for elevating the health status of participants in their studies, or are they entitled to leave unimproved the poor health standing of a population so long as the investigation meets the standard test of "doing no harm?" The revised Helsinki Declaration addresses a portion of this problem, recommending only the best proven therapy as the standard against which new treatments must be tested. But the Declaration also states that at the conclusion of the study, all subjects should be provided access to the best treatment demonstrated by the study.²⁷

Some researchers contend that the gulf between rich countries and poor ones sanctions different standards of care on its two sides, and therefore what would be unacceptable study designs in the United States are appropriate in Africa or Asia. The power of this argument lies in its appeal to practicality and compassion. Its unarticulated assumption is that the economic gap is inevitable. However, the capacity of wealthy nations to ignore moral accounts that emphasize their own responsibility to alleviate suffering helps to generate and maintain that gap. While wealth might be produced in developed nations without impoverishing the less developed world, the burden of ensuring that the poor are well cared for is a costly one. Rich countries shoulder it only up to a point.

One way to elide their own moral complicity in perpetuating the economic gap is for policy makers in developed countries to pretend that the issue is an abstract one, resolvable by attending to standards of practice

or a disingenuous appeal for medical compassion. The responsibility to care enjoins us to provide the best possible health services and the best proven therapy. Indeed, to withdraw health care because of concerns about research ethics might prove even more invidious to the health rights of developed countries than to go forward with questionable research. Still, a full realization of the morality of care would dictate action to improve the material context, so that consent will not be coerced by social circumstance.

III. CURRENT PARADIGMS

How the individual health worker should act to preserve human rights and invigorate the quest for expanding human rights is the crux of health ethics. Most modern Western ethical systems are based on universal concepts of justice and equality. A significant alternative approach, explicated only in recent years, is based on caring and attentiveness to the complexity of human interrelationships. The two paradigms often lead to identical or similar ethical decisions, and the boundaries between them are controversial.²⁸ We begin by summarizing them separately.

A. Morality of Rights

The various codes governing biomedical ethics today are grounded in liberal theories of justice, human rights, and contract theory. Levine's discussion of the basis of medical ethical codes in deontological (duty-based) and utilitarian (pleasure-based or utility-based) theories brings out the dialectical relation between them. We see these codes as revealing also a melding of Kantian rationalism with the democratic liberalism introduced by John Rawls.²⁹

Kant's categorical imperative offered the foundation for abstract morality.³⁰ It assumes that all humans have access to reason (even if we do not always use it). "True" moral principles therefore emerge as universal and could be derived not from perception, which might be shifting or faulty, but through the ubiquitous faculty of reasoning. Kantian moralism is necessarily abstract, since it rejects practice as grounds for moral decision-making. It also assumes that correct moral principles are impartial, because only impartial tenets can apply universally. Finally, because it requires that moral narratives be "read" through reason, it assumes that what is moral is correct or right. We see Kantian moralism in health care in the injunction to "do no harm." More tendentiously, we see it in the controversial contention that what is the highest standard of care for the wealthy ought also be the standard of care for the poor. Here,

justice and care can agree.

Rights-based morality draws also on the utilitarian underpinnings of Western liberalism. Utilitarian values offer a slightly different valence to moral decision-making. Jeremy Bentham and his follower, John Stuart Mill, distanced themselves from Kant, centering ethical decision-making on the principle of pleasure (Bentham) or happiness (Mill).³¹ Bentham's "felicific calculus" sought to maximize *good*, rejecting the existence of any consistent natural law that could give rise to moral *right*. Utilitarian thought can accept moral accounts on a case-by-case basis. For instance, in modern liberal decision-making, an action such as killing might be sanctioned in one set of circumstances (e.g., war against fascism) and proscribed in another (e.g., genocide). Both choices about killing are moral, because in each case the decision helped to maximize good.

In this sense, utilitarian morality moves away from the categorical nature of Kantian morality. But while utilitarianism changes the principle on which the moral code is based from truth to happiness, it shares some ideas with Kant's morality. Moral behavior is still guided by "do" and "don't." Even a resolution of an ethical dilemma that is situation specific will be based on an appeal to the abstract—good or happiness. The moral code is impartial, in the sense that the identity of the individual(s) helped by the decision is irrelevant.

In current health care ethics, we see utilitarian moralism at play in the debate about managed care, whether through private or socialized insurance. Management of health care costs allows for more efficient cost sharing and therefore minimizes payments overall. By making care provision less subject to patients' characteristics like knowledge or affluence, it provides the "happiness," or increase in community well being, of expanding the availability of adequate care. Utilitarian views also offer a justification for the State to detain and forcibly treat disease sufferers whose failure to comply with prescribed therapies makes them a threat to others. For instance, New York City has, at times, maintained locked isolation facilities at one or more municipal hospitals for the custody and treatment of tuberculosis patients who remain infectious because they failed to take anti-tuberculosis chemotherapy. While liberal justice would normally reject the incarceration of individuals who are guilty of no crime, the courts have supported detention of infectious tubercular people on the basis of protecting the public's health.

The last major influence on rights-based morality comes from democratized or populist pragmatism.³² Rawls' theory of "reflective equilibrium"³³ and agreed-upon principles of justice, and the explicit contract approach that emerges from it,³⁴ guide important aspects of ethics

that are evident in codes like the Helsinki Declaration. The indispensability of informed consent reflects contract theory: It honors a subjective decision by the participant, forged in agreement with a researcher, to seek mutually what each wants individually.

Thus, the morality-of-rights approach is based on principles that at any one time could include some of the following: impartiality, equality, beneficence, and individual autonomy. These principles lead to rules that we see in the articles of the several codes of conduct (e.g., Helsinki). They seek to uphold specific attributes of *care* for people. The conjunction of care and rights here is notable. However, it remains abstract, as we discuss below.

Some of the attributes of rights-based ethics are privacy,³⁵ the right to information,³⁶ disclosure,³⁷ risk communication,³⁸ and avoidance of harm.³⁹ Privacy, associated with deontological morals, is also a tenet of contract theory. Individuals are assumed capable of reason and judicious choice, at least on their own behalf. Privacy gives rise to the right of confidentiality, particularly in American health ethics. Here, rights are abstract: Privacy and confidentiality support equality, and thus liberal justice, but they have no obvious link to care.

The right to information comes directly from a Rawlsian view of justice: People must know what is wrong with them and what might happen to them if they are to be able to seek freely just solutions to the problems of ill health and unequally distributed resources. The information right links with the privacy right to create an uneasy equality, or at least a leveling of the playing field. And it implies that holders of information must share it. For the individual that obligation generates a right of disclosure; for the group, it generates a right to know what its risks are.

The avoidance of harm is the old Hippocratic principle, embraced by both categorical and utilitarian models (reducing harm is a virtue in itself, and it is a measure of the optimization of good or happiness). In contract approaches to justice, avoiding harm can be an index of the success of liberalization, the quality of the dissemination of rights.⁴⁰ It is the most implicit element of the philosophies underlying rights and, as we discuss below, an explicit aspect of care-based ethics. Avoidance of harm provides an important interface between the abstract ethics of rights and the empirical ethics of care.

Indeed, the principles developed through philosophies of moral imperatives are abundantly evident to caregivers, either as intuited truths or received wisdom, or through training and practice. All of the privacy and information rights are tenets of caring. Often enough, practitioners derive these principles unconsciously, through the conscious practice of

care. The distinction, we argue, lies in whether these tenets remain principles for judgment or assessment only, or move the practitioner or researcher to act. Careful health care practitioners are aware of their need to balance patients' needs for privacy and confidentiality with a right to know about threats or risks. They also seek to avoid harm to the patient as it presents itself in a given clinical situation. And they reinforce the positioning of the patient in an idiosyncratic social support system, as well as in the larger society. We will return to this distinction after reviewing the basics of a morality of care.

B. Morality of Care

The choices offered by, and decisions made from, a justice-based rights paradigm too often fail to answer the real-world concerns of individuals and populations who are the vulnerable subjects of health research. In contrast, in 1982, Carol Gilligan initially described an ethic of responsibility and care expressed by young women, which looks closely at context, including networks of relationships and power as a guide to the moral path.⁴¹ The consequences of decisions are considered, along with whether the decisions are right and just. For example, a woman debating an abortion might consider not only her personal beliefs about when life begins, but also the impact of her decision on others to whom she feels responsibilities.

Among the health professions, nursing has evidenced a particular interest in the development of an ethic of care.⁴² Because the practice of nursing in its purest form is essentially the act of caring for another human being, it is not surprising that nurse-philosophers find an ethic of care attractive. Nursing is largely a profession of women; and the fact that discussions of caring have been strongly influenced by the feminist perspective of its first theorists, Carol Gilligan and Nell Noddings,⁴³ is almost certainly responsible for some of its appeal to the profession.

There has been less formal discussion of the principles underlying an ethic of care in medicine. However, at least one philosopher-physician, Edmund Pellegrino, writes eloquently about the physician's duty to care for the patient by feeling compassion, doing for them what they cannot do for themselves, accepting responsibility, and acting competently.⁴⁴

Some writers have proposed that there is no real distinction between an ethics of justice and an ethics of care. They hold that justice is based on caring, albeit implicitly, and argue that differentiating morality as based on either rights or caring is a response to a political calculus that has to do with class, sex, and sometimes race.⁴⁵ We agree that caring underlies justice, and that rights may be derived through the practice of care as

readily as they can be received as principles enunciated in response to a philosophical view of virtue or justice. But, we emphasize a distinction between ethics based on abstract principles of right and ethics arising from a caring willingness to adjust practice to the demands placed by real situations and social structures on individuals. We argue that this distinction is important in recognizing where existing codes of medical ethics are too rigid or insensitive, and pointing the way toward a more responsive and satisfying approach.

IV. CASE STUDY: HIV/AIDS RESEARCH IN THE DEVELOPING WORLD

In 1997 discord erupted in the pages of the venerable *New England Journal of Medicine* when physicians conducting clinical trials in Africa and Asia to investigate the efficacy of strategies to reduce maternal-fetal transmission of HIV were accused of unethically exploiting the desperation of poor countries hit hard by the HIV/AIDS epidemic.⁴⁶ The charge was that the trials of simple and inexpensive anti-retroviral regimens, which included placebo arms, would have been unacceptable in the sponsoring countries. Results of an earlier study conducted in the United States and France documented the effectiveness of a more complicated and expensive regimen in reducing maternal-fetal HIV transmission.⁴⁷ The AIDS Clinical Trials Group (ACTG) protocol 076 study demonstrated that zidovudine (AZT), administered for six months during pregnancy, intrapartum, and to the newborn, reduced the probability of transmission of HIV from mother to infant. That expensive regimen quickly became the standard of care for HIV-infected pregnant women in the sponsoring countries, but was deemed impractical for the developing world.

Studies in Africa and Asia sought a shorter, cheaper prophylactic regimen, by testing possible substitutes for the ACTG-076 regimen against placebo. These studies were sponsored by a number of U.S. institutions, including academic institutions and the National Institutes of Health (NIH),⁴⁸ in collaboration with foreign researchers. Concerns emerged about the acceptability of placebo use—given that six months of AZT therapy had already been shown to be efficacious, equipoise was obviously unattainable. Investigators countered, arguing that the ACTG regimen was neither affordable nor practicable in the developing world so that testing shorter, less expensive regimens against placebo was still acceptable.

Controversy ensued. A month later, a letter from the then-heads of the U.S. Centers for Disease Control and Prevention (CDC) and the NIH called for HIV/AIDS research to be developed in concert with local authorities, acknowledging that differences in resources created differing needs.⁴⁹ In February 1998, four agencies responsible for overseeing

placebo-controlled trials of HIV/AIDS therapies in developing countries issued a joint statement asking that placebo use be halted in such trials. The CDC, NIH, Joint United Nations Programme on AIDS (UNAIDS), and the Agence Nationale de Recherche sur la SIDA stopped short of outright embargo on placebo-controlled trials, but their statement changed the debate.

In April 1998, the *American Journal of Public Health* published six articles relating to this issue.⁵⁰ Two editorials specifically addressed the ethics question. Mervyn Susser, then editor-in-chief, argued in favor of placebo-controlled trials in order to generate the information needed to produce treatment regimens affordable in the developing world.⁵¹ Ruth Faden and Nancy Kass were more equivocal.⁵² They sought to hold researchers to a high standard of justice, placing the burden of proof on investigators to show why clinical research should be conducted in a population that normally cannot avail itself of the very therapy under study. They rejected cultural relativism in research, but did ask how constraints on spending affect the ethics of research. Faden and Kass thus left open the question of whether it is the role of researchers to redress the impact of deprivation on their subjects.

Heated discussion of these issues continued in professional meetings and journals, expanding into a debate regarding the ethical obligations of researchers to care for the human subjects who participate in their trials. A subsequent study of HIV transmission between heterosexual partners in Uganda⁵³ elicited new questions about the ethics of research practice and underscored the unsettled nature of the debate.⁵⁴ The Uganda study randomly assigned residents of rural villages to receive specially provided care for sexually transmissible infections or usual care; the latter meant referral to government clinics. In addition, no anti retroviral therapy was offered to the several hundred HIV-infected subjects.

One of the outcomes of interest in the Uganda study was new HIV incidence in sex partners of already HIV-positive participants. Anti-retroviral therapy might have reduced the potential for HIV transmission, which would have biased this important study endpoint. The investigators were thus able to reach unbiased conclusions about HIV transmission because "antiretroviral drugs are not available in rural Uganda. Consequently, the HIV-1 RNA levels were not influenced by the use of anti-retroviral drugs."⁵⁵ In an editorial response, Angell looked not simply at the scientific benefit of avoiding bias, but also at the human downside. She asked whether it is sufficient for health researchers merely to do no harm, or if a higher standard is in order. She wondered whether investigators from resource-rich countries like the United States ought not be held

responsible for elevating the compromised health condition of the participants in their studies.⁵⁶

Much of the discussion about HIV/AIDS clinical trials turned on the just distribution of the risks and benefits of research among investigators, sponsors, research participants, and non-participants. In this case, such benefits included: the provision of adequate antenatal zidovudine to minimize the vertical transmission of HIV; the offering of better AIDS treatment than prevailing local standards (frequently the local standard is no treatment); the finding of information that is useful for HIV prevention or improved AIDS clinical care; and the attracting of research dollars that can generate employment or bring needed goods into resource-poor countries.

In order to address the problem of just distribution of risks and benefits of research, the assessment of risks in this case must acknowledge that real disease risk, a prediction about likeliness, is embedded in a matrix of broad concerns. A developing country is imperiled by endorsing research, largely in the form of possible financial costs or disruption of existing social and administrative structures. More serious risks are potential human rights violations that are identified but fail to be resolved. The poorer health of citizens in developing countries might become more obvious in the context of Western-sponsored and sometimes hi-tech research; certainly, the inadequacy of health care systems that must run on shoestring budgets becomes both apparent and visible to the world at large once Western research installations illustrate the disparities involved.

Ethical doubt about the HIV/AIDS research in developing countries that these problems generated was exacerbated by questions as to the investigators' equipoise and the adequacy of informed consent. In this case, equipoise, supposedly an indispensable principle of rights-based research ethics, proved to be flexible and open to redefinition once a national border had been crossed. Ratification of the research by local authorities ostensibly operating in citizens' best interest, but with opportunity to reap political or economic gain by cooperating with wealthy countries, clouded the ethical picture from a standpoint of informed consent. Informed consent was revealed in this case to be a protection wholly dependent on a subject's ability to recognize options. It was readily coerced by the wishes of the holders of financial power in resource-scarce situations. In sum, the ethical perspective of rights was confounded by the substantial differences in financial resources between the countries sponsoring the research and those serving as their venue.

We contend that any assertions of altruism in these developing-country studies should have withered in the light of their upshot: The rights of

study subjects to the “highest attainable standard of health,” as the WHO constitution avers, were denied. Whether this abrogation of human rights was the fault of feckless funders, self-interested investigators, venal national leadership, or simply a presumptively inert global economic divide became the issue—not the protection of human rights themselves. The rights-based ethical codes failed, and the particular principles those codes motivate, like informed consent and equipoise, were exposed as both inadequate and easily co-opted.

We suggest that the intensity and persistence of controversy over this research bespeaks a fundamental deficiency of the standard ethics-of-rights framework. If the most effective treatment is not available in a country, is research to find one that can be made available—even if it is clearly less effective than the best—permissible? Obviously, once a clinical trial demonstrated the efficacy of an anti-retroviral regimen in reducing perinatal HIV transmission, albeit an expensive regimen, there is no equipoise between placebo and any version of that regimen. Arguments alleging that it is truly not known whether less expensive, abbreviated regimens would be preferable to no treatment at all are disingenuous. Peter Lurie and Sydney Wolfe have advocated equivalency trials, rather than placebo-controlled trials, of HIV/AIDS medications in developing countries.⁵⁷ Their argument highlights a potential opt-out to the Helsinki Declaration requirement that subjects receive the best proven therapy. Equipoise is no guide, then, even under Helsinki. Ethical decision-making in this situation has to be more broadly based than reliance on equipoise alone will allow.

An ethics grounded in the morality of rights can be made more appropriate for the rapidly emerging global health community and better able to safeguard human rights by tempering it with an ethics based on responsibility and care. Ethical guidance to researchers and practitioners in these situations should have recognized the disparities in resources, access to health care services, and expectations about health and longevity encountered in international research. But, it should also go beyond that, to acknowledge those disparities’ consequences as well. The impact of researchers’ interventions should be shown explicitly to accord with those of health care providers: To begin by doing no harm, proceed to ensure that harm is not done to patients/subjects inadvertently or incidentally, seek to satisfy individuals’ needs, and only then aim to benefit humankind. Specifically, before research begins in a developing country, an ethics of care would ask researchers to assess the ways in which subjects in that country are presently denied access to the human right of adequate health. This approach would highlight and support professionalism and articulate

the alliance of health care with health research.

While a truly care-based model resists codification, we suggest that two key outcomes of the explicit linkage of research with care would emerge. First, an additional ethical standard would be posited: How does the proposed research seek to address inequities, eliminate the identified disparities, or otherwise respond to the absence of adequate health? An investigation in the mid-1990s that compared two different approaches to preventing mother-to-fetus HIV transmission with one as effective as that demonstrated in the ACTG-076 would meet this test. Similarly, a study of sexually transmitted diseases (STDs) and HIV transmission in Uganda that offered anti-retroviral therapy and one of two different forms of STD treatment would meet the test. Research comparing an alternative regimen for interruption of vertical HIV transmission to placebo would fail this test, as would the Quinn protocol that studied HIV transmission rates in the absence of anti-retroviral therapy. We note that both of the hypothetical investigations that would meet the proposed ethical standard would do so even if the investigations were carried out in the United States.

Secondly, at the level of individual researchers, sound ethics would require care. Specifically, investigators would consider not merely each prospective subject's consent to participate as a test criterion for ethical enrollment. Rather, they would assess whether participating in the planned study would alleviate or exacerbate health problems for each prospective subject. They would evaluate this question in light of each participant's social and economic situation. For the subjects in the poorest countries, this test would mean attending to possibly multiple and complex problems involving family and social groups (e.g., waterborne parasites, malaria, food or water scarcity, and infant diarrhea, in addition to HIV). When competing potential benefits emerged, the researcher would seek a path that generated the broadest benefit (e.g., for the family as well as the patient) or minimized potential harm or loss. The assessment would therefore be different for a head of household or family breadwinner than for a child, different for a person who is ill than for a healthy one, and different for men or women who have regular jobs than for the unemployed. The researcher would consider the potential toxicity of chemotherapeutic regimens, logistical difficulties of reaching study or treatment clinics, and the social hardships arising from the possible loss of a family member if treatment is ineffective. While the hands-on practice of delivering care might be left to professional care providers, researchers would be enjoined to make decisions that are based in the practice of care.

V. PROPOSAL

We propose that the question of what constitutes care and harm must be central to the research process. Caring, and attention to the multi-tiered complexities of upholding the human right of each individual to receive care, can serve as the foundation for clinical-research ethics that avoid harm. Technical and administrative fixes to ethical problems, like novel study designs or better oversight by international agencies, are aimed at resolving the distribution-of-justice problem, but they fail to address the fundamental question about preserving individual rights and offering good individual care. Solutions distributing risks and rewards among groups, the utilitarian moral path, fail to alleviate harm and fall short of guaranteeing the best care. Rather than distributive justice, research ethics should be guided by individual responsibility and care.

An ethical framework based on responsibility and caring is practicable for researchers and clinicians. In contrast to the difficulty most individuals experience in trying to elucidate abstract justice, both researchers and clinicians usually can discern a scale of harm to individuals either arising from a given action or pre-existing. Their professionalism lies in their ability to gauge harms accurately and assess how their own actions in a particular situation will reduce harms. Thus, standards for research ethics can take the form of supporting professional decision-making in assessing potential harms within observable relationships among those who stand to lose or gain. Ethical choice can be based on minimizing observable harms and ensuring that those who need care receive it.

Such a basis for ethics in research means that manifold health disparities might have to be redressed before research can be done. The search for a single, just standard of clinical and/or research practice will inevitably be compromised by the social and economic reality of global disparities in health status, access, and resources. Recognizing that justice will be compromised by any solution in the current context, the morality of care and human rights compels social action by health care providers. The response to Angell's question about the researchers' responsibility for the economic distress of the place where they are conducting research is answerable: Resolving disparity cannot be separated from the conduct of ethical research.

What we are proposing amounts to a reconfiguration of the debate around research ethics. We believe that the aims of health care and public health are served by organizing the discussion of international justice in research around the principle of caring and the avoidance of harm. This discussion, which should involve both investigators and health care

providers, will be of more general applicability than to the HIV/AIDS field alone.

Most painful moral problems are not simple choices between competing rights, but complex situations of conflicting responsibilities. Resolution requires an approach that is contextual and narrative, rather than formal and abstract. Morality of care tempers the rules of rights and justice, including those of human rights. It moves the researcher into alliance with the health care provider and places both in the shoes of the knowing caregiver: charging them with responsibility for the welfare of real individuals, asking them to act professionally within observable interpersonal relationships and in the context of real social forces, and seeking to reduce harms.

References

1. DHHS regulations require institutional review board oversight and establish procedures for their operation. 45 CFR 46 (revised Mar. 8, 1983). The Nuremberg Code declares voluntary consent of subjects of medical research to be "absolutely essential" and requires that risk involved in participation be proportional to the problem the research seeks to redress. 2 TRIALS OF WAR CRIMINALS BEFORE THE NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NUMBER 181-82 (1949) [hereinafter TRIALS OF WAR CRIMINALS]. The Helsinki Declaration codifies Nuremberg principles and elaborates cautions to be observed by researchers. WORLD MEDICAL ASSOCIATION, DECLARATION OF HELSINKI (adopted 1964, revised 2000), *available at* http://www.wma.net/e/policy/17-c_e.html. The Guidelines for Ethical Review of Epidemiological Studies call for informed consent and minimization of harm, and set forth standards for conflict of interest. COUNCIL FOR INTERNATIONAL ORGANIZATIONS OF MEDICAL SCIENCES, GUIDELINES FOR ETHICAL REVIEW OF EPIDEMIOLOGICAL STUDIES (1991).

2. TRIALS OF WAR CRIMINALS, *supra* note 1.

3. ROBERT J. LEVINE, ETHICS AND REGULATION OF CLINICAL RESEARCH 68 (1986).

4. WORLD MEDICAL ASSOCIATION, *supra* note 1, at item B 12.

5. "The benefits, risks, burdens and effectiveness of a new method should be tested against those of the *best current* prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of

placebo, or no treatment, in studies where no proven prophylactic, diagnostic or therapeutic method exists." *Id.* at item C 29 (emphasis added).

6. Universal Declaration of Human Rights, G.A. res. 217A (III), U.N. Doc A/810 at 71 (1948), *available at* <http://www.un.org/Overview/rights.html>.

7. U.N. G.A., International Covenant on Civil and Political Rights (June 15, 1994), *available at* http://www.unhchr.ch/html/menu3/b/a_ccpr.htm.

8. U.N. G.A., International Covenant on Economic, Social, and Cultural Rights (Dec. 16, 1966), *available at* http://www.unhchr.ch/html/menu3/b/a_ceschr.htm.

9. U.N. G.A., Convention on the Elimination of All Forms of Discrimination Against Women (Sept. 3, 1981), *available at* <http://www.un.org/womenwatch/daw/cedaw/>.

10. Not all United Nations member nations are signatories to this and the above agreements. As of April 1, 1998, 191 countries had either signed the Convention or become State Parties to it by ratification or accession. The United States has not signed the Covenant on Economic, Social, and Cultural Rights. George J. Annas, *Human Rights and Health—The Universal Declaration of Human Rights at 50*, 339 NEW ENG. J. MED. 1778, 1779 (1998).

11. *Id.* at 1778.

12. U.N. G.A., Universal Declaration of Human Rights, resolution 217 A (III), art. 25 para. 1 (1948), *available at* <http://www.un.org/Overview/rights.html>.

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26. See Marcia Angell, *Investigators' Responsibilities for Human Subjects in Developing Countries*, 342 NEW ENG. J. MED. 967 (2000).

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28. E.g., JOAN C. TRONTO, *MORAL BOUNDARIES: A POLITICAL ARGUMENT FOR AN ETHIC OF CARE* 6-11 (1993). Tronto recognizes that political context problematizes morality. She discerns at least three apparent "boundaries" to morality that are induced by the framing of moral judgment within social or political contexts: a false consciousness of a distinction between political acts and individual (thus, moral) acts; a false distance that arises from the presupposition that moral accounts must be disinterested; and a false dichotomy between public and private. She argues that care is not distinct from justice, because morality is not so readily constrained as these factitious boundaries imply. See also Robert Taylor, *The Ethic of Care Versus the Ethic of Justice: An Economic Analysis*, 27 J.

SOCIOECONOMICS 479, 479-81 (1998) (offering an economic analysis of the ethic of care and the ethic of justice).

29. JOHN RAWLS, *A THEORY OF JUSTICE* (1971).

30. IMMANUEL KANT, *CRITIQUE OF PRACTICAL REASON* 52-57 (Mary Gregor ed. & trans., Cambridge Univ. Press 1997) (1788) (providing the central discussion). See also HENRY E. ALLISON, *IDEALISM AND FREEDOM: ESSAYS ON KANT'S THEORETICAL AND PRACTICAL PHILOSOPHY* 146 (1996) (considering the categorical imperative); J.B. Schneewind, *Autonomy, Obligation, and Virtue: An Overview of Kant's Moral Philosophy*, in *THE CAMBRIDGE COMPANION TO KANT* 309-41, (Paul Guyer ed., 1992) (discussing the contingency of moral law on the pre-existence of good (and evil)); ALLEN W. WOOD, *KANT'S ETHICAL THOUGHT* 5-8, 26-30, 42-43 (1990) (discussing the valuation of good will and virtue).

31. FRED R. BERGER, *HAPPINESS, JUSTICE, AND FREEDOM: THE MORAL AND POLITICAL PHILOSOPHY OF JOHN STUART MILL* (1984). The distinction of Mills' views from Bentham's is discussed at page 12; proofs of the happiness principle are taken up at pages 30-63.

32. *THE OXFORD COMPANION TO PHILOSOPHY* 712 (Ted Honderich ed., 1995).

33. RAWLS, *supra* note 29. His introduction of the concept of reflective equilibrium offers a profound departure from categorical approaches, without requiring that the moral guidance afforded by the equilibrium depart from that of duty.

34. See, e.g., DAVID P. GAUTHIER, *MORALS BY AGREEMENT* (1986) (especially Chapter 5). Gauthier seeks to produce a form for finding justice when there is no self-evident or mutually acceptable reason

to be just.

35. E.g., Manning Feinleib, *The Epidemiologist's Responsibilities to Study Participants*, 44 J. CLINICAL EPIDEMIOLOGY 73S-79S (1991); Leon Gordis & Ellen Gold, *Privacy, Confidentiality, and the Use of Medical Records in Research*, 207 SCI. 153, 153 (1980). These authors review the responsibilities of clinical epidemiologists to protect the privacy of medical records.

36. Marjorie M. Schultz, *Legal and Ethical Considerations in Securing Consent to Epidemiologic Research in the United States*, in *ETHICS & EPIDEMIOLOGY* 97-127 (Steven S. Coughlin & Tom L. Beauchamp eds., 1996).

37. E.g., J. Higginson & F. Chu, *Ethical Considerations and Responsibilities in Communicating Health Risk Information*, 44 J. CLINICAL EPIDEMIOLOGY 51S-56S (1991); Paul A. Schulte & Mitchell Singal, *Ethical Issues in the Interaction with Subjects and Disclosure of Results*, in *ETHICS & EPIDEMIOLOGY*, *supra* note 36, at 178-96. These authors are concerned with risk communication and the ethical conundrums involved when information might not be welcomed or treatment not available.

38. U.S. DEP'T OF HEALTH & HUMAN SERVS., *HIV PARTNER COUNSELING AND REFERRAL SERVICES: GUIDANCE* (1998).

39. See Angell, *supra* note 26; World Medical Assembly, *Declaration of Helsinki IV*, in *THE NAZI DOCTORS AND THE NUREMBERG CODE: HUMAN RIGHTS IN HUMAN EXPERIMENTATION* 339 (George J. Annas & Michael A. Grodin eds., 1992).

40. We note that the "harm reduction" movement in the HIV/AIDS field, which particularly seeks to amend policies that prevent drug addicts from having sterile injection equipment, justifies itself on explicitly moral grounds. Denying access to

clean syringes is not merely unwise from a disease-control standpoint, but wrong, the movement argues.

41. CAROL GILLIGAN, IN A DIFFERENT VOICE: PSYCHOLOGICAL THEORY AND DEVELOPMENT 160 (1982).

42. Sara T. Fry, *Toward a Theory of Nursing Ethics*, 11 ADVANCES NURSING SCI. 9, 9-21 (1989); Sara T. Fry, Aileen R. Killen & Ellen M. Robinson, *Care-Based Reasoning, Caring, and the Ethic of Care: A Need for Clarity*, 7 J. CLINICAL ETHICS 41, 41 (1996).

43. NEL NODDINGS, CARING: A FEMININE APPROACH TO ETHICS AND MORAL EDUCATION (1984).

44. Edmund D. Pellegrino, *The Caring Ethic, The Relationship of Physician to Patient*, in CARING, CURING, COPING: NURSE, PHYSICIAN, PATIENT RELATIONSHIPS 8-30 (Anne H. Bishop & John R. Scudder eds., 1985).

45. See, e.g., TRONTO, *supra* note 28; Margaret Moore, *The Ethics of Care and Justice*, 20 WOMEN & POL. 1 (1999).

46. Marcia Angell, *The Ethics of Clinical Research in the Third World*, 337 NEW ENG. J. MED. 847 (1997); Peter Lurie & Sydney M. Wolfe, *Unethical Trials of Interventions To Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries*, 337 NEW ENG. J. MED. 853 (1997).

47. Edward M. Connor et al., *Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment*, 331 NEW ENG. J. MED. 1173 (1994).

48. Lurie & Wolfe, *supra* note 46.

49. Harold Varmus & David Satcher, *Ethical Complexities of Conducting Research in Developing Countries*, 337 NEW ENG. J. MED. 1003 (1997).

50. George J. Annas & Michael A. Grodin, *Human Rights and Maternal-Fetal HIV Transmission Prevention Trials in Africa*,

88 AM. J. PUB. HEALTH 560 (1998); Ronald Bayer, *The Debate Over Maternal-Fetal HIV Transmission Prevention Trials in Africa, Asia, and the Caribbean: Racist Exploitation or Exploitation of Racism*, 88 AM. J. PUB. HEALTH 567 (1998); Quarraisha Abdool Karim et al., *Informed Consent for HIV Testing in a South African Hospital: Is It Truly Informed and Truly Voluntary?*, 88 AM. J. PUB. HEALTH 637 (1998); Salim S. Abdool Karim, *Placebo Controls in HIV Perinatal Transmission Trials: A South African's Viewpoint*, 88 AM. J. PUB. HEALTH 564 (1998); Knut M. Wittkowski, Ezra Susser & Klaus Dietz, *The Protective Effect of Condoms and Nonoxynol-9 Against HIV Infection*, 88 AM. J. PUB. HEALTH 590 (1998); Isabelle de Zoysa, Christopher J. Elias & Margaret E. Bentley, *Ethical Challenges in Efficacy Trials of Vaginal Microbicides for HIV Prevention*, 88 AM. J. PUB. HEALTH 571 (1998).

51. Mervyn Susser, Editor's Note, *The Prevention of Perinatal HIV Transmission in the Less-Developed World*, 88 AM. J. PUB. HEALTH 547 (1998).

52. Ruth Faden & Nancy Kass, Editorial, *HIV Research, Ethics, and the Developing World*, 88 AM. J. PUB. HEALTH 548 (1998).

53. Thomas C. Quinn et al., *Viral Load and Heterosexual Transmission of Human Immunodeficiency Virus Type 1*, 342 NEW ENG. J. MED. 921 (2000).

54. Angell, *supra* note 46.

55. Quinn et al., *supra* note 53, at 922.

56. Angell, *supra* note 46.

57. See Lurie & Wolfe, *supra* note 46, at 855.

Last Chance Therapies: Can a Just and Caring Society Do Health Care Rationing When Life Itself Is at Stake?

Leonard M. Fleck, Ph.D.*

What does it mean to be a just and caring society (or a just and caring hospital or managed care plan) when we have only limited resources to meet virtually unlimited health care needs, and the need before us now is a person faced with death in the near future unless she or he has access to a very expensive medical intervention that offers only a relatively small chance of a relatively small gain in life expectancy? Such medical interventions are what Norman Daniels and James Sabin refer to as “last chance therapies” because patients who need them have no other medical options to forestall death in the foreseeable future.¹ It is difficult to imagine a more psychologically and morally burdensome decision than whether to offer a last chance therapy.

This Article attempts to determine how such last chance therapy rationing decisions should be made within the broad structure of the U.S. health care system—a very fragmented, public-private system for financing health care that is dominated by a variety of managed care options intended to control health care costs more effectively than the indemnity insurance system.² The focus of this Article can be interpreted in two ways: First, what moral norms should be used in making these last chance rationing decisions? Given all of the health care needs that exist in our society, and given limited resources to meet those needs (limits ultimately determined by taxpayers or members of a managed care plan), what priority should access to various last chance therapies have relative to all other health needs that make presumptively just claims on health resources? Second, what should be the political-philosophical framework of managed care plans responsible for making these last chance rationing decisions? That is, would we be more likely to get morally defensible last chance rationing decisions if the political philosophy that shaped the functioning of our managed care plan were libertarian, communitarian (Ezekiel Emanuel’s vision³), or liberal (in the Rawlsian sense)?

* Leonard M. Fleck is Professor of Philosophy and Medical Ethics in the Philosophy Department and Center for Ethics and Humanities in the Life Sciences at Michigan State University.

I will argue that limited solidarity and limited community (the “caring” part of the “Just Caring” problem) can be adequately protected under a liberal conception of health care justice, and such a limited notion is sufficient to protect these values as much as they ought to be protected. Going beyond these limits will threaten both the liberality and the justness of our society as far as health care is concerned. I will also argue that the first virtue of our health care system, and of managed care plans within that health care system, must be the virtue of justice. My intent is to reject the views of both libertarians, who would assign value preeminence to unequal liberty, and communitarians, such as Michael Sandel,⁴ who would relegate justice to the status of a minor remedial virtue of social institutions. Finally, I will argue that the best approach to resolving fairly the last chance therapy problem will be through a form of rational democratic deliberation, which I describe below. Such an approach will yield rationing decisions when life itself is at stake that are “just enough,” that protect “just liberty” adequately enough, and that sufficiently maintain the bonds of a liberal pluralistic community.

The practical implication of the philosophic claims I advance above is that we want our managed care plans to be Rawlsian-like liberal political communities on a small scale.⁵ This would mean that members of these plans would not necessarily share with one another any comprehensive vision of the good (or even a vision of the good as it related to health care). Instead, they would share a commitment to a certain set of liberal virtues and liberal social practices, the most important of which would be a commitment to rational democratic deliberation as the primary method through which social conflict within the plan would be addressed (i.e., problems such as the last chance therapy rationing problem).

Health care rationing decisions need to be made communally, if they are to be made fairly. There is no practical way for individuals as individuals to make rationing decisions for themselves of the range and complexities required by our current health care system and still preserve overall fairness. But we also readily recognize that rationing decisions need to be made freely and autonomously if they are to have moral and political legitimacy. After all, rationing (as used in this Article) is about denying individuals what all would agree is beneficial health care—albeit what is judged from some larger social point of view to be marginally beneficial, non-costworthy health care.⁶ Still, it will sometimes be the case, as with last chance therapies, that marginally beneficial care is what might make the difference between life and death for a given individual (if only for a relatively brief period of time). Given the significance of an outcome like this, in a liberal society such a decision should be endorsed at some level

by the individual who will bear the burden of that decision. Otherwise, we would need a compelling moral argument for the claim that there is someone else who has the moral authority to impose such a decision on this individual. It is not obvious what such an alternate source of moral authority might be that would still be liberally defensible.

I. FRAMING THE PROBLEM OF LAST CHANCE THERAPY RATIONING

A. Last Chance Therapies: Some Examples

For the sake of clarity, I call attention to four concrete examples of last chance therapies to focus and illustrate the problem. First, Herceptin therapy is for the 25% of women with metastasized breast cancer (roughly 12,000 women per year in the United States) who have HER-2 receptors, which unfortunately hasten the progression of cancer.⁷ Second, the left ventricular assist device (LVAD) is for patients with end-stage congestive heart failure—about 550,000 new patients suffer from this problem each year in the United States.⁸ Third, the totally implantable artificial heart (TIAH) is for patients with end-stage heart disease. This device is in the earliest stages of clinical testing,⁹ but it would offer hope of prolonged life to about 350,000 individuals per year in the United States who would otherwise die from their heart disease.¹⁰ Fourth, total parenteral nutrition (TPN) can be used for infants, usually born prematurely, who do not have a functioning gut, and hence, do not have the capacity to process food in the normal way. About 4,000 such infants are born each year in the United States.¹¹

The common features of last chance therapies that create our moral problem are the following: First, the cost of the therapy itself is very high at the individual level. In the examples above, the costs per person range from \$100,000 to several hundred thousand dollars. In the case of infants with necrotic small bowel syndrome, the costs of TPN range from \$50,000 to \$200,000 per year, and these infants can now survive for four years.¹² A medically and morally troubling fact about TPN is that the therapy that prolongs the infants' lives also destroys their livers.¹³ Liver damage will cause their deaths unless we provide them with liver transplants at a cost of about \$200,000 each.¹⁴ A liver transplant might only yield an extra two years of life, and the next alternative, being an experimental total bowel transplant, would cost \$600,000.¹⁵

Second, the aggregate cost of treating all who are in similar medical circumstances is very high and grossly disproportional to what would seem to be a reasonable share of total health resources. In the case of the TIAH, for example, we could be looking at annual increases in health care

expenditures of about \$52 billion in an economy in which we currently spend a little more than \$1.3 trillion on health care.¹⁶ If we were looking at only a few hundred or a few thousand of these high-cost interventions, the moral reality would be that we could afford such interventions, and we might be fairly judged indecent and uncaring if we failed to provide them. But the potential aggregate demand is very great and essentially unavoidable as a moral problem.

Third, the terminal prognosis itself is unaltered by all of the above interventions. There is no reasonable medical expectation that any of these interventions will bring about a medical miracle and provide an individual with an open-ended life expectancy. Each of these interventions promises some gain in life expectancy with an acceptable quality of life, but nothing more than that.¹⁷

Fourth, the gain in life expectancy will vary considerably from one individual to another, and from one therapeutic intervention to another, often depending upon a mix of factors that will not be well understood at the individual level; but fifth, from some larger social perspective the general judgment will be that the gains in life expectancy are mostly marginal. The clear case of that is Herceptin therapy where the average increase in life expectancy (compared to conventional therapy for women with metastasized breast cancer and HER-2 receptors) is five months.¹⁸

By way of contrast, treatment of HIV-positive patients with protease inhibitors and combination therapy in the later stages of that disease, or renal dialysis for patients with end-stage renal failure, both cost less and produce longer life expectancies. Costs for protease inhibitors are about \$20,000 for each year of life gained,¹⁹ while costs for dialysis are about \$45,000 for each year of life gained.²⁰ Individuals in these medical circumstances might be described as being "terminally ill" because their diseases represent the most likely causes of their future deaths, but their life expectancies are actually much more open-ended and indefinite, stretching out for a couple decades or more in the case of many dialysis patients. For this reason I think of them as being in a different category for purposes of moral analysis than the last chance category I am delineating here.²¹

Finally, all the patients I have in mind as last chance patients want access to these expensive, marginally beneficial therapies. The painful acuity of our moral problem would be significantly diminished if these therapies generally offered prolonged life filled with substantial pain and suffering. We, societal or institutional decision-makers, could then convince ourselves that the truly right and compassionate thing to do would be to expend substantial effort to persuade these patients to reject

these interventions as therapeutic mirages. This would allow us to avoid having to think of ourselves as making a rationing decision that would bring about the “premature” death of an individual. However, the medical reality is that this source of solace is generally not available in these circumstances.

B. Last Chance Therapies: Distinctive Moral Features

A number of morally relevant considerations seem to put last chance therapies into a distinctively weighty moral category, and, in addition, make rationing decisions with respect to such therapies an exceptional psychological burden.

First, it is partly for monetary reasons that we are motivated to deny an individual access to life-prolonging technology. It is for reasons of “fiscal scarcity” rather than “absolute scarcity” that we deny an individual this medical intervention.²² If we had only so many transplantable organs, we would still feel regret that we had to deny a certain individual one of those organs, but we would know that some number of individuals would be denied those organs no matter what. In the case of money, however, especially in a \$9 trillion economy, we can always imagine some other source for funds that would lift this burdensome decision from our shoulders.

Second, it is ultimately an identifiable individual who is denied this expensive life-prolonging care, someone with a name and face who will elicit our natural sympathies. It seems uncaring, cold-hearted, disturbingly calculating, and violative of the core virtues essential for any civilized community to have a medical intervention at our fingertips that offers some small hope of life prolongation an individual desperately wants, but still our intent is to deny that individual access because it is not cost-effective from a larger, abstract social point of view. Another way of making the same point is to say that it involves “putting a price on human life,” making the judgment that some lives are not worth saving. That judgment may be morally and psychologically tolerable when we are talking about “statistical lives,” but it seems intolerable when we are talking about an identified person. If, for example, we were aware of miners trapped 1,000 feet below the surface, climbers trapped in a storm on a mountain peak, or a physician in Antarctica at risk for pancreatitis, then we would never call off a rescue effort because some speedy fanatical accountant calculated that the rescue effort would cost a minimum of \$6 million with no guarantee of success (and this was really an economically irrational use of resources).

Third, we can debate about whether there is a right to health care, or

whether we have a societal moral obligation to be responsive to the health care needs of all. We can argue about precisely how we ought to define a health “need” or how encompassing the domain of health care needs ought to be. But in the last chance therapy situation I have in mind, it is unambiguously clear that if there is anything that can be called a health need, and if such a need ever generates a moral obligation to be responsive, then this is a paradigmatic situation where there is an obligation to provide access to a medical intervention that offers an individual’s only hope to forestall death for some period of time. We might interpret this as an obligation of justice (these are people whom Rawls would classify as being among the “medically least well off”) or we might interpret it as an obligation of beneficence. In either case, the operative word is “obligation,” the intent being to suggest that it would be especially inapt to consider making rationing decisions with regard to patients in these circumstances.

C. Last Chance Therapies: Why Rationing Is Inescapable

To avoid confusing the reader, I emphasize that the material in the prior section should be read as an uncritical description of the moral phenomenology associated with last chance therapies and rationing. The practical conclusion one is supposed to draw from that analysis is that decisions to deny individuals last chance therapies are just plain morally intolerable. But I reject that conclusion. The need for health care rationing in general is really inescapable. Some may be tempted to argue that getting rid of waste and inefficiency in the health care system is the real moral imperative, and those matters must be addressed completely before any rationing decisions receive a moral seal of approval. At a general enough level, I would agree with this view. But, among other things, closer inspection often will show that one person’s “waste and inefficiency” is another person’s chance at life-sustaining medical care.²³

Still, a critic might insist that if rationing is inescapable, then we should make all our rationing decisions around care where life itself is not directly at stake. Unfortunately, the fact of the matter is that we could not possibly save enough money that way to avoid the more difficult sorts of rationing decisions associated with last chance therapies.²⁴ The general line of argument, which my last chance therapy examples above are intended to illustrate, is that the proliferation of expensive life-saving and life-prolonging medical technologies has become so expansive (and has resulted in the proliferation of what we categorize from a moral perspective as “health needs”) that not even a society as affluent as our own can afford to provide these technologies to all who have the relevant

medical needs. Further, it is generally the case that these emerging technologies result in both prolonging lives and adding to the total burden of costly chronic illness in our society. Thus, providing 350,000 artificial hearts per year will substantially reduce heart disease as “the” cause of death in our society while increasing the number of people who will die from various cancers, strokes, or Alzheimer’s disease, after they have generated substantial costs for the treatment of these additional disorders. Artificial hearts do not confer eternal life on anyone. We should conclude, as I argued in an earlier article,²⁵ that we cannot avoid “putting a price on human life,” that is, accepting that there are some lives and some life-years that are too expensive to save. The real moral challenge then is to determine what our understanding of health care justice permits or requires in the way of making these rationing decisions.

In short, solving the problem of health care rationing requires that we come up with a rationally compelling moral account of what it means to be a just and caring society when we have only limited resources for meeting virtually unlimited, extremely heterogeneous health needs. It also requires a rationally compelling political/economic account of what will count as costworthy health care from a point of view that is both social and sufficiently respectful of individual judgments of costworthiness. Finally, we need a rationally compelling account of health care rationing and the social mechanisms required to implement it that is congruent with our liberal and democratic political traditions.

D. Last Chance Therapies: Why Justice?

What should be the central moral or non-moral considerations that determine how society, managed care plans, or employers make rationing decisions with respect to last chance therapies? Should the ability of individuals to pay for the therapy be that determining factor? In some circumstances, as I explain below, that is the correct answer to give. However, I hastily add that the appropriateness of those circumstances has to be shaped by certain judgments of health care justice. I reject the view that health care should be thought of as nothing more than another commodity in the market to be distributed entirely on the basis of individual ability to pay (with apologies to Tristram Engelhardt²⁶) since that view almost entirely ignores the complex problems of health care justice, which I will argue need to be addressed. To my mind, the most serious of those problems would be the failure of such a libertarian health care system to meet the health care needs of the most seriously chronically ill, who will often find themselves unemployed, uninsured, and entirely dependent upon the vagaries of local health care charitable impulses.²⁷ I

find Daniels' arguments in support of the view that health care is "morally special" quite compelling.²⁸

Our social practice is also worth noting. For example, as a society we passed the 1972 End Stage Renal Disease (ESRD) amendments to Medicare, which underwrite the costs of either renal dialysis or renal transplant for anyone in end-stage renal failure no matter what his or her work or economic status. We found it morally intolerable that a society as affluent as our own would simply allow people to die because they could not afford the cost of dialysis (roughly \$45,000 per year at present²⁹), which will often mean many extra years of life. In the year 1999, that program cost in the aggregate about \$14 billion and sustained the lives of more than 300,000 individuals.³⁰

We can argue, of course, as to what precisely was the moral motivation for that decision. I would assert that it was a matter of health care justice. Others might say it was no more than a charitable impulse expressed societally. However, I find that explanation open to serious moral criticism. Specifically, if it were no more than a charitable impulse, then it would have to be morally unobjectionable if we were to decide as a society to withdraw that funding for the indefinite future, with the result that literally tens of thousands of those individuals would likely die in the space of a year because they would be unable to afford dialysis. There is something obligatory about our continuing that funding, unlike in a situation in which I have contributed \$25,000 to cancer research for each of five years and then decide to donate no more. But someone could add that the obligation is not necessarily a matter of justice; it could be better characterized as an obligation of beneficence. That response strikes me as being ethically incomplete. Other individuals, such as hemophiliacs needing Factor VIII to sustain their lives, something that can be more expensive than dialysis, can justly complain that there should be a national program to fund their needs as well. After all, public resources are being used to fund the dialysis program. It may not be morally necessary to show that justice requires funding the dialysis program, but some argument must be made to show that it is not unjust to fund it. At least in that respect, considerations of health care justice must come into play. That minimal point is all I wish to make for now.

I want to call attention to a very provocative argument made by Allen Buchanan that deserves broader notice.³¹ He points out, contrary to popular belief, that managed care plans are for the most part immune to moral criticism, so far as matters of justice are concerned, as long as they meet their contractual obligations to subscribers, and as long as they observe basic understandings of procedural justice in the plan ("treat like

cases alike, so far as providing or denying benefits are concerned"). This is because there are no substantive social agreements regarding what should count as a basic or minimally decent package of health benefits that should be guaranteed to all in our society, nor regarding what should count as reasonable approaches to health care rationing/cost control with regard to health benefits provided to subscribers, nor regarding what should count as the level of quality of health care to be guaranteed to all subscribers within a plan. With regard to these latter points, there is no agreement among plan members, or in society at large, about what the relevant substantive values or conceptions of justice would be that could identify morally objectionable rationing judgments or morally objectionable quality deficiencies. The only reference points for such judgments are the exaggerated expectations of plan members. Buchanan writes: "Because no authoritative standard has been determined for what constitutes the types and quality of care to which everyone could be said to be entitled, complaints that patients are treated unethically when they are denied care or when they receive care of less than the highest quality are groundless."³² He also concludes that because we have no authoritative standard for the care to which everyone is entitled there is no benchmark for determining what a physician's fiduciary obligations are.

If Buchanan's analysis is correct as an empirical moral description,³³ as I believe it is, then this should be very unsettling for the average middle-class American in managed care. It means that each year I, for example, invest about \$6,700 in this health care game of chance. The rules of the game that determine when there is a payoff are less than perfectly clear, and they are subject to sudden change or definitive interpretation by two other very powerful players in the game (my employer and the insurer/managed care plan), both of whom have strong interests in denying me a payoff. I know that for small bets there are frequent and reliable payoffs, but I find that to be of small comfort. When I and/or a family member are faced with a very serious and potentially very expensive health crisis, then I most want certainty that the payoff will be there. But it seems then that there is the greatest uncertainty, and I have the least ability to control the outcome of any bargaining or adjudicative process because I have little political or moral power. Further, it would be small comfort to be told that my managed care plan is committed to formal justice, that all plan members will be treated alike in similar circumstances.

We can imagine any number of virtues that we would like to see our managed care plan display in these very difficult circumstances. But all these virtues would be nothing more than shifting in uncertain sand if the policies and practices of that managed care plan were not rooted in

explicit, substantive, and well-defined understandings of health care justice. Imagine, for example, a managed care plan that advertised itself as “caring and compassionate” and that exemplified those virtues every now and then by “investing in” an expensive life-prolonging last chance therapy for one of its plan members. Such sporadic displays of exemplary behavior would hardly assuage our own anxiety as to whether we might be the beneficiaries of such behavior in the future were we to face a life-threatening medical crisis. Further, we could not help but note the fact that it is “our money,” our premiums, that are being used to underwrite that generous response (and might not be there in the future, were we in need of a similarly generous response).

Perhaps this would not be a practical problem if our managed care plans were those single-minded idealized communities that some communitarians would like to see more generally disseminated. But, for the most part, we are moral strangers to one another in managed care plans, which is why we need a rationally defensible basis for knowing when we or others are entitled to draw on the common resources of the plan to meet health needs. Shared understandings of health care justice articulated through a shared process of rational democratic deliberation are needed, the details of which I sketch below. The virtue of such shared understandings achieved through a shared deliberative process is that they constrain morally objectionable arbitrariness by plan administrators, shift the power to make rationing decisions to those directly affected by those decisions, and protect our liberal commitments to value pluralism.

E. Last Chance Therapies: Why Non-Ideal Justice?

Though some philosophers with a more rationalistic bent might believe that our philosophic theories are capable of yielding uniquely right and uniquely rational responses to complex problems of health care justice, this belief is excessively utopian. The empirical complexities associated with our health care system and emerging medical technologies, the uncertainty with respect to medical interventions, the possibilities for trade-offs with respect to very complex mixes of rationing options—all of the factors that Rawls tries to capture under the rubric of the “burdens of judgment”³⁴—defeat the hope that philosophy would have the resources to yield complete resolutions to the justice problems associated with health care rationing.

Daniels and I agree that no theory of just health care will prove adequate to address the moral challenges alluded to above. As Daniels puts it: “The general distributive principles appealed to by claimants as well as by rationers do not by themselves provide adequate reasons for choosing

among claimants: they are too schematic.”³⁵ Ultimately, rationing decisions come down to the level of individuals, and often those individuals will be able to appeal to plausible distributional principles that would justify their not being denied some type of health care that they need. If this is true, if we have conflict and incoherence among distributional principles at the level of individuals, and if what is at stake for these individuals is access to health care that is perceived to be of great import (i.e., a last chance therapy), then this is not a state of affairs that is morally or socially tolerable. There would be enormous opportunity here for arbitrary or discriminatory judgments to be made, as Buchanan has reminded us. Here Daniels takes note of the move made by Rawls to deal with indeterminate distributive principles, namely, an appeal to fair democratic procedures to resolve the indeterminacy. Daniels, however, is not satisfied with this. He finds that there are some strong moral objections that can be lodged against this move to fair democratic procedures, which I discuss below.

The large view I defend is this: First, we should view health care as a distinct “sphere of justice,” as Michael Walzer³⁶ uses this phrase. There are features of health care in our society that make it distinct enough as a social good that it requires its own principles of distributive justice.³⁷ Three broad areas would have to be addressed by these principles: fair access, fair financing, and fair rationing/priority-setting/cost containment.

Second, the most we can hope to achieve would be a morally defensible conception of non-ideal health care justice.³⁸ We are faced with the extremely complex moral problem of coming up with a framework for fair health care rationing that can address “justly enough” the concrete problem of last chance therapies, as well as several related rationing problems at a slightly more general level. These are often referred to in the literature as the “ragged edge” problem, the “Rule of Rescue” problem, and the “priorities” problem. These are not merely philosophical problems of health care rationing; rather, these are problems that policy-makers (private or public) in our society must address. We have no reason to believe that there is any uniquely and perfectly rational, or uniquely and perfectly just, theory of health care rationing that can address all these problems. Rather, there are numerous trade-offs among competing moral considerations and among competing considerations of health care justice that will yield a pattern of rationing outcomes that will be “just enough.” Within the framework of non-ideal justice (as I conceive it) our objective is to come up with recommendations that will bring about more just policies, practices, and patterns of health care rationing than currently exist. At the very least we want to identify those features of our current rationing practices that are clearly unjust. Within managed care plans we want to

identify policies and practices with respect to health care rationing, trade-offs of various sorts, that are “just enough” and not illiberal.

Third, the theoretical underpinnings for rational democratic deliberation as an approach to just health care rationing are to be found in a theory of public reason, as articulated by Rawls.³⁹ The more theoretical side of rational democratic deliberation, that is, the construction, interpretation, specification, and mutual adjustment of the constitutional principles of health care justice, should be thought of as a matter of wide reflective equilibrium, as Rawls and Daniels would understand it.⁴⁰ The more practical side of rational democratic deliberation, that is, the construction and mutual adjustment of social policies and practices for fairly, rationally, and democratically resolving the indeterminacies, trade-offs, and priorities associated with health care rationing at the level of concrete social practice, should be thought of as a matter of public reason or democratic legitimation, as understood by Daniels and Sabin.⁴¹

The practice of reason-giving must be integral to our process of policy-making, whether in the public sphere or in private managed care plans. In addition, following John Dewey, the theoretical and practical dimensions of public reason must not be separated from one another for purposes of constructing a fair approach to health care rationing. The precise shape of the domain of practical rational democratic deliberation will change as a result of how effective resolution of concrete problems of health care rationing brings about a refinement and specification of our broad principles of health care justice. We see precisely this happening in our legal practices of constitutional interpretation as our understanding of privacy or free speech or other such broad matters evolves as a result of our grappling with emerging social problems in these areas.

Fourth, rational democratic deliberation has moral legitimacy as an approach to health care rationing because it best captures what respect for individual autonomy is about in the rationing context. Rationing decisions that involve the healthy, wealthy, and politically powerful imposing rationing protocols on the sick, the poor, the vulnerable, and the politically powerless are presumptively unjust. By way of contrast, rationing protocols that we impose upon our future selves as a result of rational democratic deliberation are presumptively just. There are, of course, alternative approaches to health care rationing besides rational democratic deliberation. These include markets/individual incentives, bureaucratic rule-making, expert medical or technical judgment, or administrative decision-making in a hospital, insurance company, or managed care plan. But I have argued elsewhere⁴² (and I take Emanuel and Emanuel to be making the same point⁴³) that all these alternative approaches are seriously

flawed as primary mechanisms for health care rationing, either from the perspective of justice or from the perspective of respect for individual autonomy. To be sure, there are appropriate places for the functioning of all these alternate mechanisms in a scheme of health care rationing, but the overarching framework for that scheme must be rational democratic deliberation.

II. LIBERAL COMMUNITARIANISM: A CRITICAL ASSESSMENT

Should we embrace the communitarian vision of managed care presented by Emanuel⁴⁴ rather than liberal rational democratic deliberation for fairly addressing rationing issues? Emanuel wants to permit, maybe encourage, managed care plans to be defined in terms of some sort of comprehensive vision of a health good. What he rejects in the liberalism of Rawls, Dworkin, and their philosophic brethren is the notion of liberal neutrality. He sees this as a sham because liberalism itself represents a fairly definite set of value commitments, which may be congenial to many comprehensive visions of the good, but which may be uncongenial to others—very often religiously based comprehensive visions. Emanuel contends that there is something fundamentally wrong with a political society that would force an individual to choose between being a good liberal citizen and being a good Catholic, a good Amish person, or a good Orthodox Jew. Thus, if we were to have some sort of national health insurance, and if abortion services, physician-assisted suicide, or embryonic genetic analysis and selection were funded benefits, then some individuals who are deeply opposed on moral/religious grounds to any or all of these practices would find themselves contributing tax dollars/premium dollars to support these practices. This strikes Emanuel as being illiberal and dishonest.

Emanuel sees the managed care movement as a way of escaping these problems that is both protective of our liberal political traditions (minus the neutrality commitment) and protective of the integrity of distinctive religious/philosophic communities. He sees managed care plans as possibly forming around differing organizational perspectives, including religious commitments. He would give each family or citizen of our society a voucher that would have a precise economic value sufficient to purchase a very good package of health care benefits. Individuals could use these vouchers to join whichever managed care plan they found congenial to them in terms of a comprehensive vision. There would then be no nationally required set of specified health care benefits/services. Instead, members of each plan would decide among themselves the precise content of their benefit package, up to whatever limit was allowed by the value of

the vouchers, plus whatever private resources they were willing to add to a common pool of resources for purchasing health care services. Emanuel says the vouchers might be "graded," increased in value to reflect the likely health needs of individuals with those vouchers so as to minimize any risk of economic discrimination against older or chronically ill individuals.⁴⁵ Otherwise there would be a serious justice problem. However, we would then need a national decision-making mechanism to do the grading. That is, someone would need to decide which medical problems, with what degree of severity, and with what likelihood of being responsive to various more or less costly medical technologies, ought to be considered for purposes of assigning a value to a particular voucher for a particular individual.

Whose vision of the good would be operative at the national level for this purpose? This is supposedly the problem that prompted Emanuel to devise his proposal in the first place. But it looks like he still has that problem, at least if he remains committed to protecting the overall justness of the system. Could those religious managed care plans object that they do not want their tax dollars spent, or the value of their own personal health vouchers reduced, to accommodate what they regard as the perverse health needs of the HIV-positive population, just as many object to the use of federal money for the funding of abortions? If the federal government were to respond positively to this challenge, then we would have *de facto* discriminatory outcomes that are both illiberal and unjust.

If protecting pluralism is important, which means in political terms protecting the right of individuals to form many kinds of communities around many conceptions of the good, then a liberal government will have to be neutral among different (sometimes competing) conceptions of the good. That neutrality will be in the "justificatory" mode rather than the "consequentialist" mode. In other words, in justifying any particular law or policy, a liberal government will have to show that it is justified by appeal to "thin" values and interests that can be reasonably construed as being supportive of the general good of liberal citizens as liberal citizens in a liberal society. That is, these are interests that transcend (but are also necessary to support) the much thicker and more specific conceptions of values that define the multiplicity of communities that comprise our society as a whole. Our conception of justice, as Rawls articulates it, is intended to be the most important value embraced by a liberal society, in part as a way of protecting the stability and peacefulness of our society. I emphasize that Rawls is a moral and political constructivist: The conception of justice (or any other basic social value) is not simply "out there" to be discovered; rather, it is constructed through rational

democratic deliberative processes, the resources of public reason, as we struggle with emerging social problems, such as health care rationing.

Let us now apply this general framework to the last chance therapy problem. Imagine that we have Emanuel-like managed care plans organized around a core value such as “sanctity of life” or “maximum healthy living.” Those committed to the sanctity of life ideal may want everything medically possible done to sustain their own lives or the lives of their loved ones; thus they will want access to Herceptin, LVADs, TIAHs, or TPN, all at plan expense. By way of contrast, those who are committed to the ideal of maximum healthy living may adhere to the belief that most of the chronic illnesses characteristic of contemporary Western society results from bad lifestyle choices that “weak-willed” individuals in society make. They want nothing to do with paying for the medical costs of this “weak-willed” misbehavior. What they want funded with their health dollars is an indefinitely large array of health-promoting practices and herbal supplements, for example. Both sets of these individuals define strong morally legitimate health needs from the perspective of their comprehensive visions of the good.

How can individuals with such radically different visions of legitimate health needs co-exist in the same health plan? This problem generates Emanuel’s vision of separating out into distinct managed care plans adherents of all these different comprehensive visions. However, this move does not solve any moral or practical problems. As noted above, if there is some sort of national commitment to “necessary health care for all,” and if that is expressed through giving health vouchers to all, then some economic value will have to be attached to the vouchers, and that value cannot be fairly or reasonably determined by reference to what adherents of different comprehensive visions judge to be their health needs. To address that problem we will need some thin conception of health care justice that can be the focal point of an overlapping consensus.⁴⁶

A more telling point, however, is that this very same problem would exist in each of these philosophically distinctive managed care plans we have postulated. This is because there are, as a psychological and sociological fact, indefinite degrees of commitment to the core vision of the good that would define any of these plans by individual members of these plans. Some members of the “maximum healthy living” plan will be ultra-health enthusiasts (and demand health resources to achieve their ultra-health goals) whereas others will be only “excellent” or “very good” or “near average” health enthusiasts (still a couple standard deviations beyond the minimal level of commitment to health promotion of the average American). The same will be true in the “sanctity of life” managed

care plan where some will enthusiastically endorse sustaining at all cost the lives of Helga Wanglie and others in a persistent vegetative state, while other plan members would see that as a wasteful and inappropriate use of limited plan resources that ought to be directed to more support for last chance therapies.

To resolve such possible conflicts within any of these plans appeal would have to be made to some conception of health care justice, and a method for justifying that conception, that is independent of the more radical and less radical commitments of plan members to their central value conception. If such a conception and method can be worked out within these plans to prevent destabilizing and fractious bickering among plan members, then the same conception and method can be appealed to for purposes of resolving conflicts among these plans with respect to how at the national level we ought to determine the value of health vouchers that would be given to all. And if it is possible to achieve that to a sufficient degree, then there is no need to try to organize health plans around differing comprehensive visions, for we would then have the resources that allowed individuals with very different deep comprehensive visions of the good (health-related or not) to function fairly in relation to one another within the bounds of liberal generic managed care plans.

My contention is that something akin to Rawls' liberal conception of justice and something akin to the version of rational democratic deliberation I describe below are necessary to achieve these objectives, while at the same time preserving the value of community and solidarity to the limited functional extent that is possible. Within the domain of health care justice, Daniels has provided a helpful approach to addressing this problem of diverse comprehensive visions with his fair equality of opportunity account for identifying and prioritizing health needs⁴⁷ since it is fundamentally neutral among competing comprehensive visions. It is a "thin" enough, but still substantive enough, value that it can address many rationing problems, including some parts of the last chance therapy problem.

III. JUST HEALTH CARE RATIONING: CRITICAL CHALLENGES

Daniels identifies four unsolved broad rationing problems.⁴⁸ I will add several more. My ultimate objective will be to show that rational democratic deliberation provides us with a reasonable approach for addressing all of these problems more fairly than any alternative. This includes the last chance therapy problem. Daniels uses the Oregon priority setting process as background for his critical observations.⁴⁹ Both Daniels and I agree that the Oregon process is seriously flawed as a model of what

rational democratic deliberation ought to be. Nevertheless, I have argued that useful moral lessons can be drawn from that policy-making effort for purposes of designing morally preferable examples of rational democratic deliberation for health care rationing.⁵⁰

The first problem Daniels identifies is the “fair chances/best outcomes” problem. At the micro level we have Alice and Betty. Both will die in a week without an organ transplant; both are the same age; both have been waiting in line for the same period of time. Alice is expected to live two years with the transplant while Betty will live twenty. What does fair treatment require in terms of determining who gets the transplant? From a best outcomes perspective, certainly not unfair or unreasonable, Betty would get the transplant. From a fair chances perspective, recognizing that those two years are of ultimate importance to Alice, there ought to be a lottery, which Alice demands. Both are plausible moral principles. How can we reasonably decide which principle ought to prevail in of our managed care plan?⁵¹

Alice and Betty are merely abstract ciphers that hardly elicit compassion. In the real world there are millions of individuals with assorted disabilities who would fear a discriminatory outcome if our consistent commitment were to best outcomes, especially if those outcomes were measured by Quality-Adjusted Life Years (QALYs).⁵² If, for example, access to Herceptin therapy at plan expense were only available through clinical trials, then most individuals with significant disabilities would be excluded from such trials. If we wanted all women with metastasized breast cancer to have fair access to limited slots in these trials, then the likely result would be less reliable trial data. Is the desire for more reliable clinical data (best outcomes) sufficient to justify denying individuals with potentially confounding disabilities access to these trials and to the possibility for prolonged life represented by Herceptin?

Daniels’ second problem is the “priorities problem.” Should we give higher priority to those who need treatments that will yield greater net benefits, or to those who are medically worse off, even if doing so does not result in greater net benefits? The relevant moral intuition at stake here is the Rawlsian Difference Principle—if inequalities are inescapable, then institutions should be structured in such a way as to make the least well off as well off as possible. Daniels asks us to imagine people with Condition 1 who are more seriously impaired by their disease/disability than people with Condition 2. Treatments 1 and 2 will yield the same net gain in benefits for either group. This suggests that priority would be given to neither treatment. But Daniels says most of us would be inclined to treat Condition 1 because these individuals were worse off to begin with, and

this would be especially true if treatment still left these individuals somewhat worse off than individuals with untreated Condition 2. But our judgments in this matter would be less confident if those with Condition 1 ended up better off after treatment than those with Condition 2, who were denied treatment. Daniels continues that if Treatment 2 yielded greater net benefit for those with Condition 2, then we would still likely favor those who were worse off to begin with. But if the worse off could gain only a very modest improvement from Treatment 1, and those with Condition 2 were denied the opportunity for very great improvement, then Daniels contends we probably would not award strict priority to the worst off.⁵³ In the context of our last chance therapies, for example, we could ask: Could a just and caring managed care plan or Medicare program deny the TIAH to individuals who had both end-stage heart disease (likely to kill them in six months) and a terminal cancer (likely to kill them in two years) so that the TIAH would be more available for individuals likely to gain at least five years of additional life from it?

Daniels' third problem is the "aggregation problem." How do we determine whether various aggregations of health benefits are just or not? For example, if we can save one life or provide computerized functional assistance to a quadriplegic that will significantly improve quality of life for that person, which allocation would be more fair? If we make these one-to-one comparisons, then we may be able to make judgments in which we are morally confident. But if we have a fixed sum of money and we can either save one life with that money or provide to ten quadriplegics that quality-of-life/functionality-enhancing computer assistance, then which of these allocations is more just, all things considered? There are some aggregation principles that are strongly morally justified, but there is no clear, well-ordered account of how various aggregation principles might be related to one another, or how they might be fairly applied in practice to deal with numerous problems of health care rationing. In the context of last chance therapies, we might pose this question: In the Medicare program is it more important from the perspective of health care justice to fund approximately 200,000 TIAHs (at an annual cost of about \$35 billion) or to fund a Medicare drug benefit with a ten-year projected cost of about \$310 billion (roughly 60% of total drug costs for the elderly)?⁵⁴ All of the TIAHs would be needed to sustain lives while only a relatively small fraction of the prescription drugs would be necessary for that purpose.

Daniels' fourth unsolved rationing problem is the "democracy problem." Daniels calls attention to the fact that in Oregon, vasectomies were given a higher priority than hip replacements for health funding. *Prima facie*, this ranking is indefensible. But if this ranking did reflect

community values and the outcome of a fair democratic process, then we ought to abide by it. On the other hand, if we are morally confident that this ranking is mistaken, then we obviously have a substantive reference point for the conclusion that calls into question the moral legitimacy of appealing to fair democratic procedures to do fair health care rationing. Obviously some concrete rationing problems ought to be entrusted to fair democratic procedures while others need to be adjudicated “by appeal to some prior notion of what constitutes a fair outcome of rationing.”⁵⁵ But what moral methodology do we have for determining which to choose in a non-arbitrary way?

Here are some additional challenges to any approach to fair health care rationing. I start with Callahan’s “ragged edge” problem,⁵⁶ which challenges the fundamentals of the Oregon priority-setting process, specifically, the reliance on medical condition/medical treatment pairs. If, for example, you have a failing heart or a failing kidney, and a treatment is available to address your health problem, then Oregon’s Medicaid program will pay for it if it has high enough priority. But there are indefinitely distinguishable degrees of failing hearts and failing kidneys for which essentially the same treatment will be available, but with results that will range from minimally to extraordinarily beneficial. In its early years dialysis yielded impressive results, at least for significant prolongation of life. However, this was an artifact of the restrictions placed on acceptable candidates when dialysis was scarce.

Today very old, very sick, very near to dying individuals are routinely candidates for dialysis, though the costs will be large and the benefits small. Why is this a routine judgment? Because there is no sharp edge, morally speaking, that will permit us to judge confidently that a given patient has a just claim to dialysis while another patient does not. In our managed care plan, what would be a just enough and liberal enough approach to addressing this problem? I earlier put dialysis outside the last chance therapy category. My comments above suggest the need for qualification. There are a significant number of cases where dialysis will prolong life for a brief period (weeks or months), and in such cases I contend we should think of it as a last chance therapy for purposes of moral assessment.

Another example pertains to TIAHs, of which we now have a working model. The cost of transplantation is around \$160,000 each.⁵⁷ What is known statistically is that each year there might be 350,000 individuals who could benefit with five extra years of life expectancy from access to this device. About 70% of those individuals would be over age sixty-five.⁵⁸ How many of these devices should a just and caring society produce each year?

If we did have some form of national health insurance, specifically, something like the competing managed care plans envisioned by the Clinton Administration, would justice require that the TIAH be a covered benefit in every one of those plans? Would justice require that it be a covered benefit for Medicare and/or Medicaid? Would it be just to allow each employer to decide to cover it or not? Would it be fair enough if we allowed individual ability to pay to determine the distribution of TIAHs? This is one dimension of the ragged edge problem with respect to TIAHs. The other dimension, as in the dialysis case, is whether we could deny a TIAH to individuals whom we knew with near certainty would be dead in slightly more than one year. The critical moral problem raised by these ragged edge examples is this: How can we justifiably create sharp moral edges for health care rationing when there are only ragged edges in reality? We might be tempted to say that the morally safer course is to provide access to such technologies whenever they offer any benefit at all. But that denies (unjustly) the reality of the "Just Caring" problem. Resources are scarce. Money spent to fund very marginal TIAHs is money not available to meet stronger just health needs.

Our next health care rationing problem is the "medical innovation/dissemination" problem. As a society we want medical innovation, though what we have gotten for our investments thus far are a lot of halfway and ten-percent-of-the-way technologies. Recall the controversies that surfaced in the recent past regarding autologous bone marrow transplants (ABMT) for breast cancer or testicular cancer. This technology is very expensive—somewhere in the vicinity of \$100,000 to \$150,000 per case.⁵⁹ Reported results in the early 1990s initially suggested projected three-year survival rates of 10%.⁶⁰ There are more than 44,000 women each year in the United States who will die of breast cancer.⁶¹ A more recent study has shown the positive results with ABMT are illusory, that ABMT does no better than available conventional therapies.⁶² As is common in the United States, this experimental technology had become semi-disseminated, resulting in extremely arbitrary (morally speaking) inclusion and exclusion of women relative to the technology. Given the original situation with ABMT, should all women who have Stage IV breast cancer, and who have failed standard chemotherapy, have an equal chance for access to ABMT, when the initial positive results seem very marginal?

This same scenario is being replayed with Herceptin today (though the cohort of women is much smaller). But the experimental medicine angle adds another dimension to both the ABMT and Herceptin problems. The additional question that needs to be posed is whether it would be just if Herceptin were available at social cost only through approved clinical trials

and only to individuals who are deemed most “fit” for those clinical trials. That is, these individuals would not have comorbidities that could confound the results of the trials and thereby diminish the reliability of the medical knowledge society would hope to gain. Our capacity to do clinical trials efficiently, and to gain genuine medical knowledge to make both more informed personal and policy choices, was substantially undermined by the premature dissemination of ABMT. This may be happening with Herceptin as well.

We turn next to the “Rule of Rescue” rationing problem. A good society ought not allow individuals to die when it has the capacity to rescue them and money alone prevents their rescue. More dramatically, we should never “put a price on human life.”⁶³ This problem is also referred to as the “identified life” versus “statistical life” problem. Coby Howard in Oregon is the perfect illustration of this (the Lakeberg conjoined twins provide another illustration).⁶⁴ Coby was the eight-year-old boy with leukemia who needed a \$100,000 bone marrow transplant for any chance at survival, but Oregon Medicaid refused to pay for it. A public example of health care rationing like this usually elicits expressions of moral outrage, often followed by funds that will give an individual access to that expensive “life-saving” medical technology. Most often, the dismal predicted results occur, with or without the funding.

Assertive middle-class women have often been successful in forcing insurance companies to pay for ABMTs for their breast cancers. They are successful because they are willing to make themselves visible as individuals in desperate need of rescue.⁶⁵ Saying to these women that it is just not worth it from a societal point of view to save their lives seems insensitive and cruel. But, as noted earlier, a defining feature of health care rationing is that *individuals* must ultimately bear the burden of rationing. If all such individuals could make themselves visible victims of rationing in need of rescue, it would subvert all just schemes of health care rationing, including last chance therapies. The Rule of Rescue is a morally feasible rule so long as its required uses are small in number. Given rapid advances in numerous, expensive forms of life-sustaining medical technology, the application of the Rule of Rescue becomes ubiquitous. In the United States, the vast majority of us are likely to require multiple such medical rescues before we die.

Two moral problems are raised at the societal level by this Rule of Rescue. One is the conflict between what justice requires of us in maintaining fair rationing practices and what compassionate caring requires of us when faced with individuals threatened with death for whom there is “some chance” they might be saved, though at very great cost to

society or to our managed care plan. The other moral problem involves a conflict between a "slice-of-time" conception of justice and a "course-of-life" conception of justice. Do we have any principled basis for distinguishing rationing situations in which one rather than the other conception of justice applies? To be clear, there may be some circumstances in which a rationing decision is made most fairly by only considering present circumstances; past use of expensive health resources would be regarded as entirely irrelevant. But there are other circumstances where past access to expensive life-prolonging medical care might justly limit present access to marginally beneficial, very expensive, life-prolonging medical care. Imagine a future situation, perhaps twenty years from now, for HIV-positive individuals whose lives were first prolonged by protease inhibitors, then integrase inhibitors (or other successor medications) at \$20,000 per year (aggregated to \$400,000 for twenty years). Could we justly deny such patients access to another life-prolonging intervention costing \$100,000 that would extend their lives for six more months, part of the moral justification being that we had provided the prior twenty years of life-sustaining care?⁶⁶

IV. JUST AND LIBERAL MANAGED CARE: KEY ELEMENTS

We cannot reasonably expect to bring about perfectly just or perfectly liberal managed care plans. This has nothing to do with a recalcitrant reality or sinful citizens. Rather, there are numerous reasonable values and numerous considerations of health care justice that pertain to the practical problems of choosing fair rationing policies and protocols, and there are an indefinite number of trade-offs among these competing considerations that will yield policies and practices that are "just enough" and "liberal enough." Any that are in fact chosen need to have both moral and political legitimacy. There are two primary sources for that legitimacy. One is that these decisions are made in bounded political space, space defined by what I refer to as constitutional principles of health care justice.⁶⁷ These society-wide principles protect society-wide justice. But they also create expansive democratic space in which there can be a plurality of morally legitimate policies and practices regarding health care rationing, which would be reflected in different managed care plans. Such space, however, cannot be devoid of justice-related structures. At this local level there must also be a pattern of public reasons that shapes democratic deliberations about health care rationing and protects to a large extent the moral legitimacy and the fairness of the outcomes.

That brings us to the second source of moral and political legitimacy: The actual trade-offs made are a product of rational democratic

deliberation that all who might be affected by specific rationing policies or protocols have had a fair opportunity to shape or endorse. At the very least that means that all these rationing policies or protocols, and the reasoning that would justify them, are public or visible. This is required by what Rawls refers to as the “publicity condition,” an element he sees as central to our shared conception of justice.⁶⁸ When decisions are just, nothing is or need be hidden. This means that rationing decisions that are invisible, hidden from public recognition or scrutiny, are presumptively unjust.⁶⁹ Further, if it can be honestly said that our rationing protocols are a product of public democratic deliberations open to all, then it can be justifiably said that these rationing protocols are freely and autonomously imposed by individuals upon themselves. In the course of explicating rational democratic deliberation it is important to respond to Daniels’ objections, especially the “democracy problem.”

Several moral lessons can be learned from the Oregon experience of health care rationing.⁷⁰ I will recall two of them. First, justice requires that there be limits to the claims that health care makes on total societal resources and that these limits are expressed in the form of hard budgets. The moral virtue of hard budgets is that they make clear and visible necessary trade-offs among competing health needs and services. Second, hard budgets give structure and coherence to a process of prioritizing health needs and services. A process of prioritizing and actual priorities that are explicit, rationally determined, and freely agreed upon protects fairness against special pleading by individuals or health interest groups.

Do terminally ill individuals really have a just claim to last chance therapies? If we ask this question in a perfectly abstract way, as a free-standing moral problem devoid of any further context, then no morally or rationally secure answer is available. But, if we ask this question in the context of a fixed health care budget, and if we have talked and thought through our health priorities with one another in a communal framework over a substantial period of time, and if we want to achieve as much health good as possible within the constraints established by certain basic considerations of health care justice, then we will be able to distinguish between just health claims by the terminally ill for life-prolonging resources, and those other claims requiring an empathic response but otherwise generating no just moral obligations. Again, the key to preserving the overall fairness of this system is that we are all part of this community over the course of a life. It is, of course, unlikely that many of us would be part of any single managed care plan over the course of a life. But we will likely be part of a society that has endorsed the broad constitutional principles of health care justice that will shape/constrain all

managed care plans that we might join over the course of our lives in that society.

We know we will die and that our dying could be a prolonged and expensive affair. A key moral concept for understanding what a just liberal community is all about is the notion of reciprocity and fair terms of cooperation. Do I believe I have a just claim to a half-million dollars worth of health resources at age eighty for six extra months of a reasonable quality of life? Again, there is no reasonable answer to this as an isolated question. We must also ask whether we would be willing to spend the additional taxes and insurance premiums required over the course of our own lives to sustain the lives of an indefinite number of strangers in our community in those same medical circumstances. If I say that they have had ample opportunity to live a full life, that other more important health needs or social priorities make a stronger claim on those dollars, or that I wish to satisfy other personal preferences with those dollars, then clearly I have no just claim to those communal resources at age eighty because I too am a moral stranger to the rest of the community.

Talk of moral strangers will strike some as disheartening and dehumanizing. It looks like a moral world surfeited with justice but devoid of compassion. If this is the moral community implicit in Oregon's efforts, then this is not a moral community worthy of national emulation. David Eddy, however, offers us an insightful way of looking at Oregon's approach to health reform, or managed care reform, that allows us to see both justice and compassion.⁷¹ He asks us to consider the case of a fifty-year-old woman with metastatic breast cancer whose only hope for survival is an ABMT at a cost of \$150,000. There is only a 5% chance of long-term survival. Should a compassionate and caring community provide her with that transplant? If that community has unlimited resources, then failing to provide the transplant would be indecent. But no community has unlimited resources. Something else always must be given up; and a just and rational community will inquire carefully about what is given up.

Eddy asks us to imagine one thousand women, relatively young, working at a factory.⁷² They have an extra \$1.5 million that can be spent over the next ten years for health benefits. They are concerned about breast cancer. Eddy asks whether they would want to spend this money on ten ABMTs or on annual screening mammograms for those thousand women. The basic math is easy. Do nothing: Thirty-six of those women will die of breast cancer over ten years. Buy ten ABMTs: Thirty-five women will die. Buy the screening mammograms: Twenty-nine women will still die. If a reasonable, prudent, and just goal is maximizing lives saved or life years saved in this situation, the choice is obvious. It seems that from every

reasonable perspective the process is fair. No one has any unfair advantage. All are behind what is a real world version of Rawls' "veil of ignorance." All know that twenty-nine women will die of breast cancer no matter what. All know they could be among those twenty-nine, and that they have denied themselves a small chance of extra life years by agreeing to this trade-off. All twenty-nine of those women will have names and faces in the future and could command our compassion. But they would not have a moral right to invoke the Rule of Rescue as a moral basis for access to an ABMT, arguing that this is their last and only chance for therapy. If such a rule had ultimate overriding moral authority, little money would be left over for any less urgent health needs. If someone needed pain relief for his or her cancer, and if there were any other opportunity to spend money for a small chance to prolong life for someone else, then this latter option would always win. Such a choice is flawed from the perspectives of prudence, fairness, compassion, and cost-effectiveness. Given this, it seems unimaginable that any rational democratic deliberative process would endorse such a choice.

Imagine that one of these twenty-nine women, Abby, was able to gain some media attention, hoping to use it to pressure the managed care plan to make an exception for her. Such pressure is often sufficiently successful. To recall Buchanan, the institutional reality in many managed care plans is that no considered judgments of health care justice shape rationing, prioritizing, and cost containment decisions within the plan. Administrators make decisions that appear to plan members and the public, if there is any awareness of them, as largely arbitrary, or driven by self-interested economic considerations alone. A woman in that situation really is alone against the plan. She likely deserves public support.

But then imagine this same woman in my deliberative version of Eddy's managed care plan. She can no longer claim that she is "alone against the plan." She made an agreement for a certain trade-off with 999 other women who "are the plan," and this was a fair agreement. If she reneges, if she gets \$150,000 in plan resources for her ABMT, if the plan subsequently stopped covering screening mammograms for a year, then the result will be that one more woman will end up with a deadly metastatic breast cancer who should otherwise have survived. We will not be able to identify her as that woman who should not have died. But her death could only be described as unjust, while the other twenty-nine are correctly described as unfortunate. In this managed care plan there has been a complex set of rationing protocols, health care priorities, and precedent-setting commitments rationally agreed to by plan members for purposes of fairly sharing the risks and controlling the costs associated with

meeting their health care needs. Abby might complain that she had not agreed to this particular rationing protocol. If so, the moral and rational burden would be on her to explain what the rational basis was for her reservations. It is difficult to imagine what that might be, and what might persuade other plan members that they made a mistake in this regard, which they should now reconsider. Further, we can imagine Abby has been part of this plan for years and has benefited from its rationing protocols. That is, the burdens and risks associated with those protocols fell upon other plan members, thereby freeing up resources for meeting Abby's health needs. This too undercuts any moral basis for Abby's request for an exception.

If we all belong to a managed care plan offering a comprehensive package of health benefits, as proposed by the Clinton Administration in 1993, where "all belong" means that (1) there is no morally objectionable sorting of individuals according to socioeconomic status, health status, or race; (2) a single health budget is used to purchase all needed health services; (3) the budget cannot possibly cover all likely needs for health services; (4) the budget is limited through a priority-setting process and mutually agreed upon rationing protocols that apply equally to all plan members; and (5) we are all largely ignorant of our future health care needs (which is mostly true), then the likelihood is that the rationing protocols and health priorities that emerge from a rational process of democratic deliberation will be "just enough" or "fair enough."

We must concede there will be future Coby Howards (the eight-year-old denied a bone marrow transplant for his cancer by the Oregon Medicaid program), or our dear Abby, that is, individuals who will die "prematurely" because they will have been denied the only medical intervention that promised them some additional opportunity for prolonged life for no better reason than that it was the informed and impartial judgment of the community that the benefits promised by these interventions were too small, too costly, and too uncertain. Still, the essential fairness of the process is secure because any member of that community, given the right combination of circumstances, could have a child that was Coby Howard or could themselves be in circumstances comparable to Abby.

We can imagine potentially biasing factors that might undercut the impartiality of the deliberative process. For example, given emerging genetic testing technology, some individuals are likely to know that they are at elevated risk of Alzheimer's disease. But what will necessarily follow from that? They will likely be tempted to give more priority for funding research and treatment related to Alzheimer's disease. If they are

reflective, however, they will realize that trade-offs have to be made within the context of hard budgets, that Alzheimer's disease occurs late in life, and that they are likely to have many other health needs they will want adequately met before they have to worry about Alzheimer's disease.

All of us are to some degree rationally self-interested, but we are also concerned about the health welfare and general well being of others—our children, parents, spouses, siblings, friends, co-workers—all of which considerably dilutes the biasing potential of our personal health concerns and increases our reliance on more rational considerations in the process of public deliberation that yields health priorities and rationing protocols. This feature of our social life protects the overall impartiality and fairness of the priority-setting process within a managed care plan. It does not require of us any heroic moral commitments. A basic sense of justice, commitment to respect fair terms of cooperation freely and mutually agreed to, is all that is necessary, along with average abilities to process rationally, medically relevant information.

A brief aside may be helpful for illustrative purposes. I have witnessed many public conversations about health care rationing under the rubric of the "Just Caring" project.⁷³ Personal responsibility for one's health elicits strong reactions. I pose this issue: Should individuals faced with very high end of life costs due in part to unhealthy personal choices, such as smoking or high-fat diets, be denied costly medical interventions at social expense because they have been irresponsible, and it is unfair that we should have to pay for their irresponsible choices?

The first responders are typically those who strongly agree, most often for the reasons suggested in the prior sentence. With a little supportive prompting the next individuals to speak are those who have some reservations. A sampling of responses would be the following: (1) How "irresponsible" must someone have been with their health to merit denial of expensive life-prolonging care? If they smoked for twenty years but have given up smoking for the past ten, would we still be justified in denying them life-sustaining care? What if during that ten-year period they relapsed four times for several months each time? How many fast food meals would one have to consume per year to be subject to this denial? And who would be keeping track? And who would judge which sorts of anti-health behaviors, such as speeding on a rain-slick highway, would result in this penalty? (2) How would a rationing protocol such as this change the professional role of physicians? Would we have to label some physicians as "prosecutorial physicians" and others as "defense physicians" so that patients would know with whom they could be candid about their health history? Would we have "Fifth Amendment rights" with respect to our

health history? (3) How would we factor in our genetic endowment in making judgments about responsibility for our health circumstances? Some people have genes that result in very high levels of the “bad cholesterol” (and early heart attacks), even if they eat what would appear to be a reasonably healthy diet. (4) And what about individuals who have been victims of abuse, who have taken up less than healthy behaviors (e.g., smoking or over-eating) in connection with that abused behavior?

This is a compact list of some considerations that emerge in this dialogic process. Further, these considerations are often quite effective in getting those who strongly agree with the suggested rationing protocol to change their minds, or at least to express much less confidence in the rightness of their moral judgment. This happens quickly, in part because individuals have not thought carefully about their views, in part because most people are more reasonable and less rigid than we expect. On a small scale, this suggests that rational democratic deliberation can be successful in the real world; it is not just a philosopher’s utopian thought experiment.

We return now to Daniels’ “democracy problem.” If we see rational democratic deliberation as a matter of pure procedural justice, then there is no correcting of results that seem counterintuitive. On the other hand, if it can be corrected by an appeal to some prior notion of what counts as a fair rationing outcome, then we wonder what the point of the democratic process is. Then there is Daniels’ “fair chances/best outcome” problem, which is related to the democracy problem. Recall Alice and Betty who both need a transplant, are the same age, and have spent the same period of time waiting for a transplant. Both will be dead in a week without the transplant. Alice will live only two years, while Betty will live twenty. Who should get the transplant? We get the best outcome, maximum number of quality-adjusted life years saved, by saving Betty. But Alice wants a lottery, arguing that each has an equal right to life. Both have reasonable and morally compelling considerations on their side. Oregon’s democratic deliberations favored the net benefit approach. Does Alice have a moral right to be aggrieved at this result? Has she been harmed in a morally significant sense? Does this undermine the moral authority of the democratic deliberative process for yielding just results?

I believe my model of rational democratic deliberation can respond to Daniels’ challenges. We assume that no matter how fine-grained a conception of health care justice we develop, it will never be fine-grained enough to generate a uniquely correct complete set of just rationing protocols. There are innumerable reasonable, morally permissible trade-offs that might be made in the course of articulating some set of rationing protocols. This moral space is “the domain of just democratic decision-

making.” Again, within this space we cannot identify the “most just” set of rationing protocols possible for our society or our managed care plan. Many possible trade-off patterns will be “just enough,” all things considered, especially when we recall that other values besides justice are a legitimate part of the overall moral equation.

Note that two critical conditions elicit the need for a democratic deliberative process and morally justify that appeal. The first is that we cannot simply allow individual liberty to operate with respect to the resolution of this particular rationing decision. For if we did allow medical, administrative, or consumer discretion to be ultimately and pervasively determinative, then there would be the potential for unjust, arbitrary, and discriminatory results, though I emphasize again that there is a domain beyond justice where such individual discretion, along with social beneficence, is morally permissible.

Imagine, for example, that our managed care plan must decide whether to use high osmolality contrast agents (HOCAs), as opposed to low osmolality contrast agents (LOCAs) for CT scans. HOCAs cost \$10 per dose while LOCAs cost \$180 per dose.⁷⁴ There is one chance in a thousand that the less expensive drug will cause anaphylactic shock, which can be reversed by health professionals who know they must be prepared for such events. The cost difference seems relatively small for any individual case. However, given the millions of CT scans done each year in the United States, we would add at least \$2 billion to total costs if we used only LOCAs, with proportional results in any managed care plan.

It is easy to imagine a health plan choosing the less expensive drug through the sort of democratic deliberative process we envision. If it meant saving \$2 billion per year that could be used to meet what plan members judged to be higher priority health needs for themselves, then that is both rational and just. But nothing is obviously wrong with choosing the more expensive drug. However, if the choice of drug were left to medical or administrative discretion, then it is easy to imagine more knowledgeable and assertive patients demanding the more expensive drug, or physicians permitting daily subtle biases associated with friendship and social class to affect their decisions. This would clearly be unfair. In this case we could allow wealthier consumers to purchase the more expensive drug with their own private resources (unsubsidized by tax deductions); and this would not be unfair because the benefits are very marginal, the majority of other plan members have traded off their access to that drug for other health benefits they judge more important, and other plan members are not harmed by private purchases.

Our second condition for appealing to the rational democratic

deliberative process is that there are plural choice possibilities, all of which have *prima facie* moral and political legitimacy, but none of which are unequivocally superior from a moral, political, or rational perspective. “*Prima facie* moral and political legitimacy” means that the constraints represented by our constitutional principles of health care justice are not violated. This is the situation regarding Alice and Betty. A good case can be made for going with a decision rule that might favor a lottery in this situation, or going with net benefits. Any number of complex decision rules might be adopted, especially if we vary morally relevant case facts, such as age of the individuals, likelihood of survival for each, morally permissible quality of life considerations, and so on. What is morally important is that whatever decision rule we adopt through the democratic deliberative process must be applied consistently over time to all members of the society/health plan. So long as that decision rule is in place and was, in fact, approved by both Alice and Betty, or their democratic representatives, when they did not know their future medical circumstances, neither one will have just cause for moral complaint, no matter what the outcome.

Again, individual participants in this democratic process are ongoing members of this community so that the trade-offs they agree to, some specific distribution of benefits and risks, is a distribution that they are imposing on themselves. That is, in many cases of rationing, say, with reference to the health care needs of the elderly (our future elderly selves), the distribution of benefits and risks does not occur simultaneously for any individual. It would clearly be unfair for a younger individual to derive the benefits of rationing health care for the elderly and then have the option of exiting that health plan as an older person in order to escape the risks and burdens of rationing for an older individual.

To address Daniels’ democracy problem, in the case of Alice and Betty a number of rational “just enough” decision rules might have been chosen. The deliberative process yields a decision among those options, provides a reasoned account for that decision, and legitimates that decision. In that respect, the process is not otiose. A philosopher or managed care administrator could have made “the same decision,” but it would not have the same moral legitimacy because the democratic deliberative process is an essential part of the legitimacy of the decision itself. This is what makes the decision an autonomous choice for all individuals in the group, even if some disagree with that specific choice. A deliberative decision can “go wrong” in all the usual ways, just as scientific research can “go wrong” in all the usual ways. Any particular deliberative decision might violate one of our constitutional principles of health care justice, just as we argue in our

legal system about whether “hate speech” ought to be protected under our constitutional commitment to freedom of speech. Or a particular deliberative decision might fail to take into account relevant scientific facts about Herceptin or the artificial heart or other medical technologies that might be the focus of a rationing decision. Or a particular deliberative decision may fail to give due weight to the pattern of reasons and prior considered judgments of health care rationing within the managed care plan, thereby creating a kind of moral incoherence that would threaten the legitimacy of the decision. In all such cases, the necessary corrective, as in the scientific enterprise, would be more democratic deliberation since no other ultimate authority exists for an appeal.

Two other points must be made briefly with respect to understanding the moral and political legitimacy of rational democratic deliberation. The first is that our constitutional principles of health care justice have emerged and will continue to emerge through the same process of moral discourse that has generated contemporary medical ethics. This means that these principles are modified, refined, and specified through their use in the deliberative process in addressing a broad range of concrete rationing problems. This is analogous to the decision-making process of the U.S. Supreme Court. The adequacy of any particular set of constitutional principles of health care justice will be determined from the perspective of wide reflective equilibrium, which is to say there are coherence considerations among the principles that would have to be worked out, as well as coherence considerations between the principles and proposed sets of rationing protocols within a given managed care plan. In addition, we would have to account for the actual empirical consequences of putting a particular set of rationing protocols in place, plus other empirical considerations related to emerging medical technologies and other aspects of medical practice.

Coherence considerations should not be overstressed. “Rough coherence” among our rationing protocols in a particular managed care plan will be “just enough.” There is no moral necessity of having perfect consistency among various rationing trade-offs that have been rationally democratically approved. Again, to address Daniels’ concerns, the constitutional principles of health care justice provide normative reference points for critically assessing the process and outcomes of our democratic decision-making process; but clearly they are incapable of yielding the outcomes that are needed from the process itself, which is to say that they do not render the process itself otiose.

My second point is this: While these principles and the democratic deliberative process together comprise the domain of health care justice,

there is also this domain beyond justice, a domain of individual freedom and social beneficence. This domain provides moral space in which individuals can use their own private resources to purchase health services not required by just health care policies, and various social groups can choose to be differentially beneficent in ways that reflect their specific comprehensive visions, which may be shared by only a small subset of the membership of a given managed care plan. That is, a church or social group may choose to raise the funds for, say, Herceptin therapy for one of their members who otherwise would be denied it because it is not included in the health services package guaranteed to all. In a liberal society this is not obviously unjust.

V. LAST CHANCE THERAPIES AND RATIONAL DEMOCRATIC DELIBERATION

Before concluding, I return to Daniels' other challenges to argue that my model of rational democratic deliberation is capable of meeting those challenges.

First, recall the moral distinction between "slice-of-time" and "course-of-life" issues of just health care rationing. "Slice-of-time" issues mean that the degree to which an individual has used the health care system in the past will be morally irrelevant to judging whether that individual has a just claim now, say, to an expensive form of life-prolonging medical care. The "course-of-life" perspective means that prior use of the health care system may justly constrain meeting current health needs. My claim is that our deliberative process, properly structured, can determine the moral appropriateness of either perspective in particular circumstances. That is, there are no strong moral principles that absolutely require we choose one or the other in specific circumstances. There is ample deliberative space. However, we should also note that the deliberative process as a whole requires a comprehensive "course-of-life" perspective if we hope to have an overall just, stable, effective approach to health care rationing. Isolated, episodic rationing decisions are almost certain to be unjust.

Some of Daniels' challenges under the "priorities" problem or the "aggregation" problem lose much of their moral force when we recognize this. For example, should we fund TIAHs in the Medicare program or a prescription drug benefit? Should we reduce our level of commitment to artificial hearts for middle-aged individuals if we can purchase instead computerized functional assistance for ten disabled persons with the same funds? The apparent moral difficulty of the examples derives from the unstated assumption that individuals are already ensconced in one or another of these groups by virtue of their being afflicted with a specific medical problem. That is, we are looking at these examples from the

current point in time. But if we go back to that prior point in time when we need to join a health plan, and if we have little knowledge of what our future health needs might be, and if we have to make a decision about a fair and prudent allocation of health resources with a limited budget, then our problem looks like simply a macro version of the Alice and Betty problem, or the Abby problem. That is, there might be a number of morally permissible, “just enough,” trade-offs we might make through a process of rational democratic deliberation, none of which are uniquely morally required.

We need to say more about the slice of time/course of life problem of health care rationing. When we are faced with the need to make a costly rationing decision, why do we sometimes consider morally relevant prior use of the health care system and at other times judge it morally irrelevant? A critic might say:

What generates a presumptively just claim to limited health resources is having a health need. A need is a need; it is morally irrelevant how often that need has occurred for a particular individual (as in the case of a serious chronic illness). If it is a genuine health need, then it must be treated consistently as such.

But my contention is that many other morally relevant considerations can come into play at different points in an individual's life and modify that health need in a way that would justify our giving that “same” need lower priority at one point in time as opposed to another. There are at least six potentially morally relevant variables that could have a bearing on whether we respond to a particular need from a course-of-life perspective or a slice-of-time perspective. These six variables are: (1) quality of life (currently and after treatment), using Daniels' fair equality of opportunity account to give moral concreteness to this notion; (2) age; (3) probability of survival if the patient has access to expensive life-prolonging intervention; (4) number of additional life-years gained as a result of treatment; (5) cost per extra life-year gained; and (6) prior just democratic rationing agreements.

Space does not permit a long explanation of each variable. But I can offer some helpful illustrative analysis in connection with our “last chance therapy” problem. I argue that age is a morally relevant consideration in making some sorts of rationing decisions.⁷⁵ Fair and prudent individuals, ignorant of their future life expectancy, would likely allocate more resources to relatively younger years than is currently the case in our society in order to maximize the probability of their achieving a normal life expectancy. This view implies we could pick an age beyond which

individuals would not have access to the artificial heart at social expense. If we picked age seventy for that purpose, we would be committing ourselves to producing and paying for about 100,000 of these artificial hearts per year, which is roughly the predicted need prior to that age. Why age seventy and why 100,000? These numbers are somewhat arbitrary. Democratic deliberation could alter these numbers up or down justifiably, depending upon a number of variables. Here are some judgments of which I am morally confident that a democratic deliberative process could justly endorse.

First, it would be unjust if there were no public funding for artificial hearts under any circumstances. This is because there would be thousands of relatively young individuals who would be faced with premature death from cardiac failure and no other medical alternative to significantly prolong their lives. It would be unjust to determine access to TIAH entirely by individual ability to pay or ability to elicit a charitable response from some local community.

Second, it would not necessarily be unjust to exclude access to the TIAH from the Medicare benefit package, thereby leaving access to individual ability to pay. To simplify what are in fact very complex possible policy trade-offs, if secure access to prescription drugs for the elderly at \$30 billion per year or more is what we have to give up as a Medicare benefit in order to cover some number of artificial hearts, then I would argue strong egalitarian, utilitarian, and prudential considerations would all justify choosing the prescription drug benefit instead of the TIAH.

Third, it is expected that on average the TIAH would increase the life expectancy of an individual by five years. I would argue that we could justly make differential distributions of the TIAH in connection with predicted life expectancy in specific medical circumstances through the deliberative process. Thus, if an individual were sixty-eight, and if we did permit access to the TIAH at Medicare expense for those under age seventy, we could have a democratically legitimated rule that such an individual would have to have a minimal predicted life expectancy of more than two years in order to have an actual just claim to the TIAH. Such a rule would not violate any constitutional principle of health care justice. That individual could still purchase a TIAH from his or her own resources, which means that a poorer individual in the same circumstances would not have been treated unjustly if he or she then dies at age sixty-eight because he or she cannot afford the TIAH. But there is another part to this rule. We could justly pay for access to the TIAH for younger individuals, say, age sixty or below, even if they were unlikely to survive two years, as long as it was likely they would survive a year, part of the moral justification being that they

had not had the opportunity to live as long a life as others.

Fourth, we can imagine a fifty-two-year-old individual who is HIV-positive, whose life has been sustained for the past twenty years by protease inhibitors (or their successors) at a total cost of \$400,000, who now has a failing heart, and who might survive no more than two to three years with the TIAH. Such an individual has a presumptively just claim to a TIAH, and our constitutional principle of health care justice regarding the protection of fair equality of opportunity would warrant that presumption. His past use of the health care system would be morally irrelevant to making a fair rationing judgment now. But if we alter this scenario just a bit, then we will get a different result. Imagine that he has moderate to advanced AIDS dementia. Then I would argue we could justifiably deny him the TIAH, appealing to the “current and future quality of life criterion” mentioned above. This is a very complicated area for moral analysis, complicated by potential threats to the rights of disabled individuals. But this issue can be justly addressed.

My goal would be to provide individuals with disabilities whatever resources were available in our society for protecting effectively their access to fair and effective equality of opportunity. We have an array of technologies today—often expensive—for providing to individuals functional equivalents for various disabilities. All other things being equal, we would have a strong moral obligation to provide access to such technologies. However, the most crucial morally relevant consideration is that such access will result in effective functional restoration to a significant degree. If such an individual developed heart failure at age fifty-two, as with our HIV-positive patient, then he would have an equally strong claim to a TIAH at societal expense, and prior societal expenditures on his behalf would be morally irrelevant. Similarly, if he were afflicted with some untreatable serious dementia, as with our HIV-positive patient who developed AIDS dementia, then he could be justly denied access to a TIAH, and this would not represent any form of unjust discrimination against disabled individuals, especially if it were the case that there were rational democratic legitimation of a general rationing guideline that would deny our own possible future demented selves access to expensive life-prolonging medical care under those circumstances. As nearly as I can tell, such a democratically endorsed judgment would not violate any constitutional principle of health care justice. It would not be discriminatory in a morally objectionable sense, nor would it violate the equal moral respect to all persons.

This analysis provides us with a helpful perspective for addressing some specific instances of last chance therapies. Again, these are just

schematic comments. Consider Herceptin. Many of the women faced with metastatic breast cancer will be relatively young or middle-aged. This would typically trigger the judgment that justice requires doing everything medically possible to prolong their lives for as long as they find their lives worth living so that they have an opportunity to achieve a normal life expectancy. However, the background assumption is that the life gained is significant and costworthy. This would be a questionable assumption if the average gain in life expectancy is only five months more than alternative available therapies, and if the cost of achieving that result is more than \$70,000, which works out to a cost per QALY of about \$160,000. Here Eddy's strategy in thinking about breast cancer options is quite apropos.

We must ask ourselves whether there are other investments for health dollars where we can save more high-quality life years at a lower cost. But perhaps a morally and politically better way to ask the question would be to consider whether there are alternate investments in cancer prevention or cancer therapy—especially cancers for which women might be at greater risk—that would reasonably and justifiably command the dollars otherwise to be spent on Herceptin. Again, if we imagine Eddy's thousand women working for a company with a better-than-average (but limited) health benefit package at an earlier point in time deciding collectively and autonomously what to include in that benefit package, it is hard to imagine that they would include Herceptin, given all their other possible health care needs. Thus, women denied access to Herceptin at social expense would not be treated unjustly.

This social judgment has other beneficial effects worth noting. It provides helpful information to women and their families in such circumstances. It says that a thoughtful social judgment has been made that this therapy is marginally beneficial at best and not costworthy, that a family that was tempted to sacrifice access to a college education for their children in order to purchase Herceptin would be making an unwise choice. Similarly, churches and other social organizations hold fundraisers to help underwrite the costs of very expensive medical interventions that offer the only hope for individuals otherwise faced with imminent death. This is the domain of beneficence, charity freely given. We generally applaud such efforts, though if the analysis above is correct, the implication is that there will be times when such applause ought to be withheld.

Though we see charitable responses as something "freely offered," not a matter of moral obligation in most specific instances, this does not mean that thoughtless or unreflective charitable giving should be commended. Again, we need to keep in mind that charitable dollars are limited; few

churches or other social organizations could afford to raise the funds for all expensive, life-prolonging medical care their members might need that are not covered by public or private insurance. Thus, if there is a public, democratically ratified rationing protocol that would deny women with metastasized breast cancer access to Herceptin for the reasons given above, then the implicit message to socially beneficent organizations is that they should not imprudently expend their resources to assist such individuals in unfortunate circumstances to gain access to Herceptin.

This same analysis helps us address the challenges posed by the Rule of Rescue and identified individuals needing access to last chance therapies. Nothing will diminish the psychological difficulty of dealing with these circumstances. The Rule of Rescue in its traditional application is morally compelling, in part, because it rarely needs to be employed, at least outside health care. But given our enormously expanding technological capacity for maintaining life, and focusing on the urgency of the present medical circumstances of an individual, the Rule of Rescue has pervasive applicability. It is wholly without the moral context that originally made it a reasonable moral rule. Applied to health care in this promiscuous fashion, it will completely undermine any fair or reasonable effort at health care rationing and health care cost containment.

Finally, the identified individuals in these urgent, tragic, and unfortunate circumstances are certainly entitled to a caring and compassionate response from our society. There are many ways in which this compassionate response might be conveyed. But the moral requirement of compassion must not be confused with the moral obligations of justice. Providing such unfortunate individuals (women wanting access to Herceptin) with health resources to which they have no just claim, thereby diminishing the pool of resources to which others have a just claim, represents a failure of both compassion and justice.

References

1. Norman Daniels & James Sabin, *Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers*, 26 PHIL. & PUB. AFF. 303 (1997); see also Norman Daniels & James Sabin, *Last Chance Therapies and Managed Care: Pluralism, Fair Procedures and Legitimacy*, HASTINGS CENTER REP., Mar.-Apr. 1998, at 27.
2. I emphasize that I am talking about the structure of the U.S. health care system as it is now (more or less) to make clear that I am not writing a utopian essay. Still, two features of our system make health care justice virtually impossible: lack of universality and the link to private employers. The Clinton health reform plan from 1993 showed that both of these features of our health system could be radically altered and that such alteration was politically realistic. Although the Clinton plan failed, it did not fail because it embraced universal coverage or because it severed the link between health insurance and employment.
3. EZEKIEL EMANUEL, *THE ENDS OF HUMAN LIFE: MEDICAL ETHICS IN A LIBERAL POLITY* (1991).
4. MICHAEL SANDEL, *LIBERALISM AND THE LIMITS OF JUSTICE* (1982).
5. JOHN RAWLS, *POLITICAL LIBERALISM* (1993).
6. Two of the more prominent writers about health care rationing who would endorse this point are David Eddy and Paul Menzel. See generally DAVID EDDY, *CLINICAL DECISION MAKING: FROM THEORY TO PRACTICE* (1996); PAUL T. MENZEL, *MEDICAL COSTS, MORAL CHOICES: A PHILOSOPHY OF HEALTH CARE ECONOMICS IN AMERICA* (1983); PAUL T. MENZEL, *STRONG MEDICINE: THE ETHICAL RATIONING OF HEALTH CARE* (1990).
7. Dennis J. Slamon et al., *Use of Chemotherapy Plus a Monoclonal Antibody Against HER2 for Metastatic Breast Cancer that Overexpresses HER2*, 344 NEW ENG. J. MED. 783, 783 (2001); see also Brett Chase, *Gene Test Company Soaring*, CHICAGO SUN-TIMES, Sept. 9, 2001, at 41.
8. The total prevalence of congestive heart failure in the United States is 4.7 million. AMERICAN HEART ASSOCIATION, 2001 HEART AND STROKE STATISTICAL UPDATE 19 (2000), available at <http://www.americanheart.org/presenter.jhtml?identifier=1928> [hereinafter HEART UPDATE]. Total deaths from all cardiovascular diseases in the United States in 1998 were 949,619. Total prevalence of all forms of cardiovascular disease in the United States is sixty-one million. *Id.* at 4. See also Mariell Jessup, *Mechanical Cardiac-Support Devices—Dreams and Devilish Details*, 345 NEW ENG. J. MED. 1490 (2001); Eric A. Rose et al., *Long-Term Use of a Left Ventricular Assist Device for End-Stage Heart Failure*, 345 NEW ENG. J. MED. 1435 (2001).
9. *Fourth Abiocr Heart Patient Recovering*, BOSTON GLOBE, Oct. 19, 2001, at A15.
10. Of all deaths from heart disease in the United States, about 220,000 are sudden. HEART UPDATE, *supra* note 8, at 3-4. Of the patients who died from heart disease, half could have benefited from a TIAH if it had been provided before their disease progressed too far. This is a very approximate figure. The reader should know that considerable confusion of medical and political/economic judgments occurs when decisions must be made regarding the number of candidates for the

TIAH. This was also true in the early years of dialysis. At that time, clinically suitable candidates for dialysis were thought to be patients between fifteen to forty-five-years-old. Today the fastest growing cohort of dialysis patients is over age seventy-five. Aaron and Schwartz document that in Britain in the 1980s "medical judgments" of suitability for dialysis masked what were really rationing judgments based on economics alone. HENRY J. AARON & WILLIAM B. SCHWARTZ, *THE PAINFUL PRESCRIPTION: RATIONING HOSPITAL CARE* 34-37 (1984).

11. See Shoo K. Lee et al., *Variations in Practice and Outcomes in the Canadian NICU Network: 1996-1997*, 106 *PEDIATRICS* 1070, 1076 (2000). This study finds that 7% of about 3,800 very low birth weight (VLBW) infants in seventeen Canadian NICUs (which represented approximately 75% of the total Canadian NICU beds) had necrotizing enterocolitis (NEC). That is approximately 300 infants. The U.S. experience is the same, which would mean about 4,000 infants are born each year in the United States with the disorder. See James A. Lemons et al., *Very Low Birth Weight Outcomes of the National Institutes of Child Health and Human Development Neonatal Research Network, January 1995 Through December 1996*, 107 *PEDIATRICS* e1 (2001), at <http://www.pediatrics.org/cgi/content/full/107/1/e1> (finding that 7% of VLBW infants in fourteen NICU sites had NEC). For survival, all of the infants would need either TPN or PN, depending upon degree of intact remaining gut.

12. Jon A. Vanderhoof & Alan N. Langnas, *Short-Bowel Syndrome in Children and Adults*, 113 *GASTROENTEROLOGY* 1767, 1774 (1997).

13. *Id.* at 1774 ("The most common life-threatening problem to face patients

with intestinal failure is the development of total parenteral nutrition-induced liver failure.").

14. See J.H. Best et al., *Trends in Expenditures for Medicare Liver Transplant Recipients*, 7 *LIVER TRANSPLANT* 858 (2001); J.C. Bucuvalas et al., *Predictors of Cost of Liver Transplantation in Children: A Single Center Study*, 139 *J. PEDIATRICS* 66 (2001).

15. Data on file with author. Also, Vanderhoof & Langnas report that prospects for liver/small bowel transplants have improved over the past several years with one-year survival rates of about 65%. Vanderhoof & Langnas, *supra* note 12, at 1774. Still, five-year survival rates will be smaller because of the many medical complications entailed by this surgery.

16. Stephen Heffler et al., *Health Spending Growth Up in 1999; Faster Growth Expected in the Future*, *HEALTH AFF.*, Mar.-Apr. 2001, at 193, 194.

17. I need to emphasize the phrase "acceptable quality of life." We are generally not talking about life-prolonging interventions that compromise quality of life to such a degree that most reasonable persons would reject them.

18. Slamon et al., *supra* note 7, at 786.

19. See *Study: HAART Less Costly Than Treatment for AIDS*, *AIDS ALERT* (American Health Consultants, Atlanta, GA), Feb. 1, 2001, at 26, at http://www.ahcpub.com/ahc_online/aa.html.

20. U.S. Renal Data System, *USRDS 2001 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*, Section K, Economic Costs of ESRD, Table K20 2001 at <http://www.usrds.org/adr.htm>. [hereinafter *USRDS Report*]. The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S.

government.

21. There is obvious room for argument here. The boundaries I am suggesting are not perfectly sharp. The TIAH, for example, promises (for the future) average gains in life expectancy of five years. It is unlikely that any of the four patients that currently have these devices will survive that long. But younger patients in the future, with fewer co-morbid conditions, are likely to survive much more than five years, making the device for them look more like dialysis and less like Herceptin.

22. E. HAAVI MORREIM, *BALANCING ACT: THE NEW MEDICAL ETHICS OF MEDICINE'S NEW ECONOMICS* 45-70 (1991).

23. The Helga Wanglie case is one well-known example of this issue. Helga Wanglie was eighty-six-years-old and in a persistent vegetative state for fourteen months before she died. Her care for that period cost about \$800,000. Many, perhaps a vast majority of us, would regard such care as wasteful and inappropriate. But her husband and children did not. Ronald Cranford, *Helga Wanglie's Ventilator*, *HASTINGS CENTER REP.*, July- Aug. 1991, at 23, 24.

24. In this Article I cannot rehearse all the arguments and evidence to support that point. See, e.g., GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* (1978); DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* (1986) [hereinafter *SETTING LIMITS*]; DANIEL CALLAHAN, *WHAT KIND OF LIFE: THE LIMITS OF MEDICAL PROGRESS* (1990) [hereinafter *WHAT KIND OF LIFE*].

25. Leonard M. Fleck, *Pricing Human Life: The Moral Costs of Medical Progress*, 34 *CENTENNIAL REV.* 227 (1990).

26. H. TRISTRAM ENGELHARDT, JR., *THE FOUNDATIONS OF BIOETHICS* 375-410 (2d ed.

1996).

27. For more detailed criticisms of Engelhardt's position, see my earlier critical assessment of his libertarian views on health care. Leonard M. Fleck, *Just Health Care (I): Is Beneficence Enough?*, 10 *THEORETICAL MED.* 167 (1989) [hereinafter *Just Health Care (I)*]. See also Ezekiel Emanuel & Linda Emanuel, *Preserving Community in Health Care*, 22 *J. HEALTH POL., POL'Y & L.* 147, 165-69 (1997).

28. NORMAN DANIELS, *JUST HEALTH CARE* 1-35 (1985) [hereinafter *JUST HEALTH CARE*].

29. USRDS Report, *supra* note 20, at Table K20. Per patient cost in 1999 for all end stage renal disease was \$45,286.

30. The number of ESRD patients in 1998 was 323,821, with 85,000 new cases each year, and 63,000 deaths. *HEART UPDATE*, *supra* note 8, at 18. The number of ESRD patients is multiplied by per patient cost to get approximate total Medicare costs.

31. Allen Buchanan, *Managed Care: Rationing Without Justice, but Not Unjustly*, 23 *J. HEALTH POL., POL'Y & L.* 617 (1998).

32. *Id.* at 618.

33. To be clear, Buchanan is not endorsing this as a morally unalterable state of affairs. On the contrary, his goal is to convince middle class members of managed care plans that if there is no just access to health care for the uninsured, then there can be no justice for them either. Secure access to needed costworthy health care requires that the middle class construct explicit socially legitimated understandings of health care justice. *Id.* at 632-33.

34. RAWLS, *supra* note 5, at 54-58.

35. Norman Daniels, *Rationing Fairly: Programmatic Considerations*, 7 *BIOETHICS* 224, 224 (1993) [hereinafter *Rationing*

Fairly].

36. MICHAEL WALZER, SPHERES OF JUSTICE: A DEFENSE OF PLURALISM AND EQUALITY (1993).

37. I explain and defend this point more fully in two of my earlier articles. See *Just Health Care (I)*, *supra* note 27; Leonard M. Fleck, *Just Health Care (II): Is Equality Too Much?*, 10 THEORETICAL MED. 301 (1989).

38. I explain and defend in greater detail what non-ideal justice is in an earlier article. See Leonard M. Fleck, *DRGs: Justice and the Invisible Rationing of Health Care Resources*, 12 J. MED. & PHIL. 165, 165-76 (1987) [hereinafter *DRGs*].

39. See, e.g., RAWLS, *supra* note 5, at 212-54; John Rawls, *The Idea of Public Reason Revisited*, 64 U. CHI. L. REV. 765 (1997); John Rawls, *Reply to Habermas*, 92 J. PHIL. 132 (1995).

40. See NORMAN DANIELS, JUSTICE AND JUSTIFICATION: REFLECTIVE EQUILIBRIUM IN THEORY AND PRACTICE (1996), especially chapters 1-3, 8, and 16. Wide reflective equilibrium is a coherentist approach to moral justification. It rejects the idea of a moral reality "out there" that correct moral judgments must match to be justified. Instead, it relies upon a web of considerations to justify and stabilize our moral judgments. That web includes scientifically established facts about human beings and the world, well-grounded moral theories, and "considered moral judgments" of all degrees of generality that have proven consistently effective in addressing real world moral problems. Justification in the law seems to work in much the same way with appeal to facts about the world, constitutional principles, established law, and case precedent to justify legal judgments made with respect to concrete legal conflicts.

41. Daniels & Sabin, *supra* note 1

(citing both articles).

42. Leonard M. Fleck, *Just Health Care Rationing: A Democratic Decisionmaking Approach*, 140 U. PA. L. REV. 1597, 1617-21 (1992) [hereinafter *Democratic Approach*].

43. Emanuel & Emanuel, *supra* note 27.

44. EMANUEL, *supra* note 3, at 97-244.

45. *Id.* at 185-92.

46. See RAWLS, *supra* note 5, at 133-73.

47. JUST HEALTH CARE, *supra* note 28.

48. *Rationing Fairly*, *supra* note 35.

49. The goal of the Oregon priority setting process was to establish a comprehensive ranking of health care interventions from those most worthy of public funding to those least worthy. A total of 709 medical conditions and associated treatments (called condition-treatment pairs) were so ranked using community values (elicited from community dialogues, polling, and focus groups), expert medical opinion regarding effectiveness, and relevant cost data. The comprehensiveness of the process and the appeal to explicit community values made this a unique social experiment. The fact that the process was limited to a much-expanded Medicaid population (a major goal of the process) opened its backers to moral criticism since Medicaid recipients were under-represented in the process. See Michael Garland, *Oregon's Contribution to Defining Adequate Health Care*, in HEALTH CARE REFORM: A HUMAN RIGHTS APPROACH 211 (Audrey R. Chapman ed., 1994).

50. Leonard M. Fleck, *Just Caring: Oregon, Health Care Rationing, and Informed Democratic Deliberation*, 19 J. MED. & PHIL. 367, 374-80 (1994) [hereinafter *Oregon*].

51. *Rationing Fairly*, *supra* note 35, at 225-27.

52. See PETER UBEL, PRICING LIFE: WHY IT'S TIME FOR HEALTH CARE RATIONING 1-10 (2000). QALYs were introduced by health

researchers to facilitate fine-grained effectiveness comparisons across numerous medical outcomes. A scale of 0 to 1 is used. Earlier discussions had only focused on saving life-years. But it was noted by some that we should not spend as much money on a life year of 0.1 quality as opposed to 0.9 quality. Many see this as threatening to the rights of disabled individuals who need expensive health care.

53. *Rationing Fairly*, *supra* note 35, at 227-28.

54. See Jackie Koszczuk, *Dried-Up Surplus Shelves RX Deal; Congress is Unlikely to Expand Medicare*, PITTSBURGH POST-GAZETTE, Aug. 31, 2001, at A17.

55. *Rationing Fairly*, *supra* note 35, at 232.

56. WHAT KIND OF LIFE, *supra* note 24, at 31-68.

57. The cost of transplantation for either the TIAH or LVAD would be approximately the same at \$160,000. See Byron Spice, *Heart Transplant Alternative?; Implantable Pump Lets Some Patients Live Longer, Live Well*, PITTSBURGH POST-GAZETTE, Nov. 13, 2001, at A3.

58. HEART UPDATE, *supra* note 8.

59. See David Eddy, *The Individual vs. Society: Is There a Conflict?* 265 JAMA 1446, 1446 (1991) [hereinafter *Individual vs. Society*].

60. See David Eddy, *High-Dose Chemotherapy with Autologous Bone Marrow Transplantation for the Treatment of Metastatic Breast Cancer*, 10 J. CLINICAL ONCOLOGY 657 (1992).

61. Slamon et al., *supra* note 7, at 783.

62. Edward A. Stadtmauer et al., *Conventional-Dose Chemotherapy Compared with High-Dose Chemotherapy Plus Autologous Hematopoietic Stem-Cell Transplantation for Metastatic Breast Cancer*, 342 NEW ENG. J. MED. 1069 (2000); see also Michelle M.

Mello & Troyen A. Brennan, *The Controversy over High-Dose Chemotherapy with Autologous Bone Marrow Transplant for Breast Cancer*, HEALTH AFF., Sept.-Oct. 2001, at 101.

63. See UBEL, *supra* note 52, at 67-95. Ubel cites social research showing people will often prefer less economically efficient means of saving lives if this means more people will have "a chance" of having their lives prolonged. That is, they categorically reject rules that would exclude individuals from any access to expensive life-prolonging care because their chance of benefit was too small.

64. Coby Howard died at age eight, having fallen short of raising the \$100,000 needed for a bone marrow transplant. Loyola University Hospital in Chicago refused to attempt separation of the Lakeberg twins. The ethics committee of the Hospital argued that this was an unjust use of resources needed to meet the health needs of the poor in the area. The twins were separated in Philadelphia at a cost of more than \$1 million. Since they shared a single six-chambered heart that needed to be reconstructed surgically, one twin was sacrificed in surgery. The other survived almost one year, never having left the hospital.

65. The Christine deMeurers case is a good example of this. See Alex London, *Bone Marrow Transplants for Advanced Breast Cancer: The Story of Christine deMeurers*, in ETHICAL ISSUES IN MODERN MEDICINE 686 (John Arras & Bonnie Steinbock eds., 1999).

66. I discuss precisely this example in my article *Just Caring: Managed Care and Protease Inhibitors*, in ETHICAL ISSUES IN MODERN MEDICINE 679 (John Arras & Bonnie Steinbock eds., 1999).

67. I speak of "constitutional principles of health care justice" in a metaphorical

sense. These are the broad moral principles needed to constrain democratic deliberation about health care rationing by identifying rationing protocols or practices that are inappropriate (i.e., violate one of these principles). In my conception, constitutional principles of health care justice would include the "publicity principle" (putting out of bounds invisible rationing), an "equal respect for persons principle" (putting out of bounds a range of improper discriminatory judgments), and a "fair equality of opportunity principle" (following Daniels in distinguishing health interventions that make stronger or weaker just claims on health resources). See JUST HEALTH CARE, *supra* note 28. I lay out the core of my views in two earlier articles: *Democratic Approach*, *supra* note 42, and *Oregon*, *supra* note 50. Space does not permit a full account of these constitutional principles of health care justice or my model of rational democratic deliberation. This will be found in a book-length manuscript I am now finishing for Oxford University Press titled JUST CARING: THE MORAL AND PRACTICAL CHALLENGES OF HEALTH REFORM AND HEALTH CARE RATIONING (forthcoming 2003). In the meantime I am sympathetic to the work of Gutmann and Thompson, who also elaborate constitutional principles that would constrain democratic deliberation. See AMY GUTMANN & DENNIS THOMPSON, *DEMOCRACY AND DISAGREEMENT: WHY MORAL CONFLICT CANNOT BE AVOIDED IN POLITICS AND WHAT SHOULD BE DONE ABOUT IT* (1996). Finally, a very important essay foundational to my conception of deliberative democracy is Joshua Cohen, *Deliberation and Democratic Legitimacy*, in *DELIBERATIVE DEMOCRACY: ESSAYS ON REASON AND POLITICS* 67 (James Bohman & William Rehg eds., 1997).

68. RAWLS, *supra* note 5, at 66-71.

69. I have argued at great length in two earlier articles for this point against Calabresi and Bobbit, who would defend invisible rationing to avoid the risk of social divisiveness, especially when life itself is at stake, as in last chance therapy situations. *Just Health Care (I)*, *supra* note 27. See also *DRGs*, *supra* note 38; Leonard M. Fleck, *Justice, HMOs, and the Invisible Rationing of Health Care Resources*, 4 *BIOETHICS* 97 (1990). Daniels & Sabin, *supra* note 1 (citing both articles), are equally strong defenders of Rawls' publicity condition and critics of invisible forms of health care rationing. The main problem with invisible rationing, from a moral point of view, is that it subverts both social trust and our capacity for democratic deliberation.

70. *Oregon*, *supra* note 50, at 374-75.

71. *Individual vs. Society*, *supra* note 59.

72. *Id.*

73. The first of these projects was conducted in Goshen Indiana over an eighteen-month period (1985-86) with the help of a grant from the Indiana Committee for the Humanities and the Goshen Hospital and Health Care Foundation. The concern of the hospital (and its community board) at the time was the effect of health care rationing, effected through the then new Medicare DRGs on the elderly. The results of that community dialogue project are summarized in a thirty-two page report. GOSHEN HOSPITAL AND HEALTHCARE FOUNDATION, *JUST CARING: JUSTICE, HEALTH CARE, AND THE GOOD SOCIETY* (1986) (pamphlet on file with author).

74. See David Eddy, *Applying Cost-Effectiveness Analysis*, 268 *JAMA* 2575, 2575 (1992) (noting that LOCAs typically cost ten to twenty times more than HOCAs).

75. See Leonard M. Fleck, *Justice, Age*

Rationing, and the Problem of Identifiable Lives,
in HEALTH CARE FOR AN AGING POPULATION
93 (Chris Hackler ed., 1994); *see also*
SETTING LIMITS, *supra* note 24; NORMAN
DANIELS, AM I MY PARENTS' KEEPER? (1988).

The Hippocratic Oath as Literary Text: A Dialogue Between Law and Medicine

Lisa R. Hasday, J.D.*†

I swear by Apollo Physician and Asclepius and Hygieia and Panacea and all the gods and goddesses, making them my witness, that I will fulfill according to my ability and judgment this oath and this covenant:

To hold him who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine, and to regard his offspring as equal to my brothers in male lineage and to teach them this art—if they desire to learn it—without fee and covenant; to give a share of precepts and oral instruction and all the other learning to my sons and to the sons of him who has instructed me and to pupils who have signed the covenant and have taken an oath according to the medical law, but to no one else.

I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.

I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and my art.

I will not use the knife, nor even on sufferers from stone, but will withdraw in favor of such men as are engaged in this work.

Whatever house I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular sexual relations with both female and male persons, be they free or slaves.

Whatever I may see or hear in the course of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about.

If I fulfill this oath and do not violate it, may it be granted to me to enjoy life and art, being honored with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot.

* Lisa R. Hasday is currently a Law Clerk to Judge Sidney R. Thomas on the U.S. Court of Appeals for the Ninth Circuit. She received her B.A. in 1998 and J.D. in 2001 from Yale University.

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An oath represents the strongest possible commitment a speaker can make. In linguistic parlance, an oath belongs to a specific class of statements known as “speech acts” or “performative utterances.” By their very articulation, such statements have the power to put their contents into effect.² In short, “speech acts” do more than just *say* something; they also *do* something.³ By swearing an oath, for example, a person promises to perform certain actions in the world. This promise is all the more powerful if, as is usually done, the oath taker swears upon some divine power and utters the oath in a public setting. Perhaps the most well-known example of an oath is the Hippocratic Oath—the famous code of medical ethics often taken by those about to begin medical practice.

This Article examines the use of this important text in contemporary judicial opinions. In these settings, the Oath does not promise to perform what it says, thus losing its quality as a speech act. We hear the voice not of the oath taker but rather that of the court. The judicial references to the Hippocratic Oath create a kind of “secondary” performative effect that serves to convince the reader of the Oath’s enduring legacy, even if courts do not abide by the Oath’s literal words.

The main argument of this Article is that the Hippocratic Oath exerts a powerful influence on modern legal controversies implicating medical ethics, leading courts to adopt an overly doctor-centered view of these disputes. This doctor-centered view results from two distinct phenomena: first, the history and enduring legacy of the Oath have served to dignify the medical profession, causing courts to treat social issues as medical ones and to displace difficult ethical choices onto doctors; and second, judicial reasoning based on the Oath treats the patient as subordinate to the physician, because the text of the Oath itself places a greater emphasis on doctors than on patients.

Part I provides a brief overview of the Oath’s history, which points to the Oath’s capacity to distinguish and legitimize the medical profession. Part II examines the text of the Hippocratic Oath, analyzing the ways in which the Oath places much more emphasis on the physician than on the patient. Part III demonstrates how leading court opinions on abortion regulation, medical treatment of mentally ill prisoners, physician-assisted suicide, and physician involvement in administering the death penalty, incorporate the Oath’s emphasis on doctors over patients even as they flout some of the Oath’s specific prohibitions. It also explores how courts have deferred to the modern medical profession’s view—in effect allowing doctors to regulate themselves on social issues where the government and judiciary ought to have a greater role. The Conclusion argues that courts should be less passive about adopting the doctor-centered view of medical

regulation embodied in the Hippocratic Oath, because reliance on the Oath in its classic form enacts that document's devaluation of patients, and even reliance on more modern, patient-centered versions unduly privileges medical approaches to social issues.

I. THE ENDURING LEGACY OF THE OATH

The Hippocratic Oath has stood as a major document of medical ethics from antiquity to the current day. Although the precise circumstances of its origin are unclear,⁴ the Oath made its earliest recorded appearance in the first century A.D.⁵ and is generally attributed to the Greek physician Hippocrates (c. 460-380 B.C.).⁶ Hippocrates and his followers used the Oath to distinguish the medical profession as a discipline unique from other occupations, most notably from philosophy⁷ and from sorcery.⁸ Prior to the Hippocratic era, the doctor and the sorcerer tended to be the same person. That person had both the power to heal and the power to kill.⁹ The mid-first-century Roman physician Scribonius Largus, the first extant ancient author to mention the Oath, noted that Hippocratic medicine was exclusively about healing, not harming: "Hippocrates, the founder of our profession...valued it highly that whoever conducted himself according to his principle with a devoted and consecrated heart would preserve the reputation and dignity of medicine, for medicine is the science of healing, not of doing harm."¹⁰

About a half-century later, Soranus of Ephesus, a Methodist physician, reported a controversy regarding the use of abortives. One party allowed abortives, but only in cases involving medical complication. The other party banished abortives, citing the Hippocratic Oath and noting that "it is the *specific task of medicine to guard and preserve what has been engendered by nature*."¹¹ The distinction between doctor and seer is documented in a fifth-century treatise attributed to Hippocrates entitled *On the Sacred Disease*, which "scorns the cathartic healer in the name of nature."¹² The Greeks may have been particularly interested in separating medicine from sorcery because sorcery was a traditionally female occupation.¹³ In addition to separating themselves from other disciplines, the Hippocratics sought to amass a body of knowledge that was peculiar among the then-emerging schools of medicine.¹⁴

Since the beginning of the scientific revolution, the Oath and variants of it have been recited at medical institutions across Europe.¹⁵ When formal medical education came to the other side of the Atlantic, so did the Hippocratic Oath. The Oath was particularly popular among American doctors in the mid-nineteenth century.¹⁶ And, again, "orthodox" practitioners demanded adherence to the Oath to mark themselves off

from other healers.¹⁷ Still today, the Oath continues to demand that physicians maintain ethics higher than those expected of society in general,¹⁸ and it remains a code of professional identity that marks off “proper” medicine from various forms of alternative healing practices.¹⁹

Many medical schools across the country continue to administer the Oath to their students in formal, public ceremonies. In fact, the use of the Hippocratic Oath in medical schools has increased dramatically throughout the course of the twentieth century.²⁰ According to one set of statistics, a mere twenty American medical schools administered the Hippocratic Oath or some version of it in 1928. By 1965, the numbers had risen to sixty-eight out of ninety-seven medical schools. The numbers have continued to rise. In 1989, at least 119 medical schools administered an oath, about sixty administering some version of the Hippocratic Oath.²¹ In 1993, the 135 American medical schools and twelve Canadian medical schools responding to a survey reported that their graduates took a professional oath, with sixty-nine schools in both countries administering some form of the Hippocratic Oath.²²

Moreover, the Hippocratic Oath retains enormous symbolic resonance for the doctors who take it, as it marks the moment when they enter a privileged profession distinguished from the rest of society. In the words of one nostalgic physician:

To most of us...the solemn and moving high spot of the doctor's career was the moment when the class stood up; and with grim or beaming faces, intoned the Oath of Hippocrates. The Oath symbolized crossing the bridge into a kind of priesthood.... No matter if some of the wording of the Oath seemed archaic. It had style and it told the public that, like the priest, we were sworn to solemn vows.²³

As this testimony indicates, the Oath very much evokes the larger medical community into which the physician is about to enter, creating what Heinrich von Staden calls a “sense of belonging to a transgenerational professional collectivity.”²⁴ Indeed, generations upon generations of medical practitioners have sworn to follow the Oath's words.

II. THE PHYSICIAN'S OATH: TRIUMPH OF DOCTORS OVER PATIENTS

The word “injustice” appears twice in the Hippocratic Oath. The oath-takers swear to “keep [the sick] from harm and *injustice*” and promise that they themselves will “remain...free of all intentional *injustice*.”²⁵ This momentary allusion to patients' rights notwithstanding, the Hippocratic Oath in fact expresses much greater concern about the role of the

physician. Indeed, it is telling that the Oath is sometimes called “The Physician’s Oath.”²⁶ The Oath places the physician in the foreground. The patient recedes into the distance, the unabashed object of the physician’s artistry. In this Part, I examine the text of the Hippocratic Oath to demonstrate its emphasis on the physician, and the larger medical community, to the exclusion of the patient.

From beginning to end, the Oath devotes much greater attention to the quality of the physician’s relationships with his gods, his teacher, and his students, than with his patients. The very order in which these parties are discussed underscores an implied hierarchy that places the gods at top and the patients at bottom. The patient, as defined in the Oath, is the ignorant, passive bearer of sickness and disease—a mere object to be examined and treated—rather than an autonomous, full participant in the healing process.

The Oath begins with an invocation to “Apollo Physician and Asclepius and Hygieia and Panacea and all the gods and goddesses.”²⁷ The physician calls upon these deities to serve as witnesses to the truth of what he is about to say. That all the divine powers are called upon is a usual feature of an ancient oath²⁸ and subsequent oaths throughout history, from the book of Genesis²⁹ to medieval canon law³⁰ to English common law³¹ to the current day.³² However, the appeal to the heavens in the Hippocratic Oath bears particular significance, as the Oath represents what might be considered a deeply religious conversion: that of layperson into medical professional. Walter Burkert has likened the practice of taking the Hippocratic Oath to a religious initiation ceremony, such as entrance into the priesthood, in that both involve the transmission of “sacred” information and the exclusion of outsiders: “Holy things are shown to holy men; such things are not permitted for the profane until they are initiated through the rites of knowledge.”³³

Next, the Oath positions the physician in relation to his teacher and students. Here the physician becomes part of a new family, as he vows to treat his teacher like a parent and his teacher’s children like his brothers. At the same time, the physician promises to pass down his knowledge to his own sons, as well as to his teacher’s sons and to all other “pupils who have signed the covenant and have taken an oath according to the medical law, but to no one else.”³⁴

The Oath then proceeds to address the ways in which the physician intends to comport himself both as a professional practitioner and as a private individual. After the physician affirms that he “will apply dietetic measures for the benefit of the sick according to [his] ability and judgment [and] keep them from harm and injustice,”³⁵ the Oath lists a number of

specific actions from which the physician vows to abstain. The oath taker promises neither to administer nor suggest the use of “a deadly drug,” not to give a woman “an abortive remedy,” not to use “the knife,” not to engage in “mischief and in particular...sexual relations with both female and male persons,” and not to “spread abroad” what he observes in the course of treatment.³⁶ In modern parlance, these prohibitions translate into bans on physician-assisted suicide, abortion, surgery,³⁷ sexual relations between doctors and their patients, and breaches of doctor-patient confidentiality.

Finally, the Oath concludes with a determined resolution on the part of the physician: “If I fulfill this oath and do not violate it, may it be granted to me to enjoy life and art, being honored with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot.”³⁸ The Oath’s closing words seem to indicate that the Hippocratic physician is more concerned about whether he will enjoy eternal fame than whether his patients will live life to the fullest.

This conception of the physician’s role is elaborated in the following passage from *Decorum*, another work attributed to the Hippocratic corpus of medical writings:

[W]atch also the faults of the patients, many of whom often lie about the taking of things prescribed. For by not taking disagreeable drinks, purgative or other, they sometimes die. The fact is never admitted but the blame is thrown upon the physician.... Perform all these things quietly, skillfully, and conceal from the patient most of what you are doing. Give necessary orders cheerfully and with serenity, turn his attention away from what is being done to him; sometimes you have to reprimand him sharply and severely, and sometimes you must comfort him with attention and solicitude.³⁹

Here, too, the concern is for the reputation of physicians, specifically that they not be blamed for the deaths of patients who fail to take prescribed medications. In recognizing that “many” patients disobey their doctors’ orders, the passage acknowledges a level of patient autonomy that is ignored in the Hippocratic Oath. Nonetheless, the *Decorum* passage places its main emphasis on the physician’s active role. The doctor performs, conceals, gives orders, distracts, reprimands, and comforts. This string of active verbs indicates that the physician we encounter in the *Decorum* passage is not so different from the one we see in the Oath.⁴⁰

The Hippocratic Oath is exceptional, however, in that it is the most personal of the more than fifty extant Hippocratic works from the classical period. Oaths naturally focus on the oath taker; the very genre after all

requires a narrator speaking in the first person. Yet nowhere else within the Hippocratic corpus does the first-person singular possessive pronoun "I" and the possessive adjective "my" or "mine" appear as often as in the Oath.⁴¹ This personalization of the Oath seems to be a way of emphasizing the oathmaker's significant individual investment in his vows. While the commitments expressed in the Oath largely concern professional conduct, the extensive use of the first-person singular form indicates that the oathmaker is committed to apply the Oath's precepts to every aspect of his or her life, both professional and personal.⁴²

III. THE OATH IN THE LAW: TRIUMPH OF MEDICINE OVER COURTS

Numerous citations to the Hippocratic Oath in contemporary judicial opinions indicate that it remains an extraordinarily important definition of medical practice. References to the Oath arise in a wide range of cases, including those that involve employment,⁴³ physicians' disciplinary proceedings,⁴⁴ the First Amendment,⁴⁵ and the disposition of frozen embryos.⁴⁶ This Article focuses on only those U.S. cases whose opinions have devoted more than passing references to the Hippocratic Oath.⁴⁷

Of course, in the context of these opinions, the Oath does not promise to perform what it says, thus losing its "performative" quality as a speech act. As the linguist J.L. Austin has explained in his "doctrine of the *Infelicities*,"⁴⁸ the persons and circumstances must be "appropriate" for an utterance to be performative.⁴⁹ Thus, for example, the words "I do" perform the act of (Christian) marriage only when the speaker is not already married, and the words "I give it to you" perform the act of gift-giving only if the speaker hands over a gift.⁵⁰ Within the context of judicial case law, the Oath is not performative in the sense that it does not commit the speaker (that is, the court) to any particular conduct. Whereas a medical student's promise to follow the Oath's tenets performs an action in the world, a citation to the Oath in a written judicial opinion strips the Oath of its linguistic performativity—the promise that the oathmaker will conduct himself according to the Oath's text. Indeed, in the realm of the judicial opinion, the voice of the oathmaker is silenced. Now the voice is an institutional one, that of the court.

The very fact that judicial opinions refer to the Oath so extensively indicates its status as a symbolic marker imbued with profound social meaning derived from generations upon generations of medical students swearing to follow its words. A kind of "secondary" performative effect of the Hippocratic Oath thus emerges beyond the linguistic performativity it may possess in certain circumstances. This additional character that the Oath assumes is, in Austin's nomenclature, "perlocutionary."⁵¹

Perlocutionary acts are those that “we bring about or achieve *by* saying something,”⁵² such as convincing, persuading, deterring, surprising, and misleading.⁵³ The courts’ references to the Hippocratic Oath subtly convince the reader that the Oath remains a persuasive statement that continues to unite the medical profession. Interestingly, even while citing the Hippocratic Oath, courts have rejected some of the Oath’s most important prohibitions—most notably those barring doctors from providing “an abortive remedy” or administering “a deadly drug.”⁵⁴

This Part examines judicial opinions that allow doctors to perform abortions for women (*Roe v. Wade*⁵⁵), to administer anti-psychotic drugs to mentally ill prisoners (*Washington v. Harper*⁵⁶), to assist patients in committing suicide (*Compassion in Dying v. State of Washington*⁵⁷), and to participate in the executions of prisoners sentenced to death (*Thorburn v. Department of Corrections*⁵⁸). These opinions directly contradict specific portions of the Hippocratic Oath. But as this Part demonstrates, the respect these opinions accord doctors and medical science reveals that they remain faithful to the Oath’s overriding desire to establish the preeminence of the medical profession. *Washington v. Harper*, *Compassion in Dying v. State of Washington*, and *Thorburn v. Department of Corrections* indicate the enormous trust the judiciary places in doctors and signals the judiciary’s trust in the medical profession to regulate itself. *Roe v. Wade*, discussed first, not only reflects the Supreme Court’s willingness to defer to the medical profession, but also adopts the Oath’s implicit emphasis on doctors at the expense of patients.

A. *Abortion: Roe v. Wade*

Tucked away in the landmark abortion rights case, *Roe v. Wade* (1973), in which the U.S. Supreme Court recognized that a woman’s right to privacy limits the legislature’s ability to proscribe or regulate abortion, are four paragraphs devoted to the Hippocratic Oath.⁵⁹ Justice Blackmun, the author of the majority opinion, had “pondered the relevance of the Hippocratic Oath” during the summer of 1972, when he immersed himself in research on abortion at the Mayo Clinic medical library in Minnesota.⁶⁰ Blackmun explained the scope of his research as follows:

I traced down, as I hoped to be able to do, the attitudes toward abortion of the American Medical Association (it had changed over the years), of the American Public Health Association, and of the American Bar Association. I wished, furthermore, to study the history of our state abortion statutes, and I wished to ascertain the origin and extent of acceptance of the Hippocratic Oath. That research, personally and very privately performed, was, I believe, rewarding.⁶¹

The enduring quality of the Oath was not lost on the Justice. In his opinion, he acclaimed the Oath as “the ethical guide of the medical profession”⁶² and “the apex of the development of strict ethical concepts in medicine.”⁶³ Blackmun noted that the Oath became particularly “popular” at the end of antiquity. With the rise of Christianity in that period, resistance against abortion and against suicide became common. In turn, the Oath “became the nucleus of all medical ethics” and “was applauded as the embodiment of truth.”⁶⁴

Although the Oath may have had its fair share of adherents at certain moments in history, Blackmun was not convinced that the Oath had found universal acceptance across time and place. Instead, Blackmun heartily endorsed a theory promulgated in 1943 by Ludwig Edelstein, a classicist and well-known historian of Graeco-Roman medicine,⁶⁵ in his short monograph entitled *The Hippocratic Oath: Text, Translation and Interpretation*.⁶⁶ In that work, Edelstein argued that the Hippocratic Oath had not really been authored by the great physician Hippocrates, but that the ideas expressed in the Hippocratic Oath—specifically the prohibitions on administering abortive remedies or poison—reflected the opinions of a “small and isolated” group of philosophers in ancient Greece named the Pythagoreans. According to Edelstein, the Pythagoreans stood alone among all Greek thinkers in outlawing abortion and suicide under all circumstances.⁶⁷ Society at large, Edelstein argued, was accepting of abortion and of suicide, both of which were freely practiced with the approval of many ancient physicians.⁶⁸

Blackmun used Edelstein’s theory to dismiss the Hippocratic Oath’s prohibition on abortion.⁶⁹ The relevant section reads as follows:

Why did not the authority of Hippocrates dissuade abortion practice in his time and that of Rome? The late Dr. Edelstein provides us with a theory: The Oath was not uncontested even in Hippocrates’ day; only the Pythagorean school of philosophers frowned upon the related act of suicide. Most Greek thinkers, on the other hand, commended abortion, at least prior to viability. See Plato, Republic, V, 461;⁷⁰ Aristotle, Politics, VII, 1335b 25.⁷¹ For the Pythagoreans, however, it was a matter of dogma. For them the embryo was animate from the moment of conception, and abortion meant destruction of a living being. The abortion clause of the Oath, therefore, ‘echoes Pythagorean doctrines,’ and ‘[i]n no other stratum of Greek opinion were such views held or proposed in the same spirit of uncompromising austerity.’

Dr. Edelstein then concludes that the Oath originated in a group representing only a small segment of Greek opinion and that it certainly was not accepted by all ancient physicians.... Thus, suggests Dr.

Edelstein, it is 'a Pythagorean manifesto and not the expression of an absolute standard of medical conduct.' This, it seems to us, is a satisfactory and acceptable explanation of the Hippocratic Oath's apparent rigidity. It enables us to understand, in historical context, a long-accepted and reversed statement of medical ethics.⁷²

In retrospect, we can say that at the particular historical moment when *Roe* was decided, the Hippocratic Oath must have been in a period of "reversal," to borrow Blackmun's language. The opinion explicitly rejected the Oath on the theory that it did not reflect most ancient physicians' attitudes. Yet, the *Roe* Court paid homage to medical science even as it departed from the Hippocratic Oath's ban on abortion.

The *Roe* Court seems to suggest that its rejection of the Oath is due only to the fact that the modern medical establishment has a new standard that the Court must take into account. The Court accepted the proposition that the ethics of the medical profession bear heavily on the question of the constitutionality of abortion regulation. It simply disputed the notion that the medical profession has consistently or uniformly opposed abortion. The Court's account of the history of the Hippocratic Oath was certainly convenient; it allowed the Court to disclaim any conflict with the medical profession.

To be sure, the soundness of Edelstein's theory has been a subject of contention among scholars. Von Staden refutes Edelstein's hypothesis by arguing that the Oath's concluding prayer does not correspond to Pythagorean ideals.⁷³ John M. Dolan believes Edelstein was biased in favor of abortion and finds his argument unconvincing.⁷⁴ Martin Arbagi points to the work of an Italian scholar, never cited to in any of these judicial opinions, that he believes modifies Edelstein's theory. Enzo Nardi's work, *Procurato Aborto Nel Mondo Greco Romano* (1971), is a compilation of every extant passage from Greek and Latin writers, from earliest times through the early Middle Ages, that has anything to do with abortion. The work includes quotations from physicians, poets, philosophers, playwrights, lawyers, historians, canonists, theologians, scientists, pagans, Jews, and Christians. Nardi concluded that a broad-based opposition to abortion, not confined to Pythagorean or Christian circles, developed from 300 B.C. onward. In discussing Nardi's work, Arbagi acknowledges the possibility that the book was not available in the United States or that it had not been translated into English by 1973, when *Roe* was decided.⁷⁵ Arbagi also raises the question of how Pythagoras can be said to have written the Oath when he apparently prohibited his disciples from taking oaths.⁷⁶

But regardless of whether *Roe* is correct about the Oath's history, the striking fact remains that the Court felt compelled to assert that its view of

the constitutionality of abortion regulation accorded with the medical profession's position on the professional ethics of performing an abortion. One scholar has gone so far as to suggest that *Roe* "read[s] like a set of hospital rules and regulations."⁷⁷ That statement may be an exaggeration, but the opinion is in fact organized within a framework created not by jurists, but by medical practitioners. Doctors often divide pregnancies into three equal stages, or trimesters, each of roughly three months. The Court bound itself to these medical divisions by prescribing a different legal rule for each stage of pregnancy. And throughout the opinion, the physician's presence never fades.

The Court held that the decision to have an abortion in the first trimester was to be left to the pregnant woman *and her physician*.⁷⁸ Indeed, it implied that a woman has *no* constitutional right to an abortion unless she can secure her doctor's permission.⁷⁹ The Court's rationale, moreover, for prohibiting government restrictions on abortion in the first trimester was also medical in nature. It reasoned that the state's interest in the life of the fetus is not implicated in the first trimester because the mortality rate for women having abortions during this trimester is lower than the rate for women who carry their fetuses to term.⁸⁰ In arriving at this decision, the Court understood abortion not as a question of the equal citizenship of women, but as a question of doctors' rights to direct, even control, their patients' treatment in the name of maternal health.

Roe's privileging of the medical profession extended into the subsequent trimesters of pregnancy. Relying on medical evidence, the Court found that the risk of maternal death through abortion in the second trimester was higher than the mortality rate for women who carry their fetuses to term.⁸¹ It was this medical statistic that established sufficient grounds for the Court's holding that state regulations during the second trimester, provided they are "reasonably related" to the mother's health, are constitutional.⁸² Such regulation might include, for instance, a requirement that the operation take place in a hospital rather than a clinic.⁸³ Here again, it was medical health and doctors' judgment—rather than any conception of women's equality—that guided the Court's decision.

This emphasis on health as the foremost consideration is all the more apparent in the Court's discussion of the third trimester. The Court stated that the fetus typically becomes "viable" at the beginning of this last stage of pregnancy.⁸⁴ It is this concept of viability that supplied the Court with the necessary "logical and biological justifications" for state regulation, or even proscription, of abortion in the third trimester.⁸⁵ Viability, a term borrowed from medicine, refers to the point at which a fetus is capable of

living outside the womb. *Roe* determined that after this point the state has a “compelling” interest in protecting the fetus, and may regulate or even prohibit abortion, even though the fetus remains in the woman’s womb.⁸⁶ However, an abortion must be permitted where it is necessary to preserve the life or the health of the mother.⁸⁷ Thus, whether the state may prohibit a woman from having an abortion during the third trimester depends on the outcome of a balancing test that weighs the fetus’ medical health against the mother’s. In justifying the state’s interest in regulating whether a woman may have an abortion, the Court explicitly relied upon a medical definition:

The pregnant woman cannot be isolated in her privacy. She carries an embryo and, later, a fetus, if one accepts the medical definitions of the developing young in the human uterus. See Dorland’s Illustrated Medical Dictionary 478-479, 547 (24th ed. 1965).⁸⁸

This account has nothing to say about a woman’s right to equal citizenship, and makes no place for such concerns.

The *Roe* Court’s deference to doctors was far from accidental. Blackmun, a former general counsel to the Mayo Clinic, had grown to respect what dedicated physicians could accomplish, and felt that doctors should not always be told how they could or could not treat their patients. While he recognized that states should have the right to enforce their legislative will, the Justice apparently sympathized with the doctor whose medical practice was interrupted by state restrictions.⁸⁹ Blackmun’s sympathy for the plight of the individual doctor is also manifest in *Doe v. Bolton*,⁹⁰ which the Court decided on the same day as *Roe*. In this companion case, also written by Blackmun, the Court held unconstitutional a Georgia law that required a hospital committee and two physicians to approve a physician’s decision to perform an abortion. The opinion’s reasoning points to Blackmun’s concern for the autonomy of the individual doctor: The committee requirement is deemed “unduly restrictive of the patient’s rights and needs that, at this point, *have already been medically delineated and substantiated by her personal physician*,”⁹¹ and the required confirmation by two other physicians “has no rational connection with a patient’s needs and *unduly fringes on the physician’s right to practice*.”⁹² While the Justice did not ignore the patient’s right to be free from these procedural requirements, he also demonstrated great concern for how the requirements infringe upon a doctor’s “best clinical judgment.”⁹³ Blackmun’s decisions were thus, according to one journalistic account, less an opportunity to decide law than to “ratify the best possible medical opinion[s].”⁹⁴

Beyond Justice Blackmun's personal respect for doctors, larger societal campaigns were also crucial in influencing the Court's decision to rely on medical science. Beginning in the early decades of the nineteenth century, the medical profession waged a deliberate, and quite successful, campaign to place the abortion issue on the national agenda.⁹⁵ The profession attempted to assert control over the issue by defending the claim that life begins at conception and highlighting the *medical* risks of abortion as reasons for prohibiting the practice.⁹⁶ Doctors voiced strong moral objections to an activity they considered an "unwarranted destruction of human life," whether performed early or late in a woman's pregnancy.⁹⁷ Allegiance to the words of the Hippocratic Oath may have moved some nineteenth-century doctors to oppose abortion,⁹⁸ but the campaign was also part of an effort by newly minted male gynecologists to take control over women's medical care from female midwives and distinguish themselves as a profession from "the irregular practitioner and the back-street abortionist."⁹⁹ New laws criminalizing abortion, with "therapeutic exceptions" allowing doctors to determine when an abortion was necessary to save a woman's life, gave these fledgling doctors the ignition they needed to consolidate control over the provision of medical care, and specifically women's reproductive health care.¹⁰⁰ This nineteenth-century campaign to criminalize abortion assuredly did not emphasize—in fact, completely ignored—any concern for women's equality.

The nineteenth-century focus on women as *bodies* rather than women as *individuals*—that is, the use of "medical analysis" rather than "social analysis"¹⁰¹—made its way into the twentieth century. Even today, it is not unknown for doctors to objectify their female patients. For example, in the modern context of in vitro fertilization, doctors have referred to women's bodies as "maternal environments" into which "harvested" eggs are "implanted" so as to "achieve" pregnancies that will result in "state-of-the-art" babies.¹⁰² In addition, standard obstetrical textbooks that are still in use consider the woman to be no more important than the fetus she bears. One asserts that "[h]appily, we live and work in an era in which the fetus is established as our second patient with many rights and privileges comparable to those previously achieved only after birth."¹⁰³ Similarly, the American College of Obstetricians and Gynecologists promulgated a statement that characterizes the relationship between a woman and a fetus as unique because it involves "two patients with access to one through the other."¹⁰⁴

Justice Blackmun's opinion in *Roe* seems to be the triumph of this view: Like the medical opponents of abortion in the nineteenth century, *Roe* framed reproduction as primarily physiological—neglecting the important

social work of reproduction that women perform. Horatio Storer and Franklin Fiske Heard, leaders of the nineteenth-century criminalization campaign, were amazingly prescient when they wrote that “medical men are the physical guardians of women and their offspring; from their position and peculiar knowledge necessitated in all obstetric matters to regulate public sentiment, and to *govern the tribunals of justice*.”¹⁰⁵ On the abortion issue, the tribunals do seem to be governed by “medical men.”

B. Medical Treatment of Mentally Ill Prisoners: Washington v. Harper

In *Washington v. Harper* (1990), the U.S. Supreme Court was called upon to decide whether a state prison policy authorizing the treatment of a mentally ill inmate with anti-psychotic drugs violated the inmate’s civil rights, when the treatment was administered against the inmate’s will and without a judicial hearing. The Washington Supreme Court had found that the policy violated the Due Process Clause of the Fourteenth Amendment of the U.S. Constitution,¹⁰⁶ and the State appealed. In the majority opinion, Justice Kennedy held that the treatment of a prisoner against his will did not violate substantive due process where the prisoner was found to be dangerous to himself or to others¹⁰⁷ and where the treatment was in the prisoner’s medical interest.¹⁰⁸ The Justice was confident that “the ethics of the medical profession,” including those inscribed in the Hippocratic Oath, would ensure that physicians would administer anti-psychotic medications only in those cases in which it is appropriate by medical standards.¹⁰⁹ Significantly, Justice Kennedy listed the Hippocratic Oath first among his list of enduring sources of medical ethics, which also includes the American Psychiatric Association’s “Principles of Medical Ethics With Annotations Especially Applicable to Psychiatry.”¹¹⁰ Kennedy’s decision, like the *Roe* decision, demonstrates how the Oath has caused the judiciary to have enormous trust in doctors.

C. Physician-Assisted Suicide: Compassion in Dying v. State of Washington

Washington State enacted a law in 1994 criminalizing physician-assisted suicide.¹¹¹ In *Compassion in Dying v. State of Washington* (1996), the U.S. Court of Appeals for the Ninth Circuit struck down the law as a violation of due process.¹¹² On the surface, it might seem that the court accorded no weight to the Hippocratic Oath. The opinion flatly rejected one of the Oath’s central doctrines—that which prohibits a doctor from administering “a deadly drug.”¹¹³ Indeed, the opinion clearly stated that “the Hippocratic Oath can have no greater import in deciding the constitutionality of physician-assisted suicide than it did in determining

whether women had a constitutional right to have an abortion.”¹¹⁴ Here the court borrowed *Roe*’s analysis of the Hippocratic Oath to dismiss the Oath’s implicit prohibition on physician-assisted suicide.¹¹⁵

But although the *Compassion in Dying* court did not adhere to what it considered the “rigid language” of the Hippocratic Oath,¹¹⁶ it tacitly acknowledged the contribution that the Oath has made to establishing the privileged position of the medical profession in society. The court granted doctors the right to assist terminally ill patients in committing suicide on the ground that “doctors would engage in the permitted practice when appropriate, and that the integrity of the medical profession would survive without blemish.”¹¹⁷ The opinion offered no specific factual evidence, however, to support this claim. It made only the generalized assertions that “sufficient safeguards can and will be developed by the state and medical profession...to ensure that the possibility of error will ordinarily be remote”¹¹⁸ and that “the ethical integrity of the medical profession remained undiminished” in the wake of *Roe*.¹¹⁹ The court took it to be essentially a matter of common sense to suppose that it could rely on the general reputation of the medical profession for veracity, honor, and integrity—a reputation that the Hippocratic Oath, of course, powerfully helped establish.¹²⁰

D. Physicians and the Death Penalty: Thorburn v. Department of Corrections

A recent California Court of Appeals case involving the death penalty, *Thorburn v. Department of Corrections* (1998), also displayed enormous respect for the medical profession, even as it explicitly rejected the plaintiffs-physicians’ reliance on the Hippocratic Oath. The court held that the participation of physicians in the lethal injection of prisoners sentenced to death is not unlawful.¹²¹ The doctors who filed the lawsuit had alleged that the participation of doctors in executions of prisoners constituted unprofessional conduct. They cited the Hippocratic Oath, among other rules and ethical codes of the medical profession, for the general principle that doctors ought “do no harm.”¹²² While the court acknowledged that “[t]he Hippocratic Oath reaches back over 2000 years and represents a fundamental principle for the medical profession,”¹²³ it maintained that physician involvement in executions is unlikely “to erode trust between individual physicians and patients who have not been sentenced to death for a capital crime, or undermine public confidence in physicians or the medical profession as a whole.”¹²⁴ This dicta again signals the judiciary’s trust in the medical profession to regulate itself rather than be subject to rigorous legal control.

CONCLUSION

The cases discussed in this Article could easily have left out any mention of the Hippocratic Oath. It is not obvious why something composed several millennia ago, aimed at doctors, has any bearing on the resolution of contemporary legal questions pertaining to medical issues. That these judicial opinions discuss the Hippocratic Oath attests to the Oath's continuing significance. It is precisely because the Oath remains so powerful that courts found it necessary to address it and deny its lasting import. The very references to the Oath, no matter courts' treatment of its literal content, may in themselves be said to constitute a "secondary" performative effect that underscores the Hippocratic Oath's enduring legacy in our society today.

Given the Oath's resolute emphasis on the doctor and its concomitant deemphasis on the rights of patients, courts would do well to be less complacent about allowing the medical profession to regulate itself according to the strictures of the Hippocratic Oath. To be sure, the judiciary should carefully consider the viewpoints of those in the medical profession. However, in assessing those viewpoints, judges must recognize that the attitudes of medical professionals are as much shaped by political motivations as are those of other parties. The temptation of the legal system to displace difficult ethical choices onto doctors is understandable. But as long as the Hippocratic Oath continues to overlook the patient, this type of legal self-regulation will not necessarily guarantee the most just results.

Today, nearly all medical schools where students swear to uphold the Hippocratic Oath administer a modified version that more closely accounts for contemporary values.¹²⁵ Students at Yale Medical School, for instance, take an oath that includes the words "gender" and "sexual orientation" in the oath's statement of non-discrimination.¹²⁶ Rather than weakening the strength of the Hippocratic Oath, these alternative oaths actually help augment its power. By incorporating modern values into the Hippocratic Oath, the alternative oaths help ensure that those who swear to them will abide by the oaths' words. These alternative oaths are beginning to place more emphasis on the patient.¹²⁷ Finally, most modern incarnations of the Oath are more sensitive to the nuances of complex ethical issues in that they do not prohibit practices such as abortion and euthanasia. Of the 135 medical schools responding to a 1993 survey, only 8% administered oaths prohibiting abortion and only 14% administered oaths prohibiting euthanasia.¹²⁸

Yet modern courts continue to accord significant weight to the

Hippocratic Oath *in its classic form*. As the more modern, patient-centered oaths gain more acceptance within the medical profession, courts ought to pay heed. That said, even if courts were to take account of the modern oaths, the judiciary ought nonetheless focus more on making decisions that do not overly privilege the views of the medical profession. A more independent perspective would ultimately better serve the best interests of the patient.

References

1. LUDWIG EDELSTEIN, THE HIPPOCRATIC OATH 3 (1943).
2. The linguist John Searle distinguishes five broad classes of speech acts: (1) assertives, also known as constatives, which commit the speaker to the truth of the proposition asserted (for example, "I swear that..."); (2) directives, which attempt to get the listener to do something ("I order you to..."); (3) commissives, which commit the speaker to a future course of action ("I swear to..."); (4) expressives, which comprise conventional acts such as thanking, greeting, and congratulating; and (5) declarations, those acts that actually bring about the state of affairs proposed (for example, marrying a couple). An oath is considered both an assertive and a commissive. JOHN R. SEARLE, *EXPRESSION AND MEANING: STUDIES IN THE THEORY OF SPEECH ACTS* 12-20 (1979). Searle's work builds on that of J.L. Austin. J.L. AUSTIN, *HOW TO DO THINGS WITH WORDS* at v-vi (J.O. Urmson & Marina Sbisa eds., 2d ed. 1975).
3. AUSTIN, *supra* note 2, at 6-7, 47. Austin provides the following example to illustrate the difference between an ordinary statement and a speech act (or, in his terminology, between a constative and a performative): The statement "he is running" is ordinary because it depends merely on the statement's truth or falsity, whereas the statement "I apologize" is a speech act because the speaker's "success" in apologizing depends on the statement's "happiness"—that is, whether the persons and circumstances are appropriate for the utterance to "perform" an apology. *Id.* at 47.
4. Robert D. Orr et al., *Use of the Hippocratic Oath: A Review of Twentieth Century Practice and a Content Analysis of Oaths Administered in Medical Schools in the U.S. and Canada in 1993*, 8 J. CLINICAL ETHICS 377, 377 (1997).
5. OWSEI TEMKIN, HIPPOCRATES IN A WORLD OF PAGANS AND CHRISTIANS 21 (1991) (noting that the Oath was first mentioned in the extant literature in the first century A.D.); *see also* Memorandum from Ann Ellis Hanson, Professor of Classics, Yale University (May 27, 1999) (on file with author) (stating that the Roman physician Scribonius Largus was the first to mention the Hippocratic Oath in the middle of the first century A.D.).
6. A DICTIONARY OF ANCIENT HISTORY 316 (Graham Speake ed., 1994).
7. Tension between philosophy, the (theoretical) art of speculation, and medicine, the (practical) art of healing, continues. *See* EDWIN BURTON LEVINE, HIPPOCRATES 54 (1971); Ben A. Rich, *Postmodern Medicine: Deconstructing the Hippocratic Oath*, 65 U. COLO. L. REV. 77, 86 (1993). It was perhaps Hippocrates' ability to differentiate medicine from philosophy that earned him the title "The Father of Medicine." *See id.* The first-century Roman encyclopedist Celsus thought that medicine, prior to Hippocrates, had been in the hands of philosophers because mental strain and insomnia had weakened their bodies. But, according to this same writer, Hippocrates was able to "separate this discipline [of medicine] from the study of philosophy." A. CORNELIUS CELSUS, *DE MEDICINA* (W.G. Spencer trans., Loeb 1935-38), *cited in* TEMKIN, *supra* note 5, at 41.
8. *See* LEVINE, *supra* note 7, at 54-55; C. Everett Koop, *Introduction*, 35 DUQ. L. REV. 1, 2 (1996).

9. *Id.*; see also WALTER BURKERT, *THE ORIENTALIZING REVOLUTION: NEAR EASTERN INFLUENCE ON GREEK CULTURE IN THE EARLY ARCHAIC AGE* 41 (1992) (remarking that seers and doctors were "closely connected" in the pre-Hippocratic era); LEVINE, *supra* note 7, at 54 (noting that "no more than the popular wisdom or foolishness about sickness, health, and the healing done by healers" prevailed before the Hippocratics).

10. Scribonius Largus, *Epistula Dedicatoria*, in *COMPOSITIONES* art. 5, §§ 2 (l20)-3 (l2) (Sergio Sconocchia ed., B.G. Teubner 1983) (c. 50), *translated in* TEMKIN, *supra* note 5, at 43.

11. SORANUS, *GYNECOLOGY* bk. 1, § 60, pp. 62-63 (Owsei Temkin trans., Johns Hopkins Univ. Press 1991) (c. 98-138), *cited in* TEMKIN, *supra* note 5, at 43-44 (emphasis added).

12. BURKERT, *supra* note 9, at 41. Ironically, even as the Oath functionally separated "rational" medicine from "magical" sorcery, it did so in a form that is classically religious. See *infra* notes 27-33 and accompanying text.

13. See ROBERT FLACELIÈRE, *DAILY LIFE IN GREECE AT THE TIME OF PERICLES* 144 (1965). Not surprisingly, the doctors referenced in the Oath are unambiguously male. The oathtaker swears "[t]o hold *him* who has taught me this art as equal to my parents and to live my life in partnership with *him*, and if *he* is in need of money to give *him* a share of mine," to regard his teacher's children "as equal to my *brothers* in *male* lineage," and to teach "my *sons* and...the *sons* of him who has instructed me." EDELSTEIN, *supra* note 1 (emphasis added).

14. See generally I. M. Lonie, *Cos Versus Cnidus and the Historians*, 16 *HIST. SCI.* 42 (1978); Wesley D. Smith, *Galen on Coans*

Versus Cnidians, 47 *BULL. HIST. MED.* 569 (1973).

15. Dale C. Smith, *The Hippocratic Oath and Modern Medicine*, 51 *J. HIST. MED. & ALLIED SCI.* 484, 485-87 (1996).

16. See *id.* at 490.

17. See Vivian Nutton, *Hippocratic Morality and Modern Medicine*, in *MÉDECINE ET MORALE DANS L'ANTIQUITÉ* 31, 47 (François Paschoud ed., 1996).

18. Koop, *supra* note 8, at 1.

19. See Nutton, *supra* note 17, at 47-48.

20. The historian Dale C. Smith hypothesizes a connection between the increasing use of the Hippocratic Oath in medical schools and the increasing fragmentation of the medical profession into specialty areas. His reasoning is that in the face of increasing specialization, the Oath provides (or, at least, attempts to provide) a necessary "sense of unity" for young physicians. Smith, *supra* note 15, at 495.

21. Nutton, *supra* note 17, at 35. These figures accord with Ralph Crenshaw's finding that seventy-eight American medical schools administered the Oath in 1969, Walter Friedlander's finding that 108 American and Canadian schools administered the Oath in 1977, and that 126 American medical schools used oaths in 1989. Smith, *supra* note 15, at 498-99. *But see* LEVINE, *supra* note 7, at 56 (citing a survey that twenty-one of eighty-four American medical schools reported administering the Hippocratic Oath in 1966).

22. See Orr et al., *supra* note 4, at 379, 380 tbl.2.

23. Smith, *supra* note 15, at 497.

24. Heinrich von Staden, *'In a Pure and Holy Way': Personal and Professional Conduct in the Hippocratic Oath*, 51 *J. HIST. MED. & ALLIED SCI.* 404, 416 (1996) [hereinafter

von Staden, *Personal and Professional*]. The sense of belonging engendered in the Oath is what makes the ancient text attractive to some commentators today, as the Oath has the potential to bind together an increasingly diversified medical profession. See Nutton, *supra* note 17, at 47 ("Even if endocrinologists and radiographers, orthopedists and oncologists, biogeneticists and trauma specialists nowadays rarely meet together for academic or even medical purposes...they can all be linked together in the solidarity produced by sharing in the Oath."); see also Smith, *supra* note 15, at 500 ("In repeating the oath, physicians ascribe to long held values but they also build bridges one to another across specialties and across time.").

25. EDELSTEIN, *supra* note 1, at 3.

26. LEVINE, *supra* note 7, at 56. The first generation of medical ethicists in the 1960s and 1970s attacked the Hippocratic Oath because "it left out the person whose rights above all should determine medical ethics—the patient." Nutton, *supra* note 17, at 51.

27. EDELSTEIN, *supra* note 1, at 3. Asclepius was the god of medicine, Hygieia the personification of health, and Panaceaia a goddess who symbolized "the power of universal healing through herbs." PIERRE GRIMAL, *THE DICTIONARY OF CLASSICAL MYTHOLOGY* 62-63, 219, 341 (A.R. Maxwell-Hyslop trans., 1986).

28. EDELSTEIN, *supra* note 1, at 50.

29. The earliest recorded oath with an appeal to God is in the book of Genesis. See Jonathan Belcher, *Religion-Plus Speech: The Constitutionality of Juror Oaths and Affirmations Under the First Amendment*, 34 WM. & MARY L. REV. 287, 291 n.29 (1992) (citing *Genesis* 21:23-24 (New International)) ("Now swear to me here before God that you will not deal falsely

with me or my children or my descendants.... Abraham said, 'I swear it.'"). The Egyptians, Carthaginians, Greeks, Persians, Romans, and Jews frequently used oaths as a way to establish truthfulness. *Id.* at 291.

30. Medieval canon law was a particularly oath-dominated sort of justice. See R. H. HELMHOLZ, *THE SPIRIT OF CLASSICAL CANON LAW* 145, 149 (1996). Those swearing to oaths took them quite seriously, as the church emphasized the damage that could result to an oathmaker's soul if he made God a witness to falsehood. *Id.* at 173.

31. The oath has also long been a part of the English common law. For a discussion of the use of the witness oath as a source of legitimacy prior to the rise of the common law jury system, see George Fisher, *The Jury's Rise as Lie Detector*, 107 YALE L.J. 575 (1997).

32. In many cultures around the world, witness oaths constitute the primary form in which disputes are litigated. See Bernard J. Hibbitts, "Coming to Our Senses": *Communication and Legal Expression in Performance Cultures*, 41 EMORY L.J. 873, 900 (1992).

33. BURKERT, *supra* note 9, at 44; cf. LEVINE, *supra* note 7, at 61 (noting that the language of *Nomos*, a text from classical antiquity dealing with medical education, is also "typical of closed associations with its strong emphasis on the arcane nature of its subject matter"). The Hippocratic Oath has through the centuries maintained its special function as a rite of initiation. Interestingly, the Oath today is taken sometimes not by medical school graduates, but by beginning students. *Id.* at 56. One study from 1993 found that 13% of medical schools in the United States and Canada administer an oath to their

students at both the beginning of medical school and at graduation. Orr et al., *supra* note 4, at 379.

34. EDELSTEIN, *supra* note 1, at 3. Ludwig Edelstein argues that the Hippocratic Oath was inspired by the Pythagoreans, a religious sect from the fourth century whose doctrines included a belief that a student should honor his teacher like an adoptive father. See *id.* at 43, 47-48. Some classicists contend that the practice of taking the Hippocratic Oath was "the equivalent of a de facto adoption," in that the pupil became like a son within a closed family guild of physicians. This arrangement served to ensure that knowledge remained within the "family." See BURKERT, *supra* note 9, at 44-45; EDELSTEIN, *supra* note 1, at vii, 39, 47. It also sparked the development of schools and apprenticeships of rationalist medicine. See LEVINE, *supra* note 7, at 55.

35. EDELSTEIN, *supra* note 1, at 3.

36. *Id.*

37. According to one set of commentators, the ban on using "the knife" originally "proscribed surgery for renal stones, by deferring to those more qualified." Orr et al., *supra* note 4, at 379 tbl.1.

38. EDELSTEIN, *supra* note 1, at 3. In this context, "art" means "the art, skill, or craft of medicine." Memorandum from Ann Ellis Hanson, Professor of Classics, Yale University (Feb. 22, 2001) (on file with author).

39. Cited in Rich, *supra* note 7, at 94 n.82.

40. A Greek poem, "On the Ethical Duties of the Physician," by the Stoic philosopher Sarapion (c. A.D. 100) might lead one to believe that the well-being of the patient superceded that of the physician, or at least was accorded equal

weight. The ancient poem reads: "Like a savior god, let [the physician] make himself the equal of slaves and of paupers, of the rich and of rulers of men, and to all let him minister like a brother; for we are all children of the same blood." TEMKIN, *supra* note 5, at 72. However, it is significant to note that even as the physician is admonished to "make himself the equal" of his patients—no matter rich or poor, free or enslaved—the poem compares the physician to "a savior god," thus placing him in a sacred realm far removed from his mortal patients.

41. See Heinrich von Staden, *Character and Competence: Personal and Professional Conduct in Greek Medicine*, in MÉDECINE ET MORALE DANS L'ANTIQUITÉ 157, 173-74 (François Paschoud ed., 1996) [hereinafter von Staden, *Character and Competence*]; von Staden, *Personal and Professional*, *supra* note 24, at 418-19.

42. See von Staden, *Character and Competence*, *supra* note 41, at 174. Von Staden argues that the physician's explicit promise to "guard [his] life and [his art]" indicates that the Oath covers not only the physician's professional conduct (his art) but also "his life as a whole, and hence his private, personal conduct." *Id.* at 191-92; see also von Staden, *Personal and Professional*, *supra* note 24, at 433. The word "life," von Staden contends, is used in the primary classical sense of the Greek word *bíos* to mean "mode of life" or the "manner of living one's life." *Id.* at 420.

43. *E.g.*, Aiken v. Employer Health Servs., No. 95-3196, 1996 U.S. App. LEXIS 6060 (10th Cir. Mar. 26, 1996) (affirming judgment that physician was not wrongfully discharged from his employment, despite physician's reliance on the Hippocratic Oath to establish he had served the interests of his patients).

44. *E.g.*, U.S. v. Rachels, 820 F.2d 325 (9th Cir. 1987).

45. *Malnak v. Yogi*, 440 F. Supp. 1284 (D.N.J. 1977) (holding that the teaching of the Science of Creative Intelligence/Transcendental Meditation in New Jersey public schools violates the establishment clause of the First Amendment, despite defendants' attempt to analogize the "puja chant" to the Hippocratic Oath).

46. *Davis v. Davis*, No. E-14496, 1989 WL 140495 (Tenn. Cir. Ct. 1989).

47. For a brief discussion of the use of the Oath in England and in Germany, see Nutton, *supra* note 17, at 61.

48. AUSTIN, *supra* note 2, at 14.

49. *Id.* at 9. See generally *id.* at 12-38.

50. These examples are ones that Austin provides. *Id.* at 8-9.

51. *Id.* at 121.

52. *Id.* at 109.

53. *Id.*

54. EDELSTEIN, *supra* note 1, at 3.

55. 410 U.S. 113 (1973).

56. 494 U.S. 210 (1990). Of course, the administration of an anti-psychotic drug to a mentally ill prisoner is not exactly proscribed by the Hippocratic oath-taker, who vows to "neither give a deadly drug to anybody if asked for it" nor to "make a suggestion to this effect." EDELSTEIN, *supra* note 1, at 3. One could argue that an anti-psychotic drug is different from "a deadly drug" and that the doctor is not administering the drug upon the patient's request. In fact, in the case at issue, the doctor treated the patient against the patient's will. See *Washington*, 494 U.S. at 213.

57. 79 F.3d 790 (9th Cir. 1996) (en banc), *overruled by* *Washington v. Glucksberg*, 521 U.S. 702 (1997).

58. 66 Cal. App. 4th 1284 (1998).

59. *Roe*, 410 U.S. 113, 130-32 (1973).

This mention of the Hippocratic Oath appears in the section of the opinion that surveys historical attitudes toward abortion, from ancient beliefs through common-law understandings.

60. BOB WOODWARD & SCOTT ARMSTRONG, *THE BRETHREN: INSIDE THE SUPREME COURT* 229 (1979).

61. Harry Blackmun, Remarks Before the Franco-American Colloquium on Human Rights 14-15 (1979) (transcript available in the Harvard Law School Library), *quoted in* Note, *The Changing Social Vision of Justice Blackmun*, 96 HARV. L. REV. 717, 723 n.34 (1983).

62. *Roe*, 410 U.S. at 130.

63. *Id.* at 131.

64. *Id.* at 132 (quoting EDELSTEIN, *supra* note 1, at 64).

65. For background on Ludwig Edelstein, see Martin Arbabi, *Roe and the Hippocratic Oath*, in ABORTION AND THE CONSTITUTION 159, 160 (Dennis J. Horan et al. eds., 1987).

66. EDELSTEIN, *supra* note 1.

67. *Id.* at 15, 16, 18, 54.

68. *Id.* at 10, 11, 13, 63. Only subsequently, with the rise of Christianity in late antiquity, did the Oath become a universally accepted expression of medical ethics, according to Edelstein's theory. *Id.* at 63-64.

69. *Roe*, 410 U.S. at 131-32.

70. PLATO, *REPUBLIC* 5 § 461a (S. Halliwell trans., Aris & Phillips 1993). This passage includes a euphemistic reference to abortion: "And we shall allow all this only after instructing them to take care, if at all possible, not to let a single foetus that might be conceived reach birth...."

71. ARISTOTLE, *THE POLITICS* § 1335b (C.D.C. Reeve trans., Hackett Publishing Co. 1998). Aristotle requires that deformed

offspring be exposed and that any offspring conceived in violation of the laws "should be aborted before the onset of sensation and life." *Id.*

72. *Roe*, 410 U.S. at 131-32.

73. See von Staden, *Personal and Professional*, *supra* note 24, at 409.

74. John M. Dolan, *Is Physician-Assisted Suicide Possible?*, 35 DUQ. L. REV. 355, 383-84 (1996).

75. See Arbagi, *supra* note 65, at 164-65.

76. See *id.* at 164. While Edelstein's argument thus "may not be accepted nowadays," Nutton explains that "there are many scholars who would agree with him that, as it stands, the Oath represents the views of a small group, and for that reason cannot be taken as representing the whole of medical opinion in Hippocratic Greece, let alone throughout Antiquity." Nutton, *supra* note 17, at 46. For a discussion of how the *Roe* Court also referred inappropriately to Plato's and Aristotle's views on abortion, see Neomi Rao, Comment, *A Backdoor to Policy Making: The Use of Philosophers by the Supreme Court*, 65 U. CHI. L. REV. 1371, 1379-80 (1998).

77. ARCHIBALD COX, *THE ROLE OF THE SUPREME COURT IN AMERICAN GOVERNMENT* 113 (1976).

78. *Roe*, 410 U.S. at 163.

79. *Id.* at 163-64. The opinion states that "the attending physician, in consultation with his patient, is free to determine, without regulation by the State, that, in his medical judgment, the patient's pregnancy should be terminated" *Id.* at 163 (emphasis added).

80. *Id.* at 163.

81. *Id.* at 148-49, 163.

82. *Id.* at 163, 164.

83. *Id.* at 163.

84. *Id.*

85. *Id.* at 163-64.

86. *Id.*

87. *Id.* at 164.

88. *Id.* at 159.

89. See WOODWARD & ARMSTRONG, *supra* note 60, at 167, 169, 174-75.

90. *Doe v. Bolton*, 410 U.S. 179 (1973).

91. *Id.* at 198 (emphasis added).

92. *Id.* at 199 (emphasis added).

93. *Id.* at 197, 199.

94. WOODWARD & ARMSTRONG, *supra* note 60, at 175. Blackmun's deference to the medical profession may have been in part a strategic measure to garner the necessary votes from the other Justices on the Court. Had Blackmun framed his decision more in the language of women's rights, the other Justices may not have signed on to the opinion. By invoking the medical profession and its high ethical standards, Blackmun may have succeeded in securing a woman's right to abortion in a way that was probably more acceptable to the other Justices. However, while this strategy may have been effective, it nonetheless subordinates the patient much as the Hippocratic Oath does.

95. See Reva Siegel, *Reasoning from the Body: A Historical Perspective on Abortion Regulation and Questions of Equal Protection*, 44 STAN. L. REV. 261, 282 (1992).

96. *Id.*

97. *Id.* This characterization of abortion became the official stance of the American Medical Association by 1859. *Id.* at 286.

98. See JAMES C. MOHR, *ABORTION IN AMERICA* 35 (1978), cited in Siegel, *supra* note 95, at 282-83 n.77. Indeed, recitation of the Hippocratic Oath at the graduation ceremonies of American medical colleges grew more common in the 1850s and 1860s. Smith, *supra* note 15, at 490.

99. Nutton, *supra* note 17, at 62; see also

Siegel, *supra* note 95, at 283-84. This problem of "irregular" practitioners was particularly pronounced in the United States. See Smith, *supra* note 15, at 490. In the mid-nineteenth century, the medical practitioners who sought to distinguish themselves from these "irregulars" did so largely on the basis of the higher levels of formal education they had attained. In time, doctors organized politically and restricted entry into their guild by convincing state governments to impose licensing requirements that blocked their competitors from entering the medical profession. See Nelson Lund, *Two Precipices, One Chasm: The Economics of Physician-Assisted Suicide and Euthanasia*, 24 HASTINGS CONST. L.Q. 903, 932 (1997).

100. Siegel, *supra* note 95, at 315. By the 1920s, most states had made abortion a crime, and most medical schools administered a modified form of the Oath that pledged to "give no drugs and perform no operations for a criminal purpose." Smith, *supra* note 15, at 494.

101. Siegel, *supra* note 95, at 275.

102. Rich, *supra* note 7, at 118.

103. *Id.* (citing JACK A. PRITCHARD ET AL., WILLIAMS OBSTETRICS xi (1985)).

104. *Id.*

105. HORATIO R. STORER & FRANKLIN FISKE HEARD, CRIMINAL ABORTION: ITS NATURE, ITS EVIDENCE, AND ITS LAW 12-13 (Boston, Little, Brown & Co. 1868), cited in Siegel, *supra* note 95, at 365 n.414 (emphasis added).

106. U.S. CONST. amend. XIV, § 1.

107. The policy in question required the State to establish by a medical finding that "a mental disorder exists which is likely to cause harm if not treated." Washington v. Harper, 494 U.S. 210, 222 (1990).

108. The opinion reads in pertinent part: "the fact that the medication must

first be prescribed by a psychiatrist, and then approved by a reviewing psychiatrist, ensures that the treatment in question will be ordered only if it is in the prisoner's medical interests, given the legitimate needs of his institutional confinement." *Id.*

109. *Id.* at 223 n.8.

110. *Id.* Here, Justice Kennedy distinguished his argument from Justice Stevens, whose concurring/dissenting opinion assumed that physicians would prescribe anti-psychotic drugs for reasons unrelated to the medical needs of patients, but rather for institutional and administrative concerns. *Id.* at 244-46. Stevens found that the Court's reliance on the Hippocratic Oath was "unavailing" because it had "no bearing" on the decisions of the prison doctors. *Id.* at 245 n.11.

111. Wash. Rev. Code § 9A.36.060(1) (1994). The law provided that "[a] person is guilty of promoting a suicide attempt when he knowingly causes or aids another person to attempt suicide." *Id.*

112. See *Compassion in Dying v. State of Washington*, 79 F.3d 790, 793-94 (9th Cir. 1996) (en banc), *overruled by Washington v. Glucksberg*, 521 U.S. 702 (1997). At the same time, the Ninth Circuit became the first appellate court in American history to uphold the constitutionality of physician-assisted suicide of terminally ill patients. Dwight G. Duncan & Peter Lubin, *The Use and Abuse of History in Compassion in Dying*, 20 HARV. J.L. & PUB. POL'Y 175, 177 (1996).

113. EDELSTEIN, *supra* note 1, at 3.

114. *Compassion in Dying*, 79 F.3d at 829.

115. See *supra* notes 65-72 and accompanying text.

116. *Compassion in Dying*, 79 F.3d at 829.

117. *Id.* at 830. To be sure, the court did not altogether neglect the interests of

patients who desire assistance in committing suicide. The opinion notes that a state-enforced prohibition against physician-assisted suicide “condemns” such patients to “unrelieved misery or torture.” *Id.* at 814.

118. *Id.* at 824.

119. *Id.* at 830. Further, the court noted that assisting a patient to end his life were there any doubt as to the patient’s actual desires would violate “the physicians’ fundamental training, their conservative nature, and the ethics of their profession.” *Id.* at 827.

120. The *Compassion in Dying* decision has since been overruled by the U.S. Supreme Court in *Washington v. Glucksberg*, 521 U.S. 702 (1997). In that case, the Court held that Washington’s ban on assisted suicide was rationally related to legitimate government interests. *Id.* at 735. The *Washington* Court did not refer to the Hippocratic Oath, but it did chronicle in some detail an over 700-year-long history in the Anglo-American common-law tradition of disapproval of both suicide and assisted suicide. *See id.* at 710-15. Perhaps the Oath’s prohibition against suicide influenced the *Washington* Court’s historical focus and its decision to deny patients the ability to decide whether to live or die.

121. 66 Cal. App. 4th 1284, 1286 (1998).

122. *Id.* at 1290 n.6.

123. *Id.*

124. *Id.* at 1293.

125. A 1993 survey of American and Canadian medical schools found that the students of only one school, the State University of New York at Syracuse, recited the Hippocratic Oath in its original form, out of a pool of sixty-nine schools that administered some form of the Oath. Orr et al., *supra* note 4, at 380.

126. Smith, *supra* note 15, at 499.

127. *See* Orr et al., *supra* note 4, at 382. Yale students now swear to “respect the moral right of patients to participate fully in the medical decisions that affect them” and Michigan students swear to “exercise [their] art solely for the good of [their] patients.” Memorandum from Ann Ellis Hanson, Professor of Classics, Yale University (Feb. 9, 1999) (on file with author).

128. *See* Orr et al., *supra* note 4, at 380, 382.

DEVELOPMENTS AND TRENDS IN THE LAW

Question:

How are states protecting the privacy of health information held by health care providers?

On April 14, 2001, the Federal Health Privacy Rule, which grants patients greater access to their medical records and more control over how their personal health information is used, took effect. The Rule addresses, among other things, the obligations of health care providers to protect health information. The Rule, however, does not preempt stronger state laws governing the privacy of medical information. It is therefore extremely important to determine how each state is protecting health information held by health care providers.

The following article by Joy Pritts argues that because the Rule only preempts conflicting, less protective state laws, there is still room for states to protect their citizens by retaining or enacting health privacy protections that mirror and improve upon those in the Rule. Following her piece is a synopsis of each state's existing case and statutory law on the subject, which has been produced by the *Journal's* editorial staff. For the purposes of this state-by-state analysis, "health provider" primarily means hospital, physician, nurse practitioner, physician assistant, and mental health professional.

Altered States: State Health Privacy Laws and the Impact of the Federal Health Privacy Rule

Joy L. Pritts, J.D.*†

Medical records contain some of the most intimate details about an individual that can be found in a single place. Health information privacy is based on the principle that individuals should be able to exercise control over this intimate information, both by having full knowledge about what information is contained in the records and by being able to control who has access to the information. Because professional ethical requirements do not adequately protect health information in today's complex health care system, we have increasingly turned to the law as a source of protection.

Until the recent promulgation of the Federal Health Privacy Rule,¹ states have been the primary regulators of health information through their constitutions, common law, and statutory provisions. Although all three of these legal sources remain important, recent focus has been on the enactment of detailed health privacy statutes that apply the fair information practice principles to health information. However, for the most part states have adopted these principles in a fairly haphazard fashion resulting in a patchwork of legal protections both within and between states.

The recently issued Federal Health Privacy Rule has effectively evened out some of this discrepancy by establishing a federal floor of privacy protections based on fair information practices. The Federal Rule, however, does not afford adequate protection of health information

* Joy Pritts is Senior Counsel for the Health Privacy Project and an Assistant Research Professor at Georgetown University's Institute of Health Care Research and Policy. The Health Privacy Project is dedicated to ensuring that people's privacy is safeguarded in the health care environment. Ms. Pritts is the primary author of *The State of Health Privacy: An Uneven Terrain (A Comprehensive Survey of State Health Privacy Statutes)*, available at <http://www.healthprivacy.org>.

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because it has limited applicability and areas of lax protection. Because the Federal Rule only preempts conflicting, less protective state laws, there is still room for states to protect their own citizens by retaining or enacting health privacy protections that mirror and improve upon those in the Federal Health Privacy Rule.

INTRODUCTION

Health information privacy is based on the principle that individuals should have some control over their own medical records.² This general principle can be broken down into two different rights: the ability to protect against unwarranted disclosures of health information (i.e., the right to protect the *confidentiality* of health information), and the right of access to one's own health information.³ Although these rights have evolved along different paths, they are equally important in today's health care system.

A. *Confidentiality of Health Information*

Quality medical care requires patients to share some of the most personal details of their lives with their doctors.⁴ As a result, a complete medical record may contain more intimate details about an individual than could be found in any single document.⁵ Since the time of Hippocrates, doctors have sworn to maintain the confidentiality of this sensitive information, in order to establish a trusting relationship with their patients.⁶

Until the twentieth century, this ethical obligation has been the primary protection of health information.⁷ But the Hippocratic Oath, which is premised on a simple one-on-one doctor-patient relationship where information can remain under the control of the doctor, does not address the complexities of the modern practice of health care. Obtaining health care today can involve an entire network of health care professionals and insurers. In an attempt to contain escalating health care costs, large amounts of health care data are collected and used by those who pay for health care, including insurers, the government, and employers. The recent revolution in information technology has encouraged a movement towards computerization of the storage and transmission of medical information. Furthermore, there is an increased demand for health care information from secondary users for purposes that are not really related to health care.

Many of these holders of health information are not subject to ethical obligations to maintain its confidentiality. Even where an ethical duty

exists, in some jurisdictions it is not enforceable by law.⁸

Given the numerous uses of health information and the number of people who have access to health information in today's complex health care system, many patients have concerns about the confidentiality of their own, identifiable health information.⁹ According to a recent poll,¹⁰ only one third of U.S. adults say they trust health plans and government programs like Medicare to maintain confidentiality all or most of the time. One in five American adults believe that a health care provider, insurance plan, government agency, or employer has improperly disclosed personal medical information. Half of these people say it resulted in personal embarrassment or harm. Patients fear that their employers, family members, or friends may discover that they have a sensitive health condition that could negatively impact their job security, relationships, or personal safety. As a result, one in six American adults say they have done something out of the ordinary to keep personal medical information confidential. Among the actions reported: going to another doctor; paying out-of-pocket for services; not seeking care; giving inaccurate or incomplete information on a medical history; and asking a doctor not to write down the health problem or record a less serious or embarrassing condition. Clearly, ethical obligations cannot sufficiently protect the confidentiality of health information in today's health care system, and additional measures are warranted.

B. Patients' Right of Access to Their Health Information

Protecting the confidentiality of health information is only a portion of the principle of health privacy. Assuring patients access to their health information is the other part of the equation. To a lay person, it may seem self-evident that individuals should be able to see the information in their health records. However, it was not until 1984 that the American Medical Association officially expressed the belief that doctors should, on request of the patient, provide a copy or a summary of patient's medical record.¹¹ Although many health care professionals have similar ethical obligations, many holders of health information, such as insurers, are not subject to these same ethical guidelines. With the increasingly wide use of health information for secondary purposes, such as employment, it has become even more important that individuals be able to verify the accuracy of their health information.¹²

Because ethical guidelines are insufficient to protect either the confidentiality of health information or to ensure an individual's access to information, individuals have increasingly turned to the law as a source of protection.

I. STATE HEALTH INFORMATION PRIVACY LAWS

Until recently,¹³ states have been the primary regulators of health information.¹⁴ State laws may protect the privacy of health information through three major venues: state constitutions, common law, and statute. The type and extent of protection afforded varies greatly from state to state and from entity to entity. Although there are many people and organizations that maintain health information, this Article focuses on the regulation of health care providers.

A. *State Constitutional Protections*

Most state constitutions afford only limited protection from the unwarranted disclosure of health information.¹⁵ All states have constitutional provisions similar to those in the United States Constitution,¹⁶ which give rise to an implied right of privacy.¹⁷ In addition, several states expressly grant the right to privacy in their constitutions.¹⁸ Whether express or implied, however, the vast majority of state constitutions protect only against state action.¹⁹ Even when state action is at issue, the individual's privacy interest is often outweighed by the state's interest in disclosure.²⁰ Thus individuals generally cannot rely on state constitutions to protect them against the unwarranted use and disclosure of health information either by private parties or by the state.

Two states, California and Hawaii, however, stand out for their constitutional protections. The constitutions of both states explicitly guarantee the right of privacy to their citizens.²¹ These constitutional rights are broad and protect individuals from invasions of privacy by private citizens as well as by the state.²² Additionally these constitutional rights to privacy extend to medical information.²³ Thus, citizens of California and Hawaii may rely on their state constitutions as a source of protection against unwarranted disclosures of health information.²⁴

B. *State Common Law Protections*

State common law provides broader protections against the disclosure of health information and affords patients a right of access to their own health information.

1. *Confidentiality of Health Information.* Recognizing that certain health care providers owe a common law duty of confidentiality to their patients, courts have found that actions may be maintained against these providers for unauthorized disclosures of health information under a number of legal theories including invasion of privacy, implied breach of contract,

and breach of fiduciary relationship.²⁵ Obtaining a remedy for disclosure of health information under any of these theories, however, is difficult.

An increasing number of states recognize the tort of invasion of privacy based on unreasonable public disclosure of private facts.²⁶ Two states, Colorado and Minnesota, have only recognized this tort within the last few years.²⁷ In contrast, New York and Nebraska have affirmatively declined to recognize an invasion of privacy tort based on this particular theory and demonstrate no indication of changing their position.²⁸ Although in the past Indiana seemed to endorse this cause of action, recently the state appears to be wavering on its position.²⁹ Some states, such as North Dakota and Wyoming, appear to have not squarely addressed the issue.³⁰

Even where the cause of action has been recognized, the success rate of plaintiffs has been extremely low, perhaps because of its strict requirements.³¹ Prevailing on a "wrongful disclosure" claim requires proof that there was a public disclosure of a private matter that was not of legitimate concern to the public and that the disclosure would be highly offensive to a reasonable person.³² Although matters concerning a person's medical treatment or condition are generally considered private,³³ proving that the publication of a particular medical condition or treatment is "highly offensive" may be more problematic.³⁴ Additionally, some courts have found that the tort requires disclosure to the general public or a wide audience, a standard that may not be met when health information is disclosed to only a few.³⁵

Having struggled in their efforts to devise a civil remedy for wrongful disclosures of health information, courts have moved towards adopting a tort for breach of confidentiality in its own right, "based on the nature of the patient-physician relationship itself, either because of its fiduciary character or because it is customarily understood to carry an obligation of secrecy and confidence."³⁶ Courts in at least twelve jurisdictions have adopted this approach, Ohio as recently as 1999.³⁷ The underlying duty of confidentiality is not absolute, and the courts have indicated that there is no breach of confidentiality when a disclosure is made as required by statute (such as mandatory reporting to state officials of infectious or contagious diseases) or common law (such as a duty to disclose information concerning the safety of third persons).³⁸

In sum, there are a number of common law actions upon which a patient can bring an action for the unauthorized disclosure of her health information. And most courts seem to be willing to find some theory under which they can address the wrongful disclosure of health information.

2. *Patient Access to Health Information.* Another aspect of health

informational privacy is the ability to know the contents of one's medical records. Although there is not a surfeit of common law in this area, states that have confronted the issue generally have recognized a qualified common law right to inspect one's own medical records.³⁹ Some courts based this right of access on property principles, holding that although the health care provider may own the actual medical record, the patient has a property right in the information contained in the record sufficient to afford reasonable access rights to that information.⁴⁰ Other courts have based the common law right of access to medical information on a health care provider's fiduciary duty to reveal to a patient information that is in her best interest to know.⁴¹

Although the common law establishes a general right of access to one's own health information, it gives little guidance as to what constitutes "reasonable access." These cases also fail to define parameters as to the degree of discretion the health care provider has in determining what information is in the best interest of the patient.

C. State Statutory Protections

Beginning in the 1970s, the trend has been to augment existing state constitutional and common law rights with statutory protections specifically designed to protect the confidentiality of health information and to ensure that individuals have access to their own information. Although common law developments continue to be important, states have increasingly focused on enacting distinct statutory requirements.

This shift to statutory protections can be seen as an outgrowth of the development of fair information practice principles.⁴² Although these standards have been grouped and characterized in various fashions, with respect to health information, they may generally be seen as encompassing the following principles:

- A patient should have the right to see and copy her own health information.
- A patient should have the right to amend or correct such information.
- There should be defined limits on how identifiable health information can be used and shared. A patient's authorization should be obtained before using or disclosing health information for purposes not related to health care.
- An entity that maintains and shares identifiable health information should provide individuals with a notice of its information practices.

- Entities that maintain health information should be required to have procedures and practices in place to safeguard the information from unwarranted intrusion.
- Entities should be held accountable if they violate these principles.⁴³

Although states have applied many of these principles to health information, most have done so in a fairly ad hoc fashion, addressing particular entities or medical conditions, and applying certain principles but not others. Furthermore, in spite of some concerted efforts,⁴⁴ these principles have not been adopted uniformly among states. The net result is a patchwork of state health privacy laws that provide little consistency from entity to entity or from state to state.

1. *Patients' Access to Their Own Health Information.* Patients should be able to see and copy their own health information.⁴⁵ There are a variety of policy factors supporting this principle, not the least of which is a matter of basic fairness. If others outside the medical system are using health information to make important employment and insurance related decisions about individuals, those individuals should at least have the right to see and verify the information upon which those decisions are based.⁴⁶ Moreover, patients who have access to their medical information can better understand their medical conditions and participate more actively in treatment.⁴⁷

In 1977, only nine states clearly granted a patient the right to inspect, and in some instances obtain a copy of, her own medical record, while ten other states had "vaguely worded statutes or regulations that allow a patient, relative, physician or attorney to access the patient's medical record."⁴⁸ Although these numbers have significantly improved, there is still a wide disparity in statutory access rights both between states and within many given states.

Currently, more than thirty states statutorily grant patients an unencumbered right to inspect and/or copy their medical records that are held by hospitals and health care professionals, including doctors.⁴⁹ Some states, such as Ohio and Wyoming, provide a statutory right of access only to records held by hospitals.⁵⁰ Other states afford access rights only to records held by hospitals and doctors, while yet others define the term health care provider broadly to encompass a variety of health care professionals.⁵¹ Nebraska, for instance, recently passed an act that for the first time statutorily provided patients access to their medical records maintained by a wide range of health care providers.⁵² A few state statutes grant patients access to their medical records only through an attorney.⁵³ Some states, such as Iowa, Kansas, and Vermont, however, have no general

statutory right of access to medical records.⁵⁴

Many states have begun to recognize the need to extend the right of access beyond doctor and hospital records. For example, almost one third of the states have statutes that expressly grant patients access to health records maintained by pharmacists.⁵⁵ Some states, such as Montana and Washington, have purposefully chosen to exclude pharmacists from their access provisions on the grounds that, traditionally, the relationship between a pharmacist and a patient more closely resembled a seller-customer relationship than a provider-patient relationship.⁵⁶ This perspective, however, fails to take into account the increasingly complex role that pharmacists play in today's health care systems.⁵⁷

With the growing popularity of alternative health care,⁵⁸ states are beginning to subject some of these non-traditional providers to patient access requirements.⁵⁹ For example, at least sixteen states clearly grant patients the right to see and copy their health information that is maintained by acupuncturists.⁶⁰ Similarly, as states begin to recognize naturopaths and homeopaths as legitimate health care providers, they have also begun to statutorily grant patients access to the records maintained by these alternative care providers.⁶¹

The result of this piecemeal approach is that in any given state patients may have a statutory right of access to health records maintained by only a fraction of the health care professionals who are engaged in their care. For instance, in Ohio, patients have a statutory right of access to their hospital records, but not the records of their doctors.⁶² Oklahoma statutorily grants patients access rights with respect to health information maintained by hospitals and doctors, but not with respect to similar information maintained by pharmacists.⁶³ And Rhode Island citizens have the statutory right of access to health information maintained by physicians, but not to information held by hospitals, pharmacists, or other health care providers.⁶⁴ Thus, even within a particular state, there may be, at best, a sporadic application of the fair information principle of individual access.

The same holds true when comparing access rights between different states, with the result that citizens in neighboring states can have vastly different rights with respect to their health information.⁶⁵ For instance, Maryland provides its citizens with a broad right to see, copy, and amend their health information maintained by a wide range of health care providers and health care facilities.⁶⁶ In contrast, its neighboring state, Delaware, does not statutorily grant its citizens the right of access even to health information held by hospitals and doctors.⁶⁷

2. *Patients' Right to Amend Health Records.* A patient should be able to not only review her medical records but also should be able to correct any

errors or amend any inadequacies in them.⁶⁸ The accuracy of health care information is obviously important for the delivery of quality health care. However, accuracy is equally important for many of the non-medical uses of health information. Medical information may be used to evaluate applications for life and health insurance, to make employment decisions, or used in civil litigation, totally unrelated to the quality of health care received (such as child custody cases).⁶⁹ Given the potentially serious repercussions of having incomplete or inaccurate medical records, patients should be able to at least supplement or amend their health information.⁷⁰

Yet, only a handful of states, including California, Maine, Maryland, Montana, New York, Texas, and Washington afford patients the right to amend or supplement medical records maintained by health care providers and facilities.⁷¹ Generally, these states have taken a consistent approach: If there is a right of access to health information held by a particular health care provider, there is also a right to amend that information.

3. *Restrictions on Use and Disclosure of Health Information.* There should be clear rules delineating the appropriate uses and disclosures of health information. Widespread demands for health information from parties both within and beyond the health care system and increasing reliance on computer-based information systems threaten to undermine the confidentiality of the physician-patient relationship.⁷² Statutorily imposing restrictions on the use and disclosure of health information is beneficial for both patients and health care providers. From the patient's perspective, there will be no surprises. The statutory restrictions spell out to whom their health information can be shared and under what circumstances.⁷³ From the provider's perspective, a concrete set of rules often can function essentially as a shield: If the provider discloses health information in accordance with the rules, he will not be liable for an improper disclosure. Equally important, enforceable limits on disclosure can serve as the basis for refusing outside demands for health information.⁷⁴

While every state has some statutes restricting the use and disclosure of medical information, few states have taken a comprehensive approach. Rather, state statutes protecting the confidentiality of health information tend to be either condition specific or entity specific, leaving much information in the health care system uncovered.

One type of health privacy statute is common to virtually every state. States provide some protection to health data collected for public health purposes.⁷⁵ All states require health care providers to report to state agencies certain types of patient health conditions, such as contagious or infectious diseases, HIV/AIDS, cancer, and congenital defects, and

typically place restrictions on the agency's use and disclosure of the reported information. The level of protection afforded by these statutes often varies with the type of health condition.⁷⁶

Most states also have some type of statutory provider-patient privilege, which affords some limited protection of health information. The provider-patient privilege allows a patient to restrict her physician (and sometimes other health care providers) from disclosing in judicial and administrative proceedings health information received in confidence during treatment. Some experts believe that even this limited restriction has been seriously eroded in recent years.⁷⁷ Moreover, there are a number of states that do not provide for the physician-patient privilege in statute and, because the privilege did not exist at common law, therefore do not recognize the privilege at all.⁷⁸

Many states also have more general provisions that restrict the use and disclosure of health care information by specific health care providers. These statutes are often contained in licensing provisions, enacted at different times. As a result, coverage is piecemeal. For instance, Vermont imposes statutory restrictions on hospitals but not on physicians or other health care providers.⁷⁹ Oklahoma statutorily limits the disclosures by dentists and chiropractors but not by physicians or hospitals.⁸⁰ And West Virginia has statutory restrictions on pharmacists, but not on most of the other major categories of health care providers.⁸¹ Oregon has taken a singular approach and statutorily restricts the use and disclosure of health information by public health care providers in a fairly detailed fashion, while merely encouraging private health care providers to adopt similar guidelines.⁸² The result of this ad hoc approach is that in many states, there is no statutory guidance as to the proper use and disclosure of health information with respect to many of the major providers of health care.

It naturally follows that this discrepancy is also evident in doing comparisons between states. For instance, North Dakota statutorily restricts when and how hospitals may disclose health information, and South Dakota does not.⁸³ Indiana statutorily regulates the use and disclosure of health information by a broad range of health care providers, but Ohio, its neighbor state, has no similar statutory protections.⁸⁴

States also vary widely in terms of the restrictions or prohibitions they impose on disclosures of medical records and medical information. Some states have fairly perfunctory provisions that deem records confidential and provide little additional guidance.⁸⁵ However, an increasing number of states have detailed provisions governing how health care providers may use and share identifiable health information.⁸⁶ Many of these statutes have the same general framework. They allow health care providers to use and

disclose patient-identifying information without the patient's authorization for certain purposes such as treatment, payment, peer review, and research. The statutes then often impose conditions that must be met prior to disclosing health information under these circumstances. For uses and disclosures not specified in the statute, the patient's written authorization is required. Many statutes specify the particular elements that a valid authorization form must include, such as the patient's dated signature and the identification of the intended recipient of the information.

Although the general framework of these statutes may be the same, the details of the statutes can vary widely from state to state. Arizona, for example, statutorily provides that the recipient of health information from a health care provider may not further disclose the information unless it obtains the patient's authorization.⁸⁷ In contrast, Montana and Washington have no such requirement.⁸⁸ Virginia permits the release of health information pursuant to a subpoena only if the person seeking the records has adhered to detailed procedures intended to give the subject of the record notice that her records are being sought have been followed.⁸⁹ But Connecticut permits the release of health information pursuant to a subpoena without any specific requirements.⁹⁰ Florida permits the release of identifiable health information to researchers only with the permission of the patient.⁹¹ Rhode Island, in contrast, allows the disclosure of health information to qualified researchers without patient authorization so long as any resulting report does not identify the patient.⁹²

4. *Notice of Information Practices.* Under the principles of fair information practices, patients should be given notice, in plain language, of the information practices of those who generate and maintain their health information.⁹³ The notice should inform patients how information will be used and to whom it will be disclosed.⁹⁴ It should also advise patients of their right to see and amend (if applicable) their health information.

A notice of information practices can serve several important functions. In one sense, such notices serve a market function, enabling people to "make informed, meaningful choices about uses and disclosures of their health information."⁹⁵ Furthermore, absent such notices, patients may be ignorant of the rights that they have with respect to their health information (such as their right to see and copy the information). Notices can also serve to bolster trust between health care providers and patients to the extent they remove the element of surprise about the use and disclosure of health information.⁹⁶

Although there seems to be little dispute that the principle of providing a notice of information practice is a sound one,⁹⁷ only a few states require health care providers to furnish such notices to their

patients.⁹⁸ Even Maryland's Confidentiality of Medical Records Act, which provides broad access and amendment rights, does not include such a requirement.⁹⁹

5. *Security Safeguards.* Health care providers should have in place appropriate safeguards to protect health information from unauthorized use or disclosure.¹⁰⁰ These safeguards identify the means by which a provider protects the confidentiality of health information, and may include such procedures as requiring individuals to provide identification prior to furnishing access to health information.¹⁰¹ A few states such as California, Florida, and Washington have statutorily required providers to undertake security measures to ensure that health information is used and disclosed properly. Florida, for example, requires those who maintain medical records to develop and implement policies, standards, and procedures to protect the confidentiality and security of the medical record, and to train their employees in these policies, standards, and procedures.¹⁰²

6. *Accountability.* To be truly effective, health privacy statutes must be supported by strong remedies and penalties for violations.¹⁰³ States have instituted a wide range of mechanisms for holding health care providers accountable for violations of state health privacy statutes. With respect to wrongful refusals to give patients access to their health information, some state statutes expressly grant patients the right to bring suits for equitable relief, often making the provider liable for any attorney fees resulting from the need to file suit.¹⁰⁴ Other states, such as Louisiana, presume such a right to sue exists, and statutorily limit the recovery of the aggrieved patient to attorney fees and expenses incurred.¹⁰⁵ Several states have no statutory remedies for violations of their statutory access provisions.¹⁰⁶

There is an even wider range in the remedies and penalties available for disclosures of health information in violation of state health privacy laws. South Carolina, for example, has no statutory remedy for disclosures in violation of its Physicians' Patient Records Act.¹⁰⁷ At the other end of the continuum, Rhode Island statutorily provides that a person who violates its Confidentiality of Health Care Communications and Information Act may be liable for actual and punitive damages.¹⁰⁸ If the violation is knowing or intentional, the person may be subject to criminal penalties including fine and imprisonment.¹⁰⁹ Many states have statutory remedies that are somewhere in the mid-range, allowing actions for damages, but not providing for punitive awards.¹¹⁰

7. *Towards a More Uniform Approach.* By incorporating only isolated elements of the fair information principles into their statutes, most states have failed to accomplish any uniformity. There are a few exceptions. For

example, through the enactment of various statutes over a period of time, California has crafted some of the most consumer-protective health privacy laws in the nation. Through the Information Practices Act, the Patient Access to Medical Records Act, the Confidentiality of Medical Information Act, and the Insurance Information and Privacy Protection Act, California affords patients access rights to most of the major holders of health care information.¹¹¹ The state not only restricts disclosures by health care providers and HMOs to employers, but also directly regulates the use and disclosure of health information by employers.¹¹² Moreover, individuals have the right to sue to enforce their rights under these statutes.¹¹³ As recently as 1999, California amended its law to broaden the category of record holders covered by its Confidentiality of Medical Records Act and to increase the penalties for violating that Act.¹¹⁴ Yet, even California law is lacking in two major areas. There is no requirement that health care providers furnish a notice of information practices and policies to patients. The result of this lack of notice is that many individuals may be unaware of their rights with respect to their health information. Additionally, the statutory right of access to health information is not sufficiently broad. It does not cover pharmacists, a group that maintains a vast amount of health information. Neither does it cover acupuncturists and other alternative health care providers, to whom patients are increasingly turning for health care.

Although most recent state legislation continues to be undertaken in a piecemeal fashion, a few states, such as Maine and Hawaii, enacted more comprehensive statutes regulating the privacy of health information. In the late 1990s, Maine substantially revised its health privacy laws by providing patients the right to amend their medical records and enacting comprehensive provisions governing the use and disclosure of health information by a wide range of health care practitioners (including doctors, pharmacists, and others) and health care facilities.¹¹⁵ The statute incorporates the main fair information practice principles. Maine statutorily provides patients the right to see, copy, and amend health information.¹¹⁶ The statute generally prohibits disclosure of health information without the patient's authorization and then lists the circumstances under which no such authorization is required.¹¹⁷ Using health information for marketing purposes is prohibited unless the patient's authorization has been obtained.¹¹⁸ At certain times, patients are entitled to a notice of information practices.¹¹⁹ Additionally, Maine's statute requires health care providers to implement policies to ensure information is not negligently, inappropriately, or unlawfully disclosed.¹²⁰ In order to hold health care providers accountable, the statute provides that the state

attorney general may enforce it.¹²¹ The statute also expressly grants patients a private right of action for intentional disclosures and explicitly leaves in place any common law remedies that may be applicable, including actions based on negligence.¹²²

Hawaii enacted a truly comprehensive health privacy law in 1999, with the intention of addressing the threats to health care information in the modern health care environment.¹²³ The Privacy of Health Care Information Act applied to all major holders of health information including health care providers, health plans, employers, health data organizations, and educational institutions.¹²⁴ Broadly defining health information, it protected identifying information that relates to a person's physical or mental condition, including tissue and genetic information. Individuals had the right to see, copy, and amend their health information. The Act imposed restrictions on the use and disclosure of health information, allowing it to be used freely for certain core purposes such as treatment and payment, so long as the patient had been given notice of its potential use. For other uses and disclosures, the Act required the individual's written authorization. There were, of course, major exceptions in which health information could be disclosed without the individual's authorization, such as for public health purposes and to health oversight agencies. In order to enforce the Act, individuals had the right to sue violators and could collect actual and punitive damages. The Act also provided for civil and, in certain circumstances, criminal penalties.¹²⁵ In short, Hawaii had the most comprehensive health information privacy statute in the nation. It applied all of the fair information practice principles to all of the major holders and users of health information in the state.

II. THE FEDERAL HEALTH PRIVACY RULE UNDER HIPAA

The role of states as the predominant regulators of the privacy of health information may have changed dramatically with the recent issuance of federal regulations governing the use and disclosure of health information by the U.S. Department of Health and Human Services (HHS).¹²⁶ The rule constitutes the first broad-ranging federal health privacy law, and effectively injects the federal government into an arena that had previously been primarily occupied by the states. Since the rule does not preempt stronger state law, however, state laws should still play an important role in protecting health information.

A. Background

HHS promulgated the Federal Privacy Rule under authority granted it in the “Administrative Simplification” provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).¹²⁷ In enacting these provisions, Congress primarily sought to encourage the use of electronic technology in the health care industry as a means of improving efficiency and reducing costs.¹²⁸ Recognizing the privacy concerns arising from an electronic health information system, Congress also required new safeguards to protect the security and confidentiality of that information.¹²⁹ HIPAA specified that if Congress failed to pass comprehensive health privacy legislation by August 1999, HHS must promulgate such privacy protections by regulation.¹³⁰ Congress missed the deadline for enacting legislation.

As required under HIPAA, the Secretary of HHS issued final health privacy regulations in December 2000.¹³¹ After a short delay, the final regulation, known as the “Privacy Rule,” became effective April 14, 2001, and compliance is generally required by April 2003.¹³²

B. General Requirements of the Federal Health Privacy Rule

The Federal Health Privacy Rule covers a core group of entities that use and share information in the health care system including: health plans, health care clearinghouses, and health care providers who transmit health information in electronic form in connection with certain financial and administrative transactions.¹³³ The rule incorporates many of the basic fair information practices into the health care setting.¹³⁴

1. *Patients’ Access.* The Federal Rule gives individuals the right to see and copy their own health information that is maintained by most health care providers.¹³⁵ The procedures for initiating and responding to requests for access to health information are specified in detail, giving clear guidance as to what is expected.¹³⁶ The Rule sets out specific limitations on when a provider may deny a patient access to her medical records (such as when the requested access is reasonably likely to endanger the life or physical safety of the individual or another).¹³⁷ These standards for denial are more concrete than the common law approach of granting access to information that is “in the best interest of the patient.”

2. *Patients’ Right to Amend Health Information.* The Federal Rule also grants patients the right to request that their health information be amended.¹³⁸ Patients do not have the right to delete information from their records, but can request that information be added to an incomplete or erroneous record.¹³⁹ There are detailed requirements for requesting an

amendment and responding either affirmatively or negatively to such a request, including provisions designed to ensure that those who need accurate health information are informed of any changes.¹⁴⁰ Even if the provider determines to deny the request to amend, the patient still has the opportunity to submit a brief statement of disagreement into his or her record, which must be provided along with future disclosures of the underlying disputed information.¹⁴¹

3. *Restrictions on Use and Disclosure.* The Federal Health Privacy Rule imposes restrictions on how providers may use and disclose health information.¹⁴² Perhaps most notable from a provider's perspective is the requirement that providers obtain a patient's written permission (i.e., "consent") prior to using or sharing that patient's health information for treatment, payment, or health care operations.¹⁴³ To disclose health information for other purposes, a provider must have an "authorization," a more detailed written permission, specifying, among other things, to whom the information may be released, the type of information to be disclosed, and a date or event upon which the authorization expires.¹⁴⁴ Like most state disclosure laws, the Federal Rule lists a number of exceptions under which health information can be disclosed without the individual's written permission, such as for law enforcement and research purposes.¹⁴⁵ Under many of these exceptions, specific conditions must be met prior to disclosing health information.¹⁴⁶

4. *Notice of Privacy Practices.* In order to ensure that patients are informed of their rights with respect to their health information and are aware of how their health information may be used and disclosed, the Federal Health Privacy Rule requires health care providers to furnish to patients a notice of their privacy practices.¹⁴⁷ Such a notice must describe the rights that patients have with respect to their health information, including their rights to see, copy, and amend their own records. Additionally, the notice must inform patients of the anticipated uses and disclosures of their health information that may be made without the patient's consent or authorization.¹⁴⁸

5. *Security.* The Federal Privacy Rule requires providers to have appropriate administrative, technical, and physical safeguards in place to protect the privacy of health information, and to reasonably safeguard such information from intentional or unintentional use or disclosure.¹⁴⁹ HHS has also issued a separate set of proposed security regulations specifically designed to address security issues surrounding the electronic transmission of health information, which should become final in the near future.¹⁵⁰

6. *Accountability.* HIPAA establishes civil and criminal penalties for

violations of the Privacy Rule.¹⁵¹ There is a \$100 civil penalty up to a maximum of \$25,000 per year for each standard violated. Criminal penalties may be imposed for knowing wrongful disclosures of health information. Criminal penalties are graduated, escalating to a maximum of \$250,000 for particularly egregious offenses. HHS, which has authority to enforce the Privacy Rule,¹⁵² has expressed an intention to stress cooperation over enforcement.¹⁵³

HIPAA does not create a federal private right of action based on violations of the Privacy Rule, giving enforcement responsibility solely to HHS.¹⁵⁴ However, there is at least the potential that individuals may be able to enforce the Privacy Rule through state causes of action. To the extent the new federal rule may be seen as creating a new duty of care with respect to health information, violations of the rule possibly may serve as the grounds for state tort actions.

C. The Interaction Between the Federal Health Privacy Rule and State Law

HIPAA employs an issue preemption scheme with respect to state health privacy laws.¹⁵⁵ State laws that are contrary to the federal regulation and that are less protective are preempted.¹⁵⁶ Existing or future state laws related to the privacy of health information that are “more stringent” than the federal rule will remain in effect, even if they are contrary to the federal regulation.¹⁵⁷

Generally, a state law is “more stringent” when it provides greater privacy protection for the individual who is the subject of the information.¹⁵⁸ With respect to uses and disclosures, a state law is more stringent if it prohibits or restricts a use or disclosure that would be permitted under the federal regulation.¹⁵⁹ As for laws that govern patient access, a state law is “more stringent” when it provides patients with greater access to their own health information.¹⁶⁰ Thus, the federal privacy regulations establish a “floor” for protecting the privacy of health information, leaving the states free to impose privacy protections on health information that are similar to or more stringent than the federal privacy regulations.

D. Gaps and Weaknesses of the Federal Health Privacy Rule

As lengthy and detailed as it is, the Federal Health Privacy Rule is not truly comprehensive. The regulation is limited in scope, leaving gaps in the protections of health information as it flows through the health care system. Furthermore, some of its provisions are weak and do not provide adequate protection of health information. This section addresses some of

these major gaps and weaknesses.

Due to HIPAA's limited delegation of authority, the Federal Health Privacy Rule only covers a limited group of persons and organizations that hold health information: health plans, health care clearinghouses, and health care providers who transmit health information in electronic form in connection with HIPAA standard transactions.¹⁶¹ This limited applicability leaves a broad range of entities that maintain health information unregulated by the federal rule. First, health care providers who do not engage in electronic standard transactions (e.g., those who rely solely on paper claims) are not covered by the regulations. Second, the Privacy Rule does not directly regulate some major entities that are responsible for generating and maintaining health information, such as employers and life insurers. Furthermore, the Privacy Rule is not directly applicable to many of those who receive health information from covered health care providers.¹⁶² Thus, the Federal Health Privacy Rule is sporadic in coverage, leaving unprotected many areas where health information routinely flows.

Additionally, the Federal Health Privacy Rule is not fully enforceable. There is no federal private right of action. Any individual whose rights under the law have been violated should be permitted to bring an action for actual damages and equitable relief.¹⁶³ As HHS, itself has stated: "Only if we put the force of law behind our rhetoric can we expect people to have confidence that their health information is protected, and ensure that those holding health information will take their responsibilities seriously."¹⁶⁴

Furthermore, the office charged with enforcing the Privacy Rule traditionally has limited resources, and has indicated that it intends to use a "triage" approach to complaints, focusing on violations that have a wide impact.¹⁶⁵ Although this makes perfect sense from an administrative point of view, it offers little solace to an individual who suffers from an isolated violation (e.g., a patient whose doctor will not furnish a copy of her medical record).

One of the most criticized aspects of the Federal Health Privacy Rule, is its lax restrictions on the use and disclosure of health information for marketing activities.¹⁶⁶ The regulation allows a provider to use a patient's health information for marketing activities without obtaining the patient's informed consent.¹⁶⁷ A patient only has the opportunity to opt out of such uses after he has received the initial marketing materials.¹⁶⁸

Additionally, the Federal Rule has only minimal protections with respect to disclosing health information to law enforcement personnel.¹⁶⁹ The rule permits health information to be disclosed to law enforcement

officials under three types of legal process, two of which do not require any independent judicial review.¹⁷⁰

III. STATE ACTIVITY IN THE POST-HIPAA ERA

The promulgation of the Federal Health Privacy Rule will certainly affect some state health privacy laws. As a practical matter, states will need to review their statutes relating to health privacy to determine what impact the Federal Rule has on state law.

The Federal Rule preempts weaker, conflicting state law. In states that have weak or few state laws, the Federal Rule will provide the predominant protection of health privacy information. But states that already have, or are willing to enact, strong health privacy laws will maintain a large role in protecting the health information of their citizens.

The issuance of the federal privacy regulations already has caused some states to reevaluate their efforts to protect health privacy at the state level. It is too early to discern any definitive trends in state law post-HIPAA. One state has used the promulgation of the Federal Health Privacy Rule as justification for reducing protections at the state level. However, other states have demonstrated their intent to maintain and increase strong state laws.

At one extreme is Hawaii, which prior to the promulgation of the federal health privacy regulations had one of the most comprehensive, consumer-protective health privacy laws in the nation.¹⁷¹ In July 2001, Hawaii repealed its state health privacy statute, finding that there was "little support for a Hawaii Medical Privacy Law in light of the adoption of federal rules and regulations on medical privacy by the United States Department of Health and Human Services."¹⁷²

The state has essentially reverted to a statutory scheme that has no generally applicable restrictions on the use and disclosure of health information. State statutory access rights are now limited to a few specified health care providers, and there is no statutory right to amend health information.¹⁷³

Although the Federal Health Privacy Rule does establish a minimum floor of protection, Hawaii's reliance on the federal rule in lieu of a comprehensive state law is misplaced. Taken together, the federal and state laws provide at best intermittent coverage. Many of the major entities that use and maintain health information, such as employers and other secondary recipients (who would have been regulated under Hawaii's comprehensive law) are now unregulated at both the federal and state level. Furthermore, patients have no remedy for violations of the Federal

Health Rule, other than filing a complaint with HHS. Thus, Hawaii's repealing its state law in reliance on the Federal Privacy Rule has the net effect of weakening health privacy protections in the state.

In contrast to Hawaii, other states have demonstrated a more privacy protective policy following the issuance of the Federal Privacy Rule. Some have reaffirmed their existing health privacy laws, while others have acted to fill gaps and strengthen the weaknesses evident in the federal privacy rule.

For example, at the time the federal privacy rule was issued, Maine had a fairly comprehensive health privacy statute.¹⁷⁴ Some of the protections afforded by Maine's privacy statute exceed those contained in the Federal Privacy Rule.¹⁷⁵ However, the state statute contained a sunset provision under which the privacy statute was scheduled to expire in March 2002.¹⁷⁶ After the issuance of the Federal Privacy Rule, Maine repealed the sunset provision of its privacy statute,¹⁷⁷ thereby allowing the state statute to co-exist with the Federal Rule indefinitely. As a result, the citizens of Maine will enjoy the floor protections afforded by the Federal Privacy Rule and enhanced protections under state law.

Florida achieved a similar result by amending its health privacy statute to strengthen some of the perceived weaknesses of the federal health privacy regulation. In particular, Florida enacted legislation that prohibits disclosing health information for marketing purposes without the patient's written consent or authorization that would specifically permit this activity.¹⁷⁸ Thus, the state law affords higher protections than the Federal Rule. Moreover, the state attorney general can enforce the state law by obtaining injunctive relief or fines up to \$5,000 per violation. As a result, Florida citizens will be afforded more stringent protections against marketing that can be enforced locally.

Texas' response to the Federal Health Privacy rule is diametrically opposed to that of Hawaii. While maintaining its existing health privacy protections, Texas recently adopted a broad health privacy statute that both mirrors and expands upon the Federal Health Privacy Rule.¹⁷⁹ The Texas statute applies to a broader range of persons and entities that obtain or maintain health information than the Federal Rule. For instance, it directly regulates the recipients of health care information as well as *all* health care providers (not just those engaged in electronic transactions). The state statute requires these entities to comply with the Federal Health Privacy Rule, essentially enabling the state to enforce the federal standards. Disapproving of the Federal Rule's approach towards marketing,¹⁸⁰ Texas requires a provider to obtain a patient's consent or authorization specifically for marketing purposes.¹⁸¹ Additionally, the Texas statute

provides for civil penalties, disciplinary action by the respective licensing boards, and potential exclusion from state programs for violations of the state standards.¹⁸² Notably, the statute preserves any right of a person under other law to bring a cause of action or otherwise seek relief with respect to violations.¹⁸³ Thus, Texas has both mirrored and improved upon the protections afforded in the Federal Health Privacy Rule.

IV. RECOMMENDATIONS FOR STATE ACTION

States have traditionally been the primary regulators of health care information. While the promulgation of the Federal Health Privacy Rule changes the regulatory landscape, it need not supplant the importance of state health privacy laws. In fact, states have often become more active after the enactment of federal privacy laws, enacting statutes that either mirror or build upon the federal protections. This approach, endorsed by the Privacy Protection Study Commission in the 1970s, ensures that the states will be able to enforce the law and protect their citizens.¹⁸⁴ Because the Federal Health Privacy Rule does not preempt current or future stronger state health privacy laws, the states have ample opportunity to fill the gaps and strengthen the weaknesses of the federal regulation.

States therefore should not rely solely on the Federal Health Privacy Rule to protect the privacy rights of their citizens. Rather, states should take advantage of the need to evaluate their health privacy laws in light of the Federal Health Privacy Rule and take appropriate action.

States with little statutory protection of health information in place may want to use Federal Health Privacy Rule as a roadmap for enacting comprehensive state health privacy laws. At a bare minimum, states can mirror the federal protections, thereby allowing enforcement to occur at the state level. However, to afford truly comprehensive protection, states should directly regulate not only the entities governed by the Federal Health Privacy Rule, but also the other major generators and holders of health information (such as employers and life insurers). Additionally, states should directly regulate the recipients of health information from these core record keepers. Furthermore, states should strengthen some of the weak provisions of the Federal Health Privacy Rule, such as the use of health information for marketing purposes.

States with fairly well developed health privacy rules should also re-evaluate their laws in light of the Federal Health Privacy Rule. Some state and federal rules may accomplish the same goals through slightly different requirements (e.g., different content requirements for a notice advising the patient of information practices). In this situation, a state may want to harmonize its provisions with the Federal Rule in order to avoid confusion

and to afford some degree of uniformity between states. States should also use this as an opportunity to fill in gaps in state law that may exist (such as having statutory access rights to hospital records but not doctor's records).

SUMMARY

Although the Federal Health Privacy Rule has evened out some of the inconsistencies between states' health privacy laws, gaps in protection still remain. Furthermore, the Federal Rule contains some lax standards for the disclosure of health information. State laws can play a vital role in filling these gaps and strengthening the protections afforded health information.

By enacting legislation that has higher privacy-protective standards than the Federal Health Privacy Rule, states can play three important roles. First, because they can directly regulate entities that are beyond HHS's mandate, states can afford their citizens a broader degree of privacy protection than the Federal Health Privacy Rule. Second, by having state health privacy laws, states can enforce privacy protections at the local level. Finally, action by the states can positively influence health privacy policies at the federal level by raising the standard as to what constitutes sufficient privacy protection. High privacy protections imposed by states may serve as the standard for comprehensive federal legislation, if and when Congress reconsiders the issue.

So far, states' reactions to the Federal Privacy Rule have been mixed. Only time will tell whether states will assume the mantle of leadership on health privacy or relinquish their role as the primary protectors of health information.

APPENDIX

*State Statutes Providing Patients the Right of Access to, and Right to Amend, Their Health Records (as of November 2001)*¹

State	Physician Records		Hospital Records		Pharmacist Records	
	Right of Access	Right to Amend	Right of Access	Right to Amend	Right of Access	Right to Amend
Alabama	No	No	No	No	No	No
Alaska	Yes	No	Yes	No	Yes	No
Arizona	Yes	No	Yes	No	Yes	No
Arkansas	No ²	No	No ²	No	No	No
California	Yes	No	Yes	No	No	No
Colorado	Yes	No	Yes	No	No	No
Connecticut	Yes	No	Yes	No	Yes	No
Delaware	No	No	No	No	No	No
District of Columbia	No	No	No	No	No	No
Florida	Yes	No	Yes	No	No	No
Georgia	Yes	No	Yes	No	Yes	No
Hawaii	Yes	No	Yes	No	Yes	No
Idaho	No	No	No	No	No	No
Illinois	No	No	Yes	No	No	No
Indiana	Yes	No	Yes	No	Yes	No
Iowa	No	No	No	No	No	No
Kansas	No	No	No	No	No	No
Kentucky	Yes	No	Yes	No	No	No
Louisiana	Yes	No	Yes	No	Yes	No
Maine	Yes	Yes	Yes	Yes	Yes	Yes
Maryland	Yes	Yes	Yes	Yes	Yes	Yes
Massachusetts	Yes	No	Yes	No	No	No
Michigan	No	No	Yes	No	No	No
Minnesota	Yes	No	Yes	No	Yes	No
Mississippi	No	No	No	No	No	No
Montana	Yes	Yes	Yes	Yes	No	No
Nebraska	Yes	No	Yes	No	No	No
Nevada	Yes	No	Yes	No	Yes	No

APPENDIX (CONTINUED)

State	Physician Records		Hospital Records		Pharmacist Records	
	Right of Access	Right to Amend	Right of Access	Right to Amend	Right of Access	Right to Amend
New Hampshire	Yes	No	Yes	No	No	No
New Jersey	Yes	No	Yes	No	No	No
New Mexico	No	No	No	No	No	No
New York	Yes	Yes	Yes	Yes	No	No
North Carolina	No	No	No	No	No	No
North Dakota	No	No	No	No	No	No
Ohio	No	No	Yes	No	No	No
Oklahoma	Yes	No	Yes	No	No	No
Oregon	No	No	No	No	No	No
Pennsylvania	Yes	No	Yes	No	No	No
Rhode Island	Yes	No	No	No	No	No
South Carolina	Yes	No	Yes	No	No	No
South Dakota	Yes	No	Yes	No	Yes	No
Tennessee	Yes	No	Yes	No	Yes	No
Texas	Yes	Yes	Yes	Yes	Yes	Yes
Utah	No	No	No	No	No	No
Vermont	No	No	No	No	No	No
Virginia	Yes	No	Yes	No	Yes	No
Washington	Yes	Yes	Yes	Yes	No	No
West Virginia	Yes	No	Yes ³	No	No	No
Wisconsin	Yes	No	Yes	No	Yes	No
Wyoming	No	No	Yes	No	No	No

1. This chart does not address access to mental health records. State statutes that grant access to medical records only through an attorney are treated as not granting a patient access since obtaining an attorney may impose a formidable barrier for some patients.
2. Release to patient only in contemplation of a legal proceeding.
3. The West Virginia access statute appears to apply to hospitals. The statute covers "health care providers," a term that is not defined in the statute. *See* W. VA CODE §§ 16-29-1 and 16-29-2 (2001). However, other parts of the West Virginia Code define the term "health care provider" as including hospitals. *See* W. VA CODE §§ 16-2D-2(k) and 16-29B-3 (2001).

References

1. See discussion *infra* Part III regarding the recent issuance of federal health privacy standards by the United States Department of Health and Human Services.

2. See generally THE REPORT OF THE PRIVACY PROTECTION STUDY COMMISSION, PERSONAL PRIVACY IN AN INFORMATION SOCIETY 276-290 (1977) [hereinafter PRIVACY COMMISSION REPORT] (discussing the elements of privacy in relation to medical care).

3. *Id.*

4. See American Medical Association, Current Opinions of the Council on Ethical and Judicial Affairs, *Ethical Opinion E10.02: Patient Responsibilities* (June 2001), <http://www.ama-assn.org/ama/pub/article/4301-4412.html> (stating that successful medical care requires an ongoing collaborative effort between patients and physicians, and that for their part "[p]atients have a responsibility to provide a complete medical history, to the extent possible, including information about past illnesses, medications, hospitalizations, family history of illness and other matters relating to present health").

5. PRIVACY COMMISSION REPORT, *supra* note 2, at 282 (quoting testimony of the Executive Director of the American Medical Record Association).

6. See David Graham, *Revisiting Hippocrates: Does an Oath Really Matter?* 284 JAMA 2841 (2000) (citing text of traditional and modern versions of the Hippocratic Oath).

7. Smith v. Driscoll, 162 P. 572 (Wash. 1917) appears to be one of the premier

cases addressing the issue of whether there is a cause of action against a physician for wrongfully divulging confidential communications. See also *Biddle v. Warren Gen. Hosp.*, 715 N.E.2d 518, 523 (Oh. 1999) (holding that an independent tort exists for the unauthorized disclosure to a third party of medical information that a physician or hospital has learned within the physician-patient relationship).

8. See *Quarles v. Sutherland*, 389 S.W.2d 249, 251 (Tenn. 1965) (holding that a physician obtained by the opposing party has no duty of medical confidentiality to the individual he examined).

9. See Fox News and Opinion Dynamics Poll, *Online Privacy*, (June 2000), at <http://pollingreport.com/computer.htm> (reporting that 69% of American adults were very concerned about their ability to keep personal information, such as medical or financial records, confidential. Another 17% of adults were somewhat concerned with confidentiality of these records.).

10. Princeton Survey Research Associates for the California HealthCare Foundation, *Confidentiality of Medical Records: National Survey* (January 1999), <http://www.chcf.org/press/index.cfm>.

11. DIANN JOHNSON & SIDNEY M. WOLFE, *MEDICAL RECORDS: GETTING YOURS*, at viii (Public Citizen's Health Research Group, 1995).

12. PRIVACY COMMISSION REPORT, *supra* note 2, at 288-89.

13. See discussion *infra* Part III regarding the recent issuance of federal health privacy standards by the United Department of Health and Human Services.

14. Francoise Gilbert, *Privacy of Medical*

Records? The Health Insurance Portability and Accountability Act of 1996 Creates a Framework for the Establishment of Security Standards and the Protection of Individually Identifiable Health Information, 73 N.D. L. REV. 93, 93 (1997).

15. People have not relied upon state constitutions as the basis for a patient's right of access to his or her own medical records.

16. ROBERT ELLIS SMITH, *COMPILATION OF STATE AND FEDERAL PRIVACY LAWS*, at iv (1997).

17. *See, e.g., King v. State*, 535 S.E.2d 492, 494-95 (Ga. 2000) (recognizing an implied right to privacy of personal medical records under Georgia's constitution).

18. SMITH, *supra* note 16, at 50-51. The District of Columbia Bill of Rights also expressly grants the right of privacy with respect to health records. D.C. BILL OF RIGHTS § 4.

19. Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 498 (1995). *See, e.g., Chizmar v. Mackie*, 896 P.2d 196, 206 (Alaska 1995) (dismissing an invasion of privacy claim brought against a private physician who disclosed results of an HIV test on grounds that the right to privacy enumerated in the Alaska Constitution protects against intrusions only by the government, not by private parties).

20. *See, e.g., Stone v. City of Stow*, 593 N.E.2d 294 (Ohio 1992) (finding that individuals' interests in pharmaceutical records under Ohio and federal constitutions were outweighed by the state's interest in reviewing records). *See generally* Gostin, *supra* note 19, at 498 (discussing difficulties in prevailing on claims based on violation of a constitutional right to privacy).

21. CAL CONST., art. I, § 1; HAW. CONST.

art. I, § 6.

22. *See Hill v. National Collegiate Athletic Ass'n*, 865 P.2d 633, 644 (Cal. 1994) (holding that the California constitution protects against invasions of privacy by private citizens as well as by the state); *Hawaii Op. Atty. Gen.* 94-01 (1994) ("The constitutional history of this section indicates that the provision was added . . . to protect against possible abuses in the use of highly personal and intimate information in the hands of the government or private parties."); *see also Nakano v. Matayoshi*, 706 P.2d 814, 818 (Haw. 1985) (citing the opinion of the attorney general in dictum).

23. *Jeffrey H. v. Imai*, 101 Cal. Rptr. 2d 916, 921 (Cal. Ct. App. 2000) (stating that disclosure of a medical condition concerned 'the core value' protected by California Constitution, article I, section 1, informational privacy); *Hill*, 865 P.2d at 658 (stating that "[a] person's medical profile is an area of privacy infinitely more intimate, more personal in quality and nature than many areas already judicially recognized and protected.") (quoting *Board of Med. Quality Assurance v. Gherardini*, 156 Cal. Rptr. 55 (Cal. Ct. App. 1979)); *Painting Indus. of Hawaii Market Recovery Fund v. Alm*, 746 P.2d 79, 82 (Haw. 1987) (holding that the state constitutional right to privacy extends only to highly personal and intimate information such as medical, financial, educational, or employment records).

24. *Compare Jeffrey H.*, 101 Cal. Rptr. 2d 916 (right of privacy in California constitution protects against inappropriate disclosures of private information by private parties), *with Chizmar*, 896 P.2d at 206 (rejecting constitutional invasion of privacy claim against private physician who disclosed HIV test results without authorization of patient on ground that

Alaska constitution protects only against governmental action).

25. Gostin, *supra* note 19, at 508-09. *See, e.g.,* Horne v. Patton, 287 So. 2d 824 (Ala. 1974) (allowing privacy, fiduciary, and contract causes of action to proceed against physician for disclosure of confidential information); MacDonald v. Clinger, 446 N.Y.S.2d 801, 802 (N.Y. App. Div. 1982) (finding a physician's disclosure of confidential information a violation of fiduciary duty implicit in doctor-patient relationship).

26. Ozer v. Borquez, 940 P.2d 371, 377 (Colo. 1997). There are four causes of action encompassed by the invasion of privacy tort: (1) intrusion upon seclusion, (2) appropriation of likeness, (3) public disclosure of private facts, and (4) false-light publicity. *Hill*, 865 P.2d at 647 (citing William Prosser, *Privacy*, 48 CAL. L. REV. 381, 389 (1960)). Causes of action based on the alleged wrongful disclosure of health information are usually brought under the category that addresses the public disclosure of private facts.

27. *See Ozer*, 940 P.2d 371 (deciding on a case of first impression to recognize tort); Lake v. Wal-Mart Stores Inc., 582 N.W.2d 231, 234 (Minn. 1998) (same).

28. *See Wilkinson v. Methodist, Richard Young Hosp.*, 612 N.W.2d 213 (Neb. 2000) (finding that the state does not recognize common law or statutory cause of action based on public disclosure of private facts); Howell v. New York Post, 612 N.E.2d 699 (N.Y. 1993) (same).

29. *See Doe v. Methodist Hosp.*, 690 N.E.2d 681 (Ind. 1997) (concluding with two justices declining to recognize that the public disclosure of private facts may form the basis of a civil action, and three justices concurring in result but disagreeing with legal conclusion that Indiana does not

recognize such a tort).

30. *See Hougum v. Valley Mem'l Homes*, 574 N.W.2d 812 (N.D. 1998) (stating that the court has not yet decided whether a tort action exists in North Dakota for invasion of privacy). Wyoming does not appear to have any reported cases addressing the issue.

31. *Methodist Hosp.*, 690 N.E.2d 681.

32. *Doe v. Mills*, 536 N.W.2d 824, 828-29 (Mich. Ct. App. 1995) (citing RESTATEMENT OF TORTS SECOND).

33. *Id.* (stating that a woman's election to have an abortion was a private fact). *See also Y.G. v. Jewish Hosp.*, 795 S.W.2d 488 (Mo. Ct. App. 1990) (finding that the decision to undergo in vitro fertilization was private).

34. In *Mills*, 536 N.W.2d 824, for example, a television station defended itself in an invasion of privacy action by asserting that a reasonable person would not be embarrassed by the publication of the fact that they were undergoing in vitro fertilization treatment.

35. *Compare Brown v. Mullarkey*, 632 S.W.2d 507, 509-10 (Mo. Ct. App. 1982) (holding that no public disclosure occurred when information in a personnel file was disclosed to one or two others on the basis that it was not communication to the public in general or to a large number of persons), with *McSurely v. McClellan*, 753 F.2d 88, 112-13 (D.C. Cir. 1985), *cert. denied*, 474 U.S. 1005 (1985) (finding that disclosure of information to a limited number of people when a special relationship exists is sufficient to state an invasion of privacy claim under Kentucky law).

36. *Biddle v. Warren Gen. Hosp.*, 715 N.E.2d 518, 523 (Oh. 1999).

37. *See id.* at 524 (recognizing the independent tort for the unauthorized,

unprivileged disclosure to a third party of nonpublic medical information that a physician or hospital has learned within a physician-patient relationship). In addition to Ohio, jurisdictions cited as adopting a similar cause of action are: Pennsylvania, West Virginia, Texas, New Jersey, Massachusetts, New York, the District of Columbia, Oregon, Alabama, Utah, and Nebraska. *Id.* at 523-24.

38. *Id.* at 524; *Morris v. Consolidated Coal Co.*, 446 S.E.2d 648 (W. Va. 1994) (stating that a physician's ex parte disclosure to employer of health information of employee was actionable, but would not have been had it taken place in accordance with workers' compensation requirements).

39. *See, e.g., Emmett v. Eastern Dispensary and Casualty Hosp.*, 396 F.2d 931, 935 (D.C. Cir. 1967) (holding that a patient or her personal representative has a right of access to her hospital records); *Ruffin v. Strange*, 434 So. 2d 1200, 1202 (La. Ct. App. 1983) (holding that a physician's failure to furnish a medical record to a patient or her personal doctor was actionable at common law); *Striegel v. Tofano*, 399 N.Y.S.2d 584 (N.Y. App. Div. 1977) (finding that a patient has a right of access to dental records); *Wallace v. University Hosp. of Cleveland*, 164 N.E.2d 917, 918 (Oh. Ct. Common Pleas 1959), *modified and aff'd*, 170 N.E.2d 261 (Oh. Ct. App. 1960) (stating that a patient or her authorized representative has a right to inspect her hospital records); *Hutchins v. Texas Rehab. Comm'n*, 544 S.W.2d 802 (Tex. Civ. App. 1976) (noting that the patient has a common law right to inspect her medical records).

40. *Striegel*, 399 N.Y.S.2d 584 (finding that although a doctor or dentist has primary custodial rights to the treatment

record, a patient has a property right sufficient to afford reasonable access rights to those records); *accord In re Gerkin*, 434 N.Y.S.2d 607, 608 (N.Y. Sup. Ct. 1980) (holding that a patient has property rights in her medical records that can be exercised by her surviving spouse). *See also Wallace*, 164 N.E.2d 917 (finding that a patient has a property right in his hospital records and that he, or an authorized representative, has a right to inspect these records).

41. *Emmett*, 396 F.2d at 935 (stating that the hospital has a fiduciary duty to reveal to the patient or her personal representative information that is in her best interest to know, including what is in the medical record); *Cannell v. Medical & Surgical Clinic*, 315 N.E.2d 278, 280 (Ill. App. Ct. 1974) (finding that the fiduciary qualities of the physician-patient relationship require disclosure of medical data to the patient or her agent at the patient's request).

42. The concept of Fair Information Practice principles was first formulated in U.S. DEP'T OF HEALTH EDUC. & WELFARE, RECORDS, COMPUTERS AND THE RIGHTS OF CITIZENS: REPORT OF THE SECRETARY'S ADVISORY COMMITTEE ON AUTOMATED PERSONAL DATA SYSTEMS, at xx-xxiii (1973). These standards have formed the basis for subsequent codes and laws related to information collection, such as the Privacy Act of 1974 and the Video Privacy Protection Act.

43. *See* HEALTH PRIVACY WORKING GROUP, BEST PRINCIPLES FOR HEALTH PRIVACY (1999), http://www.healthprivacy.org/usr_doc/33807%2Epdf. The Health Privacy Working Group, an initiative of the Health Privacy Project of Georgetown University's Institute for Health Care Research and Policy, was comprised of a

group of diverse stakeholders in the health care system who were able to reach some consensus about the general principles that should be applied to protecting the privacy of health information. *See also* PRIVACY COMMISSION REPORT, *supra* note 2, at 277-318 (setting forth some of these same principles). Although both of these reports include additional, more detailed principles, this paper focuses only on these six general concepts.

44. The Uniform Health Care Information Act of 1985 [hereinafter Uniform Health Care Act], drafted by the National Conference of Commissioners on Uniform State Law, incorporated the fair information principles contained in the Privacy Commission Report. *See* Prefatory Note to the Uniform Health Care Information Act of 1985, <http://www.nccusl.org/nccusl/pubndrafts.asp>. The Uniform Act was only adopted by two states, Montana and Washington. Wyoming also appears to have adopted the Uniform Act, but has restricted its applicability to hospitals. *Compare* WYO. STAT. ANN. §§ 35-2-605 to 35-2-617 (Michie 2001), *with* the Uniform Health Care Act.

45. HEALTH PRIVACY WORKING GROUP, *supra* note 43, at 18; PRIVACY COMMISSION REPORT, *supra* note 2, at 288-89, 295-99.

46. JOHNSON & WOLFE, *supra* note 11, at 22; PRIVACY COMMISSION REPORT, *supra* note 2, at 289.

47. JOHNSON & WOLFE, *supra* note 11, at 1-2. *See also* Hayley Rosenman, Note, *Patients' Rights to Access Their Medical Records: An Argument for Uniform Recognition of a Right of Access in the United States and Australia*, 21 FORDHAM INT'L L.J. 1500, 1540-41 (discussing broad policy considerations in favor of a right of access).

48. PRIVACY COMMISSION REPORT, *supra* note 2, at 295.

49. *See* Chart in Appendix of this Article. (Nearly every state permits patients some limited access to their mental health records. This chart does not encompass this type of record.) All states with access statutes permit providers to deny a patient access to her medical records if the provider believes harm will result. Seven states impose additional restrictions on the right of access to physician or hospital records. *See* ARK. CODE ANN. § 16-46-106 (Michie 2001) (statute provides for release only in contemplation of legal proceeding); ME. REV. STAT. ANN. tit. 22, § 1711 (West 2000) (providing right of access to hospital records only after discharge); MISS. CODE ANN. § 41-9-65 (2001) (patient must demonstrate good cause to obtain hospital records); N.M. STAT. ANN. § 14-6-3 (Michie 2001) (statutory access provided to applicants for disability benefits); OR. REV. STAT. § 192.525 (1999) (state health care providers are required to give access to records, but private health care providers are only urged to adopt voluntary guidelines); S.D. CODIFIED LAWS § 34-12-15 (Michie 2001) (providing right of access to hospital records only after discharge); TENN. CODE ANN. § 63-2-101(2000) (health care providers and hospitals have option of providing only a summary instead of full record). Although Maine gives health care providers the option of providing a narrative, the statute requires that the narrative contain all relevant information. ME. REV. STAT. ANN. tit. 22, § 1711-B (West 2000).

50. *See* OHIO REV. CODE ANN. § 3701.74 (Anderson 2001); WYO. STAT. ANN. § 35-2-611 (Michie 2001).

51. *Compare* 735 ILL. COMP. STAT. 5/8-2003 (providing access to physician records), 5/8-2001 (2001) (providing access to hospital records), *with* MINN.

STAT. § 144.335 (2000) and chapters cited therein (providing access to records held by a broad range of health care practitioners and health care facilities).

52. See NEB. REV. STAT. §§ 71-8401 to -8407 (2001). The legislature recognized that "[p]atients need access to their own medical records as a matter of fairness to enable them to make informed decisions about their health care and correct inaccurate or incomplete information about themselves." Ironically, it did not include any such right to amend in the statute, leaving a substantial gap in patients' rights under state law.

53. 735 ILL. COMP. STAT. § 5/8-2003 (2001) (physician records released to attorney, not patient); UTAH CODE ANN. § 78-25-25 (2001) (access provided to attorney).

54. These states do, however, provide a limited right of access to certain mental health records. See IOWA CODE § 229.25 (2001) (requiring the release of mental health records upon request to the attorney or advocate of a hospitalized mental health patient who has a waiver signed by patient); KAN. STAT. ANN. §§ 65-5602, 65-5603 (2000) (mental health treatment facilities generally may not claim "privilege" and refuse to furnish treatment information to patient unless the head of the facility has made a written determination that disclosing records would be injurious to patient); VT. STAT. ANN. tit. 18, § 7103 (2001) (clinical information related to commitment proceedings may be released pursuant to written consent of the patient, presumably including to patient, herself, or patient's attorney).

55. See Appendix of this Article.

56. Official Comments to MONT. CODE ANN. § 50-16-505 (2001). Montana and

Washington adopted this position in reliance on the 1986 version of the Uniform Health Care Information Act.

57. See Jannet M. Carmichael & Janice A. Cichowlas, *The Changing Role of Pharmacy Practice—A Clinical Perspective*, 10 ANN. HEALTH L. 179 (2001) (explaining the changing role of pharmacists). It should be noted that the National Conference of Commissioners on Uniform State Laws has proposed to revise the Uniform Health Care Information Act to include pharmacists as health care providers.

58. See Kristen J. Josefek, Note, *Alternative Medicine's Roadmap to Mainstream*, 26 AM. J.L. & MED. 295 (2000).

59. See, e.g., 1990 Alaska Sess. Laws 6 § 10 adding acupuncturists to the "health care providers" from whom patients have the right to obtain a copy of their health care records), codified at ALASKA STAT. § 18.23.070 (Michie 2001) (defining "health care provider" for purposes of access provisions in § 18.23.005.)

60. The states that clearly grant patients access to medical records maintained by acupuncturists include: Alaska, Arizona, Colorado, Florida, Georgia, Maine, Maryland, Massachusetts, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, Washington, and Wisconsin. See ALASKA STAT. §§ 18.23.005 (Michie 2001) (access provision), 18.23.070 (defining health care provider as including licensed acupuncturists); ARIZ. REV. STAT. §§ 12-2293 (2000) (access provision), 12-2291 (health care provider defined as person licensed under title 32), 32-3921 (acupuncturists license requirement); COLO. REV. STAT. § 25-1-802 (2001) (acupuncturists included as health care providers who must furnish access); FLA. STAT. ANN. §§ 456.057 (West 2000) (licensed practitioners must furnish

access), 457.105 (requiring acupuncturists to be licensed); GA. CODE ANN. §§ 31-33-1 (2000) (defining provider as including any person licensed under title 43, chap. 34), 31-33-2 (health care providers must furnish access), 43-34-64 (license requirement for acupuncturists); ME. REV. STAT. ANN., tit. 22, §§ 1711-B (West 2000) (requiring health care practitioners to give access), 1711-C (defining health care practitioners as those licensed to practice health care), tit. 32 §§ 12511-12513 (requiring acupuncturists to be licensed); MASS. GEN. LAWS ch. 112, §§ 12CC (2001) (requiring persons providing medical care to provide access), 148 (defining acupuncture as the practice of medicine based on Oriental theories), 151 (license requirement for acupuncturists); MINN. STAT. §§ 144.335 (2000) (requiring health care providers to furnish access and defining providers as including persons who are licensed under chap. 147B), 147B.02 (requiring license for practice of acupuncture); MO. REV. STAT. §§ 191.227 (2000) (duly licensed practitioner must furnish patient access to medical records), 324.487 (license requirement for acupuncturists); MONT. CODE ANN. §§ 37-13-103 (2001) (defining acupuncture), 37-13-301 (requiring license for practice of acupuncture), 50-16-541 (health care providers required to provide access to records), 50-16-504 (defining health care provider as those licensed to provide health care); NEB. REV. STAT. §§ 71-1,346 (2001) (acupuncturists must be licensed to practice), 71-8402 (provider means any licensed practitioner), 71-8403 (health care provider must furnish access); NEV. REV. STAT. §§ 629.031 (2001) ("health care provider" includes doctor of any Oriental medicine), 629.061 (health care provider must furnish records upon request); N.H. REV. STAT. ANN. §§ 328-G:1

(2000) (recognizing acupuncture as a distinct health care profession), 328-G:9 (license requirement for acupuncturists), 332-I:1 (requiring health care providers to give access and defining provider as any person licensed to provide health care); WASH. REV. CODE §§ 18.06.010 (2001) (defining acupuncture as a health care service based on Oriental medicine), 18.06.020 (license requirement for acupuncturists), 70.02.010 (defining health care provider as including any person licensed to provide health care), 70.02.080 (requiring health care providers to furnish access); WIS. STAT. ANN. §§ 146.81 (West 2000) (defining health care provider as including licensed acupuncturists), 146.83 (requiring health care providers to provide access to records).

61. *See, e.g.*, NEV. REV. STAT. §§ 629.031 (2001) (defining "provider of health care" as including those licensed under Chapter 630A), 629.061 (requiring "providers of health care" to give patients access to their health records), and tit. 54, chap. 630A (providing for the licensing of practitioners of homeopathic medicine); N.H. REV. STAT. ANN. §§ 332-I:1 (2000) (requiring all licensed health care providers to furnish patients with a copy of their medical records upon request), 328-E:3 (requiring naturopathic health care practitioners to be licensed).

62. *See* OHIO REV. CODE ANN. § 3701.74 (Anderson 2001).

63. *See* OKLA. STAT. tit. 76, § 19 (2000).

64. *See* R.I. GEN. LAWS § 5-37-22 (2001).

65. *Compare* MD. CODE ANN., HEALTH-GEN. §§ 4-301 to 4-304 (2001) (requiring a broad range of health care providers and health care facilities to allow patients to see, copy, and amend their health information), *with* DEL. CODE ANN. tit. 16, §§ 5161, 1121 (2000) (failing to contain

any provisions granting such access rights).

66. See MD. CODE ANN., HEALTH-GEN. §§ 4-301 (defining "health care provider" as including those licensed under the Health Occupations article), 4-304 (2001).

67. Delaware does grant minimal access rights to information held by a few isolated categories of health care providers such as mental health hospitals and nursing homes. See DEL. CODE ANN. tit. 16, §§ 5161, 1121 (2000).

68. HEALTH PRIVACY WORKING GROUP, *supra* note 43, at 19. See PRIVACY COMMISSION REPORT, *supra* note 2, at 300.

69. See Nat'l Conf. of Comm'rs on Unif. State Laws' Health Care Info. Act, *Comments on Section 4-101 of the Uniform Act*, <http://www.nccusl.org/nccusl/pubndrafts.asp>.

70. HEALTH PRIVACY WORKING GROUP, *supra* note 43, at 19. Because of potential malpractice liability issues, most experts support policies that permit the addition of corrected information without deleting the information that is being amended. NAT'L COMM. ON QUALITY ASSURANCE & THE JOINT COMM'N ON ACCREDITATION OF HEALTH CARE ORG., PROTECTING PERSONAL HEALTH INFORMATION: A FRAMEWORK FOR MEETING THE CHALLENGES IN A MANAGED CARE ENVIRONMENT 20 (1998), <http://www.ncqa.org/pages/communications/news/confrel.htm>).

71. ME. REV. STAT. ANN. tit 22, § 1711, 1711-B (West 2000); MD. CODE ANN., HEALTH-GEN. § 4-304 (2000); MONT. CODE ANN. § 50-16-543 (2001); N.Y. PUB. HEALTH LAW § 18 (Consol. 2001); WASH. REV. CODE § 70.02.100 (2001); 2001 TEX. GEN. LAWS 1511.

72. PRIVACY COMMISSION REPORT, *supra* note 2, at 278-82, 305-07. See Bartley L. Barefoot, Comment, *Enacting a Health Information Confidentiality Law: Can Congress*

Beat the Deadline?, 77 N.C. L. REV. 283, 286-93 (1998) (discussing the increased demand for health information due to internal pressures such as integrated health care, and the desire to control health care spending, as well as secondary users such as employers, law enforcement, and the media.)

73. PRIVACY COMMISSION REPORT, *supra* note 2, at 305.

74. *Id.*, at 305-06.

75. Lawrence O. Gostin, Scott Burris & Zita Lazzarini, *The Law and the Public's Health: A Study of Infectious Disease Law in the United States*, 99 COLUM. L. REV. 59, 111 (1999).

76. *Id.*

77. See Robert M. Gellman, *Prescribing Privacy: The Uncertain Role of the Physician in the Protection of Patient Privacy*, 62 N.C. L. REV. 255, 272 (1984) (noting that "In recommending against including a physician-patient privilege in the Federal Ruels [sic] of Evidence, the Judicial Conference Committee found that exceptions to the privilege in many states are 'so numerous as to leave little if any basis for the privilege.'").

78. See, e.g., *Ex parte Smitherman Bros. Trucking Inc.*, 751 So. 2d 1232, 1236 (Ala. 1999) (Alabama law does not recognize a general physician-patient privilege); *Commonwealth v. Senior*, 744 N.E.2d 614, 617 (Mass. 2001) (Massachusetts does not recognize a statutory patient-physician testimonial privilege); *Butler-Tulio v. Scroggins*, 774 A.2d 1209, (Md. Ct. Spec. App. 2001) (there is no physician-patient privilege in Maryland either by statute or under common law) (citing *Robinson v. State*, 238 A.2d 875 (1968)); *McCormick v. England*, 494 S.E.2d 431, 434 (S.C. Ct. App. 1999) (South Carolina does not recognize physician-patient evidentiary privilege);

Quarles, 389 S.W.2d at 251 (Tennessee follows the common law rule that no evidentiary privilege exists between a physician and her patient and state has no statute creating such a privilege); *State v. Bedell*, 454 S.E.2d 77, 80 (W. Va. 1994) (West Virginia has “no statutory scheme establishing a physician/patient privilege, nor has this Court judicially recognized such a privilege”).

79. *See* VT. STAT. ANN. tit. 18, § 1852(a)(6)-(7) (2001) (establishing restricted uses and disclosures of health information in hospital setting).

80. *See* OKLA. STAT. tit. 59, §§ 328.32 and 161.18 (2000).

81. *See* W. VA. CODE § 30-5-7 (2001). West Virginia also imposes restrictions on licensed social workers and other professional counselors. W. VA. CODE §§ 30-30-12, 30-31-13 (2001).

82. *See* OR. REV. STAT. § 192.525 (1999).

83. *See* N.D. CENT. CODE § 23-16-09 (2001).

84. *See* IND. CODE §§ 16-39-5-3 (imposing restrictions on providers), 16-18-2-295 (defining “provider”) (Michie 2001).

85. *See, e.g.*, MO. REV. STAT. § 338.100 (2000); N.J. STAT. ANN. 26:2H-12.8 (West 2001).

86. *See, e.g.*, ARIZ. REV. STAT. §§ 12-2291 to 12-2297 (2000); CAL. CIVIL CODE § 56.10 (West 2001); FLA. STAT. ANN. §§ 456.057 (West 2000); ME. REV. STAT. ANN., tit. 22, §§ 1711-C (West 2000); MD. CODE ANN., HEALTH-GEN. § 4-303 (2000); MINN. STAT. § 144.335 (2000); MONT. CODE ANN. §§ 50-16-525 (2001); R.I. GEN. LAWS § 5-37.3-4 (2001); TEX. OCC. CODE ANN. §§ 159.002 to 159.009 (West 2000); VA. CODE ANN. § 32.1-127.1:03 (Michie 2001); WASH. REV. CODE §§ 70.02.010 to 70.02.904 (2001); WIS. STAT. ANN. §§ 146.81, 146.82 (West 2000); WYO. STAT. ANN. §§ 35-2-606 to 35-2-616

(Michie 2001) (statutory restrictions cover only hospitals).

87. *See* ARIZ. REV. STAT. § 12-2294 (2000).

88. *See* MONT. CODE ANN. § 50-16-501 to § 50-16-553 (2001); WASH. REV. CODE §§ 70.02.010 through 70.02.904 (2001).

89. *See* VA. CODE ANN. § 32.1-127.1:03 (Michie 2001).

90. *See* CONN. GEN. STAT. § 20-626 (2001).

91. *See* FLA. STAT. ANN. § 456.057 (West 2000).

92. *See* R.I. GEN. LAWS § 5-37.3-4(d) (2001).

93. HEALTH PRIVACY WORKING GROUP *supra* note 43, at 19; Nat'l Conf. of Comm'rs on Unif. State Law, *Comment on §5-101 of the Uniform Health Care Act*, *supra* note 44. *See also* PRIVACY COMMISSION REPORT, *supra* note 2, at 313.

94. HEALTH PRIVACY WORKING GROUP, *supra* note 43, at 19-20.

95. *Id.* at 19.

96. *Id.*

97. Although the eight comprehensive health privacy bills introduced at the federal level in the 106th Congress varied in many aspects, they uniformly included a requirement that covered health care providers and health plans furnish a notice of information practices to patients. *See* Health Information Act, H.R. 1941, 106th Cong. § 204 (1999); Personal Medical Information Protection Act of 1999, H.R. 2404, 106th Cong. § 103 (1999); Consumer Health and Research Technology Protection Act, H.R. 2455, 106th Cong. § 203 (1999); Medical Information Protection and Research Enhancement Act of 1999, H.R. 2470, 106th Cong. § 103 (1999); Medical Information Privacy and Security Act, H.R. 1057, 106th Cong. § 103 (1999); Medical Information Privacy and

Security Act, S. 573, 106th Cong. § 103 (1999); Health Care Personal Information Nondisclosure Act of 1999, S. 578, 106th Cong. § 103 (1999); Medical Information Protection Act of 1999, S. 881 106th Cong. § 103 (1999).

98. *See, e.g.*, ME. REV. STAT. ANN., tit. 22, §§ 1711-C (West 2000); MINN. STAT. § 144.335(5)(a) (2000); N.J. STAT. 26:2H-12.9 (West 2001) (requiring the Bill of Rights for Hospital Patients to be posted); WASH. REV. CODE § 70.02.120 (2001).

99. *See* MD. CODE ANN., HEALTH-GEN. §§ 4-301 through 4-309 (2000).

100. HEALTH PRIVACY WORKING GROUP, *supra* note 43, at 20; PRIVACY COMMISSION REPORT, *supra* note 2, at 304-05.

101. *Id.*

102. FLA. STAT. ANN. §§ 456.057(9) (West 2000).

103. PRIVACY COMMISSION REPORT, *supra* note 2, at 293, 427-28.

104. *See, e.g.*, CONN. GEN. STAT. §§ 20-7c(c) (right to file petition with superior court if provider refuses to grant access). MONT. CODE ANN. § 50-16-553 (2001) (providing for equitable relief as well as damages); N.H. REV. STAT. ANN. § 151.30 (2000) (granting a right to maintain action for equitable relief and for damages).

105. *See* LA. REV. STAT. ANN. § 40:1299.96 A (West 2001). *See also* 735 ILL. COMP. STAT. 5/8-2003 (2001) (physician who fails to comply with request for access in set time is liable for expenses and attorneys' fees incurred with relation to any court ordered enforcement).

106. *See* COLO. REV. STAT. § 25-1-802 (2001); GA. CODE ANN. §§ 31-33-1 to 31-33-4 (2000); IND. CODE § 16-39-1-1 (Michie 2001); MASS. GEN. LAWS ch. 112, §§ 12CC (2001) (none of which contain statutory remedies for wrongful denials of access).

107. *See* S.C. CODE ANN. §§ 44-115-10 to

44-15-150 (Law. Co-op. 2001).

108. R.I. GEN. LAWS §5-37.3-4 (2001).

109. *Id.*

110. *See, e.g.*, TENN. CODE ANN. § 68-11-1504 (2000); WASH. REV. CODE ANN. § 70.02.050 (2001); WYO. STAT. ANN. § 35-2-606 (Michie 2001).

111. *See* CAL. CIV. CODE §§ 56-56.37 (Confidentiality of Medical Information Act), 1798-1798.78 (Information Practices Act) (West 2001); CAL. INS. CODE §§ 791-791.27 (Insurance Information and Privacy Protection Act) (West 2-001); CAL. HEALTH & SAFETY CODE §§ 123100 to 123149.5 (Patient Access to Medical Records Act) (West 2001).

112. *See* CAL. CIV. CODE §§ 56.10, 56.20 (West 2001).

113. *See* CAL. CIV. CODE § 56.35 (West 2001).

114. 1999 Cal. Stat. 526.

115. 1997 Me. Laws 793, as amended by 1999 Me. Laws 512.

116. ME. REV. STAT. ANN. tit. 22, §§ 1711, 1711-B (West 2000).

117. ME. REV. STAT. ANN. tit. 22, § 1711-C (West 2000).

118. ME. REV. STAT. ANN. tit. 22, § 1711-C(8) (West 2000).

119. ME. REV. STAT. ANN. tit. 22, § 1711-C(7) (West 2000).

120. *Id.*

121. *See* ME. REV. STAT. ANN. tit. 22, § 1711-C(13) (West 2000).

122. *Id.*

123. Privacy of Health Care Information Act, 1999 Haw. Sess. Laws 87, *repealed by* Act of June 14, 2001. This act was repealed prior to its scheduled effective date of July 2001. In enacting the Privacy of Medical Information Act, the legislature found: "[I]ndividuals have a constitutional right to privacy with respect to their personal health information and records, and with

respect to information about their medical care and health status. Traditionally, the primary health care relationship existed only between the patient and the doctor, and was founded upon the principle that all information transmitted between the patient and the doctor was confidential. With advancements in modern technology and systematic changes in health care practices, the patient-doctor relationship has expanded into a multi-party relationship that includes employers, health plans, consulting physicians and other health care providers, laboratories and hospitals, researchers and data organizations, and various governmental and private oversight agencies. These multiple relationships have fundamentally changed the handling and use of medical information. The legislature acknowledges that individuals are often unaware of how their medical information is being used and disclosed in the modern health care delivery system. Currently, there is no statute that comprehensively governs the disclosure of medical records. Most individuals sign a one-time blanket consent to release their medical records when they sign up for medical insurance, and doctors, hospitals, and insurance companies share these records as they see fit. Thus, the legislature believes that an individual's right to privacy of their medical records is currently unclear and at risk." *Id.* at § 1.

124. *Id.* at § 2.

125. *Id.* at § 2.

126. Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. §§ 160, 164 (2001) [hereinafter Federal Privacy Rule or Privacy Rule].

127. Health Insurance Portability and Accountability Act, Pub. L. No. 104-191 §§ 261-264 (1996) [hereinafter HIPAA] (most

sections codified at 42 U.S.C. §§ 1320d - 1320d-8 (2001)).

128. *See* 65 Fed. Reg. 82469 (Dec. 28, 2000) (HHS summarizing Congressional objectives in the preamble to the final Health Privacy rule).

129. *Id.*

130. HIPAA, *supra* note 127, § 264.

131. *See* 65 Fed. Reg. 82463-82829 (Dec. 28, 2000) (for preamble to rule, HHS' response to comments to proposed rule, as well as text of final rule itself).

132. Correction of Effective and Compliance Dates, 66 Fed. Reg. 12434 (Feb. 26, 2001).

133. 45 C.F.R. §§ 160.102, 164.104 (2001). *See* 42 U.S.C. § 1320d-1 (2001) (establishing scope of applicability of HIPAA administrative simplification standards).

134. *See* Recommendations of the Secretary of Health and Human Services, Confidentiality of Individually-Identifiable Health Information, § I(G) (Sept. 11, 1997) (stating that recommendations to Congress were based on fair information practices in a health care setting); 64 Fed. Reg. 59923 (1999) (preamble to proposed Health Privacy Rule) (stating that recommendations served as a template for privacy rule).

135. 45 C.F.R. § 164.524 (2001).

136. 45 C.F.R. § 164.524(b)-(d) (2001).

137. 45 C.F.R. § 164.524(a) (2001).

138. 45 C.F.R. § 164.526 (2001).

139. *See* 45 C.F.R. § 164.526(a) (2001); *see also* 65 Fed. Reg. 82736 (HHS, in response to comments to the proposed Health Privacy Rule, clarified "that covered entities are not required by this rule to delete any information...").

140. 45 C.F.R. § 164.526(c)-(d) (2001).

141. 45 C.F.R. § 164.526(d) (2001).

142. 45 C.F.R. §§ 164.502 - 164.514

(2001).

143. 45 C.F.R. § 164.506 (2001). This requirement differs from provisions in most state laws which permit health care providers to use and disclose health information for these purposes without any written permission from the patient. *See e.g.*, ARIZ. REV. STAT. § 12-2292 (2000) (disclosure without patient authorization permitted to attending and consulting health care providers for purpose of diagnosis and treatment); WIS. STAT. ANN. § 146.82 (West 2000) (permitting disclosure to health care providers, volunteers, and others rendering assistance to the patient).

144. 45 C.F.R. § 164.508 (2001).

145. *See* 45 C.F.R. § 164.512 (2001).

146. *Id.*

147. *See* 45 C.F.R. § 164.520 (2001).

148. *Id.*

149. 45 C.F.R. § 164.530(2)(c) (2001).

150. *See* Security and Electronic Signature Standards, 63 Fed. Reg. 43242 (proposed August 12, 1998) (to be codified at 45 C.F.R. pt. 142); HIPAA Advisory, *Braithwaite Exits HHS with New Reg Release Predictions* (Nov. 2, 2001), at <http://www.hipaadvisory.com/news/recentnews.htm>.

151. *See* 42 U.S.C. §§ 1320d-5, 1320d-6 (2001). There are no provisions governing penalties in the Privacy Rule. Rather, HHS intends to promulgate separate regulations addressing penalties in the future. 65 Fed. Reg. 82487 (Dec. 28, 2000).

152. *See* 42 U.S.C. §§ 1320d-5, 1320d-6 (2001). Within HHS, the responsibility for enforcing the Privacy Rule has been delegated to the Office of Civil Rights. Statement of Delegation of Authority, 65 Fed. Reg. 82381 (Dec. 28, 2000).

153. 64 Fed. Reg. 6002 (Nov. 3, 1999) (preamble to proposed Health Privacy Rule).

154. *See* 42 U.S.C. §§ 1320d-5, 1320d-6 (2001).

155. *See* HIPAA, *supra* note 127, § 264.

156. 45 C.F.R. § 160.203 (2001) (detailing how preemption of state law will work).

157. HIPAA, *supra* note 127, § 264; 45 C.F.R. § 160.203(b) (2001).

158. 45 C.F.R. 160.202 (2001) (defining "more stringent").

159. *Id.*

160. *Id.*

161. 45 C.F.R. §§ 160.102, 164.104 (2001). "Standard transactions" are transactions made in connection with the financial and/or administrative activities related to the provision or payment of health including processing health claims or equivalent encounter information; enrolling or disenrolling in a health plan; establishing or verifying eligibility for a health plan; sending health care payment and remittance advice; and other activities. *See* 42 U.S.C. § 1320d-2 (2001).

162. 64 Fed. Reg. 59924 (Nov. 3, 1999). In the preamble to the proposed Privacy Rule, HHS stated "[B]ecause we do not have the authority to apply these standards directly to any entity that is not a covered entity, the proposed rule does not directly cover many of the persons who obtain identifiable health information from the covered entities." Examples of persons who receive this information include contractors, third party administrators, researchers, public health officials, life insurance issuers employers, and firms. *Id.*

163. *Id.* at 59923.

164. *Id.*

165. Louis Altarescu, Address at the Health Privacy Project's National Consumers' Summit on Navigating the New Federal Health Privacy Regulations (Feb. 5, 2001).

166. See Robert. O'Harrow, Jr., *Patient Files Opened to Marketers, Fundraisers; Critics Decry Exemptions Won Through Lobbying*, WASH. POST, Jan. 16, 2001, at E1.

167. When a patient signs a consent permitting the use and disclosure of health information for "treatment, payment and health care information purposes, they are unwittingly consenting to the use of their health information for marketing purposes." As long as certain conditions are met, the term "health care operations" includes marketing. See 45 C.F.R. §§ 164.501 (2001) (defining health care operations and marketing), 164.514(e) (setting out the conditions that must be met in order for marketing to be considered to be a health care operation). However, there is nothing in the consent form to indicate that it includes marketing, and it is not at all self-evident that the term "health care operations" would include this activity. See 45 C.F.R. §§ 164.506, 164.520 (2001) (establishing the required contents for a notice of privacy practices). This clearly does not constitute "informed" consent.

168. In order for marketing to come within the definition of health care operations, the provider must meet a number of conditions. See 45 C.F.R. § 164.514(e) (2001). In addition to informing the patient of her right to opt out, the communication must also identify the provider as the party making the communication, and disclose whether the provider is being paid for marketing the product. *Id.* If a provider targets the marketing based on a patient's health status or condition, the communication must explain why the individual has been targeted. *Id.*

169. 45 C.F.R. § 164.512(f) (2001).

170. *Id.*

171. See *supra* text accompany notes 123-125.

172. 2001 Haw. Sess. Laws 244.

173. See HAW. REV. STAT. §§ 671-1, 622-57 (2001).

174. See *supra* text accompany notes 117-122.

175. For instance, Maine's law covers blood and organ banks, unlike the Federal Health Privacy Rule. MAINE REV. STAT. ANN. tit. 22, § 1171-C(1)(c) (West 2000). The state law also prohibits disclosure of health care information for the purpose of marketing or sales without the individual's authorization. MAINE REV. STAT. ANN. tit. 22, § 1171-C(8) (West 2000).

176. MAINE REV. STAT. ANN. tit. 22, § 1711-C(17) (West 2000).

177. 2001 Me. Laws 346.

178. 2001 Fla. Sess. Law Serv. 277 §§ 139-142 (West).

179. 2001 Tex. Gen. Laws 1511.

180. See Todd Ackerman, *Medical Leaders Ask for Closure of Privacy Loophole; State Bills Could End Exemption to Rules*, HOUS. CHRON., Jan. 22, 2001, at A1 (stating that state legislators had said that the loopholes in the federal regulations show why there needs to be a Texas law).

181. The state statute accomplishes this by first removing "marketing" from the definition of "health care operations." 2001 Tex. Gen. Laws 1511 § 1. This eliminates the possibility that consent for treatment, payment and health care operations includes permission to use the information for marketing. See *supra* note 167 (explaining treatment of marketing under Federal Privacy Rule). Then the statute prohibits a covered entity (including a provider) from using or disclosing health information for marketing purposes without the consent of the individual who is the subject of the information. 2001 Tex.

Gen. Laws 1511 § 1.

182. *Id.*

183. *Id.*

184. *See* PRIVACY COMMISSION REPORT, *supra* note 2, at 307 (recommending that the Department of Health, Education and Welfare promulgate regulations protecting the confidentiality of health information, and stating that to be “fully effective” the regulations “should be adopted by statutory enactment in each of the 50 states. If this is not done the individual patient will...have to rely on the Department of Health, Education and Welfare to act on her behalf when a provider violates its duty of confidentiality to him.”).

Synopsis of State Case and Statutory Law

The Journal's Editorial Staff

ALABAMA

Case Law

Ex parte Smitherman Bros. Trucking, 751 So. 2d 1232 (Ala. 1999): The Supreme Court of Alabama stated that Alabama law does not recognize a general physician-patient privilege.

Ex parte United Serv. Stations, 628 So. 2d 501 (Ala. 1993): In a negligence action for injuries, the Supreme Court of Alabama denied defendant landlord's petition for a writ of mandamus that directed the lower court to compel discovery of plaintiff tenant's psychological records. The court held that the plaintiff's psychological records were protected by the psychotherapist-patient privilege even though the plaintiff sought damages for injuries of a mental nature.

Grippen v. Charter Southland Hosp., 534 So. 2d 286 (Ala. 1988): The Supreme Court of Alabama ruled that a medical center's release of a patient's medical records to his employer without consent was unlawful, though the employer could have required the patient to produce the medical records by the terms of his employment contract. In this case the employer did not order the plaintiff to produce the records, and even if the employer had, the plaintiff could have refused to do so and resigned from the company. The unauthorized release amounted to breach of an implied contract of confidentiality on the part of the doctor.

Ex parte Rudder, 507 So. 2d 411 (Ala. 1987): A physician claimed libel and invasion of privacy against a television station and its reporter for broadcasting information relating to abusive prescription drug practices by the physician. The defendants sought to have the plaintiff physician produce all of his medical and psychiatric records relating to treatment of the particular patient mentioned in the broadcasts, and the Supreme Court of Alabama issued a protective order to prevent the discovery of these records. The court ruled a patient did not waive his privilege to his medical records because he was not party to the suit.

Horne v. Patton, 287 So. 2d 824 (Ala. 1973): The Supreme Court of Alabama ruled that the defendant physician's release of confidential medical information to the plaintiff's employer against the plaintiff's express instructions constituted a

breach of the continuing obligation to keep information obtained in the doctor-patient relationship confidential. The court stated that public knowledge of the Hippocratic Oath's secrecy provision or of the ethical standards of the medical profession may well have been justification for a reasonable expectation of privacy.

Harbin v. Harbin, 495 So. 2d 72 (Ala. Civ. App. 1986): The court held that privileged medical information can be subpoenaed in custody cases in which the issue of mental state of a party to a custody suit is clearly in controversy, and proper resolution of the issue requires disclosure of these records.

Statutes

Access

ALA. CODE § 12-21-6.1 (2001): Any person required to release copies of medical records may ask for a reasonable payment for reproducing the medical records. Reasonable payment shall not be more than \$1.00 for each page of the first twenty-five pages, and not more than \$0.50 for each page in excess of twenty-five pages, and a search fee of \$5.00.

ALA. CODE § 22-9A-21 (2001): The State Registrar may review medical records to provide for a system for death reviews.

ALA. CODE § 22-56-4b (2001): Consumers of mental health services shall have the same general rights as other citizens, including the right to access upon request all information in the consumer's mental health, medical, and financial records, unless a clinical determination has been made by professional staff that access would be detrimental to the consumer's health.

Disclosure

ALA. CODE § 34-26-2 (2001): The confidential relations and communications between licensed psychiatrists and their patients shall be placed upon the same basis as those provided by law between attorney and client and shall be considered privileged. Generally, privilege can only be waived by the patient. Waiver should be granted in custody trials in which the mental state of a party to the suit is clearly in controversy and for presentation of evidence of insanity by a defendant in addition to a plea of insanity.

ALASKA

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes***Access***

ALASKA STAT. § 18.23.005 (Michie 2001): Notwithstanding other provisions, a patient is entitled to inspect and copy any records developed or maintained by a health care provider or other person pertaining to the health care rendered to the patient.

Disclosure

ALASKA STAT. § 18.08.087 (Michie 2001): When requested for the purpose of evaluating the performance of an emergency medical technician, mobile intensive care paramedic, or physician who provided emergency medical care or other assistance to a sick or injured person, a licensed physician, advanced nurse practitioner, or physician assistant may disclose to an emergency medical technician, a mobile intensive care paramedic, or physician, the medical or hospital records of a sick or injured person to whom the paramedic, technician, or physician is providing or has rendered emergency medical care or assistance. However, disclosure shall be limited to the records that are considered necessary by the discloser for evaluation of the paramedic's, technician's, or physician's performance in providing the emergency medical care or assistance. A mobile intensive care paramedic, emergency medical care technician, or physician to whom confidential records are disclosed under this section may not further disclose the information to a person not entitled to receive that information.

ARIZONA***Case Law***

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes***Access***

ARIZ. REV. STAT. § 12-2293(A) (2001): On written request of a patient for access to, or copies of, his or her medical records, the health care provider in possession of the record shall provide medical records to the patient, or person designated in writing by the patient, unless the attending physician or psychologist determines and notifies the health care provider in possession of the record that access is contraindicated due to treatment of the patient for a mental disorder. Psychologists are exempt from making available raw test data and psychometric testing materials. If the attending physician or psychologist determines that the patient should not have access to his or her records, the physician or psychologist shall note this determination in the patient's medical record.

ARIZ. REV. STAT. §§ 12-2293(B)-(D) (2001): On written request of a patient's health care decision-maker for access to, or copies of, the patient's medical records, the records shall be provided to the health care decision-maker or person designated in writing by the health care decision-maker unless access is limited by the patient. Records that are not in written form shall be released only if the patient or patient's health care decision-maker specifically requests and identifies in writing the type of record desired. If the patient receives treatment for a mental disorder, the health care provider may refuse to provide records that indicate confidential information between the patient and the health care professional. If the attending physician determines that the health care decision-maker should not have access to that part of the patient's medical record, the attending physician shall note this determination in the patient's medical record and shall provide the health care decision-maker with a written explanation of the reason for denial. The health care provider shall release medical record information to the health care decision-maker that includes the patient's therapy treatment plan and medication information.

Disclosure

ARIZ. REV. STAT. § 12-2292(A) (2001): Unless otherwise provided by law, all medical records and the information contained in medical records are privileged and confidential. A health care provider may only disclose information that is authorized pursuant to law or the patient's written authorization.

ARIZ. REV. STAT. §§ 12-2292(B)-(C) (2001): If necessary for its own business operations, or in response to a request for a copy of the patient's medical record, a health care provider may release a patient's medical record to a contractor for the purpose of duplicating or disclosing the record on behalf of a health care provider. A contractor shall not disclose any part, or all of, a patient's medical record in its custody except as provided in this article. After duplicating or disclosing a patient's medical record, a contractor shall return the record to the health care provider who released the medical record to the contractor.

ARIZ. REV. STAT. §§ 12-2294(B), (E)-(F) (2001): A health care provider may disclose medical records or the information contained in medical records without the patient's written authorization to (1) attending and consulting health care providers who are currently providing health care to the patient for the purpose of diagnosis or treatment; (2) health care providers who have previously provided treatment, to the extent that the records pertain to the provided treatment; (3) ambulance attendants for the purpose of providing care to the patient; and (4) the patient's health care decision-maker at the time of the patient's death. Medical records that are not in written form shall only be released if the written request specifically identifies the type of record desired. A person who receives medical records pursuant to this section shall not disclose those records without the written authorization of the patient or the patient's health care decision-maker,

unless otherwise provided by law.

ARKANSAS

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Disclosure

ARK. CODE ANN. §14-14-110(b) (Michie 2001): Personal records, medical records, and other records that relate to matters in which the right to individual privacy exceeds the merits of public disclosure shall not be available to the public unless the person they concern requests that the records be made public.

CALIFORNIA

Case Law

Pettus v. Cole, 57 Cal. Rptr. 2d 46 (Cal. Ct. App. 1996): An employee requesting disability leave sued his employer and two employer-selected psychiatrists for unauthorized release of medical information in violation of the Confidentiality of Medical Information Act (CMIA), invasion of the constitutional right of privacy, and unauthorized use of medical information. The court held that (1) the psychiatrists violated the CMIA by providing the employer with a detailed report without specific written authorization for disclosure; (2) the employee made a prima facie showing of invasion of privacy by the psychiatrists; and (3) the employer violated the CMIA and the employee's state constitutional rights to autonomy and informational privacy when it terminated the employee's employment on the basis of the disclosed information.

Division of Med. Quality v. Gherardini, 156 Cal. Rptr. 55 (Cal. Ct. App. 1979): In response to a petition by the State Board of Medical Quality Assurance, the court held that (1) the defendant hospital, as a third-party recipient of privileged matter, had standing to claim physician-patient privilege on behalf of absent, non-consenting patients; and (2) the patients' rights of privacy that were sought to be invaded fell squarely within constitutional protection.

Statutes

Access

CAL. BUS. & PROF. CODE § 2290.5(4) (West 2001): All existing laws regarding patient access to medical information and copies of medical records apply.

CAL. HEALTH & SAFETY CODE § 123110(a) (West 2001): Except as provided in section 123115, any adult patient of a health care provider, any minor patient authorized by law to consent to medical treatment, and any patient representative shall be entitled to inspect patient records upon presenting to the health care provider a written request for those records and upon payment of reasonable clerical costs incurred in locating and making the records available. A health care provider shall permit this inspection during business hours within five working days after receipt of the written request. The inspection shall be conducted by the patient or patient's representative requesting the inspection, who may be accompanied by one other person of his or her choosing.

CAL. HEALTH & SAFETY CODE § 123110(b) (West 2001): Any patient or patient representative shall be entitled to copies of all or any portion of the patient records that he or she has a right to inspect, upon presenting a written request to the health care provider specifying the records to be copied, together with a fee to defray the cost of copying that shall not exceed \$0.25 per page or \$0.50 per page for records that are copied from microfilm, and any additional reasonable clerical costs incurred in making the records available. The health care provider shall ensure that the copies are transmitted within fifteen days after receiving the written request.

CAL. HEALTH & SAFETY CODE § 123110(c) (West 2001): Copies of x-rays or tracings derived from electrocardiography, electroencephalography, or electromyography need not be provided to a patient or patient representative under this section if the original x-rays or tracings are transmitted to another health care provider upon written request by the patient or patient representative within fifteen days after receipt of the request. All reasonable costs, not exceeding actual costs, incurred by a health care provider in providing copies pursuant to this subdivision may be charged to the patient or representative requesting the copies.

CAL. HEALTH & SAFETY CODE § 123115(a) (West 2001): The representative of a minor shall not be entitled to inspect or obtain copies of the minor patient's records if the minor has a right of inspection under section 123110, or if the health care provider determines that access to the patient records requested by the representative would have a detrimental effect on the provider's professional relationship with the minor or the minor's well being. The decision of the health care provider as to whether a minor's records are available for inspection under this section shall not attach any liability to the provider unless the decision is found to be in bad faith.

CAL. HEALTH & SAFETY CODE § 123115(b) (West 2001): When a health care provider determines there is a substantial risk of significant adverse or detrimental consequences to a patient in seeing or receiving a copy of mental health records requested by the patient, the provider may decline to permit inspection or provide

copies of the records subject to the following conditions: (1) The health care provider shall make a written record, to be included with the mental health records requested, noting the date of the request and explaining his or her reason for refusing to permit inspection or provide copies of the records, including a description of the specific adverse or detrimental consequences to the patient that the provider anticipates would occur if inspection or copying were permitted; (2) the health care provider shall permit inspection by, or provide copies of the mental health records to a licensed physician, surgeon, psychologist, marriage and family therapist, or clinical social worker designated by request of the patient, and these parties shall not permit inspection or copying by the patient; and (3) the health care provider shall inform the patient of the provider's refusal to permit the patient to inspect or obtain copies of the requested records and inform the patient of the right to require the provider to permit inspection by, or provide copies to, a licensed physician, surgeon, psychologist, marriage and family therapist, or clinical social worker, designated by written authorization of the patient.

CAL. HEALTH & SAFETY CODE § 123130(a) (West 2001): A health care provider may prepare a summary of a medical record for inspection and copying by a patient.

CAL. HEALTH & SAFETY CODE § 123130(b) (West 2001): A health care provider may confer with a patient in an attempt to clarify the patient's purpose and goal in obtaining his or her record. If the patient only requests information about certain injuries, illnesses, or episodes, this subdivision shall not require the provider to summarize other information.

CAL. HEALTH & SAFETY CODE § 123149(a) (West 2001): Providers of health services that utilize only electronic record-keeping systems shall comply with the additional requirements of this section. These additional requirements do not apply to patient records if hard copy versions of the patient records are retained.

CAL. HEALTH & SAFETY CODE § 123149(b) (West 2001): Any use of electronic record-keeping to store patient records shall ensure the safety and integrity of those records at least to the extent of hard copy records. Providers set forth in subdivision (a) shall ensure the safety and integrity of all electronic media used to store patient records by employing an offsite backup storage system, an image mechanism that is able to copy signature documents, and a mechanism to ensure that once a record is input, it is unalterable.

CAL. HEALTH & SAFETY CODE § 123149(d) (West 2001): A printout of the computerized record shall be considered the original.

Disclosure

CAL. CIV. CODE § 56.10(a) (West 2001): No provider of health care, health care service plan, or contractor shall disclose medical information regarding a patient without first obtaining authorization, except as provided in subdivision (b)

or (c).

CAL. CIV. CODE § 56.10(b) (West 2001): A provider of health care, a health care service plan, or a contractor shall disclose medical information if the disclosure is compelled by judicial or administrative proceedings, or by a patient or patient representative.

CAL. CIV. CODE § 56.10(c)(1) (West 2001): A provider of health care or a health care service plan may disclose medical information to providers of health care, health care service plans, contractors, or other health care professionals or facilities for diagnosis or treatment of the patient.

CAL. CIV. CODE § 56.10(c)(2) (West 2001): A provider of health care or a health care service plan may disclose medical information to an insurer, employer, health care service plan, hospital service plan, employee benefit plan, governmental authority, contractor, or any other person or entity responsible for paying for health care services rendered to the patient, to the extent necessary to allow responsibility for payment to be determined and payment to be made.

CAL. CIV. CODE § 56.10(c)(7) (West 2001): A provider of health care or a health care service plan may disclose medical information to public agencies, clinical investigators (including investigators conducting epidemiologic studies), health care research organizations, and accredited public or private nonprofit educational or health care institutions for bona fide research purposes, but no information so disclosed shall be further disclosed by the recipient in any way that would disclose the identity of any patient.

CAL. CIV. CODE § 56.10(c)(8) (West 2001): A provider of health care or health care service plan that has created medical information as a result of employment-related health care services to an employee conducted at the specific prior written request and expense of the employer may disclose to the employer that part of the information that (1) is relevant in a law suit, arbitration, grievance, or other claim or challenge to which the employer and the employee are parties and in which the patient has placed in issue his or her medical history, mental or physical condition, or treatment, provided that information may only be used or disclosed in connection with that proceeding, or (2) describes functional limitations of the patient that may entitle the patient to leave work for medical reasons or limit the patient's fitness to perform his or her present employment, provided that no statement of medical cause is included in the information disclosed.

CAL. CIV. CODE § 56.10(c)(9) (West 2001): Unless the provider of health care or health care service plan is notified in writing of an agreement by the sponsor, insurer, or administrator to the contrary, medical information may be disclosed to a sponsor, insurer, or administrator of a group or individual insured or uninsured plan or policy that the patient seeks coverage by or benefits from, if the information was created by the provider of health care or health care service plan

as the result of services conducted at the specific prior written request and expense of the sponsor, insurer, or administrator for the purpose of evaluating the application for coverage or benefits.

CAL. CIV. CODE § 56.10(c)(10) (West 2001): A provider of health care or a health care service plan may disclose medical information to a health care service plan by providers of health care that contract with the health care service plan and may be transferred among providers of health care that contract with the health care service plan, for the purpose of administering the health care service plan.

CAL. CIV. CODE § 56.10(c)(13) (West 2001): A provider of health care or a health care service plan may disclose medical information to an organ procurement organization or a tissue bank processing the tissue of a decedent for transplantation, but only with respect to the donating decedent, for the purpose of aiding the transplant.

CAL. CIV. CODE § 56.10(d) (West 2001): Except to the extent expressly authorized by the patient, enrollee, subscriber, or as provided by subdivisions (b) and (c), no provider of health care, health care service plan, contractor, or corporation and its subsidiaries and affiliates shall intentionally share, sell, or otherwise use any medical information for any purpose not necessary to provide health care services to the patient.

CAL. CIV. CODE § 56.10(e) (West 2001): Except to the extent expressly authorized by the patient, enrollee, subscriber, or as provided by subdivisions (b) and (c), no contractor or corporation and its subsidiaries and affiliates shall further disclose medical information regarding a patient to any person or entity that is not engaged in providing direct health care services to the patient or his or her provider of health care, health care service plan, insurer, or self-insured employer.

CAL. CIV. CODE § 56.13 (West 2001): A recipient of medical information pursuant to an authorization as provided by this chapter or pursuant to the provisions of subdivision (c) of section 56.10 may not further disclose that medical information except in accordance with a new authorization, or as specifically required or permitted by other provisions of this chapter or by law.

CAL. CIV. CODE § 56.14 (West 2001): A provider of health care, health care service plan, or contractor that discloses medical information pursuant to the authorizations required by this chapter shall communicate to the person or entity to which it discloses the medical information any limitations in the authorization regarding the use of the medical information. No provider of health care, health care service plan, or contractor that has attempted in good faith to comply with this provision shall be liable for any unauthorized use of the medical information by the person or entity to which the provider, plan, or contractor disclosed the medical information.

CAL. CIV. CODE § 56.16 (West 2001): Unless there is a specific written request

by the patient to the contrary, nothing in this part shall be construed to prevent a provider, upon an inquiry concerning a specific patient, from discretionally releasing any of the following information: the patient's name, address, age, and sex; a general description of the reason for treatment; the general nature of the treated condition; the general condition of the patient; and any information that is not medical information.

CAL. CIV. CODE § 56.25(c) (West 2001): A provider of health care that is an employer shall not be deemed to have violated section 56.10 by disclosing, in accordance with chapter 3 (commencing with section 56.20), medical information possessed in connection with employing the provider's employees. Information maintained by a provider of health care in connection with employing the provider's employees shall not be deemed to be medical information, unless it would be deemed medical information if received or maintained by an employer that is not a provider of health care.

CAL. CIV. CODE § 56.245 (West 2001): A recipient of medical information pursuant to an authorization as provided by this chapter may not further disclose such medical information unless in accordance with a new authorization, or as specifically required or permitted by other provisions of this chapter or by law.

COLORADO

Case Law

Bodelson v. City of Littleton, 36 P.3d 214 (Colo. 2001): The Colorado Open Records Act prohibits disclosure of medical records to anyone other than the person in interest, unless otherwise provided by law. However, COLO. REV. STAT. § 30-10-606(6)(a)(I) expressly grants the coroner's office access to ambulance reports relevant to investigations in which emergency medical technicians and ambulance medical crews are health care providers.

People v. Paloma, 31 P.3d 879 (Colo. 2001): Drug screening and physical ability tests administered to employees fall under physician-patient privilege only if performed in order to enable physicians to treat employees. Employees submitting to tests for the benefit of their employers are not considered patients (and such tests, then, are not conducted on the patient's behalf) for purposes of the physician-patient privilege and their corresponding medical information may be subject to disclosure.

Beth Israel Hosp. v. District Court, 683 P.2d 343 (Colo. 1984): The mere use of patient medical records as part of a review committee's proceedings does not make them "records of a review committee," that cannot be viewed by the patient's primary care physician. Patient records are not privileged simply because they are part of the peer-review process.

Clark v. Dist. Ct., 668 P.2d 3 (Colo. 1983): If a patient initiates a civil action

alleging his or her physical/mental condition as the basis of a claim for damages, he or she implicitly waives the physician-patient privilege with respect to that medical condition (including all relevant medical information). However, such an implied waiver is specific only to that medical condition (not all personal medical matters).

Statutes

Access

COLO. REV. STAT. § 8-43-404 (2001): In the case of injury, an employee maintains a right to compensation so long as he or she submits to a physical examination/vocational evaluation upon the written request of his or her employer. The employee is entitled to receive a copy of any report made by the examining physician/chiropractor at the same time information is made available to his or her employer or insurer.

COLO. REV. STAT. § 25-1-801 (2001): Health care facilities, upon reasonable notice, must allow patients access to their medical records at reasonable times.

COLO. REV. STAT. § 25-1-802 (1) (2001): All patient medical records in the custody of health care providers, except those pertaining to mental health problems, shall be available to the patient upon submission of a written authorization-request, at reasonable times, upon reasonable notice, and at a reasonable cost.

COLO. REV. STAT. § 26-11.5-108 (2001): An ombudsman, upon presenting a long-term care ombudsman identification card, shall have access to a long-term care facility and the medical records of patients eligible for ombudsman services, provided they have consented to such review.

COLO. REV. STAT. § 30-10-606(6)(a)(I): A coroner has the authority to request and receive a copy of any autopsy report or medical information from any health care provider if such report/information is relevant to his or her investigation.

Disclosure

COLO. REV. STAT. § 6-18-103 (1) (2001): Disclosure of individually identifiable health information, collected by a health care cooperative, is prohibited except when it is (1) given to an individual associated with the information; (2) authorized by informed consent; (3) sought by federal, state, or local law enforcement agencies for lawful purposes; or (4) used for bona fide research projects.

COLO. REV. STAT. § 8-73-108 (4)(b)(III) (2001): Any physician who performs or is present at an examination required by the provisions of the workers' compensation statutes may be called on to testify as to the results of his or her examination. However, he or she shall only disclose confidential communications related specifically to the treatment given and necessary for a proper understanding of the case.

COLO. REV. STAT. § 12-43-218 (1) (2001): Without the client's consent, a mental health professional, his or her employee/associate, or any person involved in group therapy with the client shall not disclose any confidential communications made by the client, or advice given thereon, in the course of his or her professional employment.

COLO. REV. STAT. § 13-21-110 (1) (2001): Medical records made available by law to a health care facility's utilization review committee are confidential and can only be used in the exercise of proper committee functions. A physician may provide any such review committee with records concerning any patient he or she examined/treated, or who was confined in such hospital/health care facility, relating to the committee's proper function.

COLO. REV. STAT. § 13-90-107(1)(d) (2001): A physician or nurse shall not be examined as a witness on any information, acquired through attending to a patient, necessary to enable him or her to prescribe or act for the patient, unless he or she is being either sued (or is in contact with another being sued) by the patient for care given or reviewed by a relevant committee.

COLO. REV. STAT. § 18-4-412 (1) (2001): Without a court order or the written authorization of the patient, anyone who obtains a patient's medical record/information for his or her own use or the use of another, who steals or discloses to an unauthorized person a patient's medical record/information, or who makes or causes to be made an unauthorized copy of a patient's medical record/information, commits theft.

COLO. REV. STAT. § 24-72-204 (3)(a) (2001): A custodian of medical/mental health records shall deny the right of their inspection to anyone other than the person in interest, unless otherwise provided by law.

COLO. REV. STAT. § 27-10-120 (2001): With respect to the care and treatment of the mentally ill, all information obtained and records prepared in the course of providing care shall be confidential and privileged. Such information may only be disclosed in communications between referring physicians; to an individual designated by the patient; and to adult family members actively involved in the care of the mentally ill patient.

CONNECTICUT

Case Law

Falco v. Institute of Living, 757 A.2d 571 (Conn. 2000): The plaintiff was a patient at defendant psychiatric hospital and was attacked by another patient in the hospital. The plaintiff wanted to obtain the name, last known address, and social security number of his attacker, but the defendant turned down the request, contending that there is a psychiatrist-patient privilege statute (CONN. GEN. STAT. § 52-146e), which prohibits the disclosure of communications and record

identifying a patient. Although the superior court and appellate court granted the request of disclosure, on appeal, the supreme court reversed, contending that the psychiatrist-patient privilege can only be overridden by the exceptions listed in the statute.

Cornelio v. Stamford Hosp., 717 A.2d 140 (Conn. 1998): Plaintiff patient was seeking possession of medical specimen slides that pertained to her. The patient alleged that she used the slides to ascertain whether she had a good basis for bringing a malpractice claim against the hospital. The superior court held that the patient lacked a right to obtain the slides as they are specimens that cannot be duplicated, thus falling within the hospital's right to retain original health records under CONN. GEN. STAT. § 19a-490b. The supreme court affirmed the superior court's ruling.

Statutes

Access

CONN. GEN. STAT. § 4-104 (2001): Each private hospital, public hospital, society, or corporation receiving state aid shall, upon the demand of any patient who has been treated in such hospital and after his discharge, permit such patient or his physician or authorized attorney to examine the hospital record, including the history, bedside notes, charts, pictures, and plates kept in connection with the treatment of such patient, and permit copies of such history, bedside notes, and charts to be made by such patient, his physician, or authorized attorney.

CONN. GEN. STAT. § 10-15b (2001): Upon request to the board of education, a parent is entitled to knowledge of, and access to, all medical records maintained in the student's record under this statute.

CONN. GEN. STAT. § 17a-548 (2001): Following discharge from a mental health facility, a patient has the right, upon written request, to inspect and make copies of his records. This provision applies to any hospital, clinic, ward, psychiatrist's office, or other facility that provides services relating to the diagnosis or treatment of a patient's mental condition. Access is not granted if the facility determines that disclosure would create a substantial risk that the patient would hurt self or others; cause severe deterioration in mental status of the patient; or violate an assurance of confidentiality furnished to another person.

CONN. GEN. STAT. § 19a-490b (2001): Upon the written request of a patient, all licensed health care institutions, including hospitals, nursing homes, and others, must supply a copy of his or her health record to the patient. The record includes, but is not limited to, copies of bills, laboratory reports, prescriptions, and other technical information used in assessing the patient's health.

CONN. GEN. STAT. § 20-7c (2001): Upon request, a patient is entitled to access his or her current and complete information concerning any diagnosis, treatment and prognosis of the patient possessed by the health care providers including

physicians, dentists, pharmacists, and chiropractors. Within thirty days of receiving a patient's written request, the provider must also furnish a copy of his health record, including, but not limited to, bills, x-rays, copies of lab reports, contact lens specifications, and other technical information used in assessing the patient's health condition. However, access can be denied if the provider reasonably determines that the information is detrimental to the physical or mental health of the patient, or is likely to cause harm to the patient or others.

Disclosure

CONN. GEN. STAT. § 1-210 (2001): All medical information, record of interviews, written reports, and statements, including data concerning a person's medical or emotional condition or history maintained by any public agency are exempt from disclosure under the state's Freedom of Information Act.

CONN. GEN. STAT. § 52-146d (2001): Communications and records of communications between a patient and a psychiatrist relating to the diagnosis or treatment of a patient's mental condition are confidential.

CONN. GEN. STAT. § 52-146e (2001): No person may disclose or transmit any communications and records that identify a patient to any person, corporation, or governmental agency without the consent of the patient or his authorized representative.

DELAWARE

Case Law

Green v. Bloodsworth, 501 A.2d 1257 (Del. Super. Ct. 1985): The superior court held that a plaintiff waives the patient-physician privilege under Delaware law when a personal injury suit is filed. As medical authorizations in injury cases are routine, the plaintiff's refusal in the future could be subject to sanctions.

Statutes

Access

DEL. CODE ANN. tit. 16, § 1121 (2001): Each patient has the right to inspect all of his or her records upon written or oral request within twenty-four hours notice. The patient upon written request can also make photocopies of these records with a two-day advance notice. If a patient is adjudicated or medically considered to be incompetent or cannot communicate, all of the above rights shall be relayed to the next of kin, guardian, or representative.

DEL. CODE ANN. tit. 16, § 2509 (2001): An individual authorized to make decisions regarding the health care of a patient has the same rights as that patient to have access to that patient's medical records and the consent to disclose any health-related information.

Disclosure

DEL. CODE ANN. tit. 16, § 1121 (2001): Patients in nursing facilities and other such facilities shall receive respect and privacy in their medical care programs. Case discussion, consultation, treatment, and examination must be confidential, and all medical and personal records are considered confidential. These records shall not be made public without the consent of the patient, unless they are needed for the patient's transfer, required by law, or through a third party payment contract.

DEL. CODE ANN. tit. 16, § 5161 (2001): The medical information of individuals in mental health facilities are not considered public and are not to be disclosed without the permission of the patient. These records shall not be released to any person or agency outside the department in which the patient resides, unless to a parent or another health care professional if the patient is a minor, pursuant to an order of a court, to the patient's attorneys, to rights-protection agencies entitled to access by law, to departmental contractors to the extent necessary for professional consultation, to the state bureau of investigation, or as otherwise required by law.

DEL. CODE ANN. tit. 16, § 9926 (2001): In regards to the Delaware Health Information Network, the Delaware Health Care Commission must ensure that a patient's health information only be released with the consent of the patient. This information is neither subject to the Freedom of Information Act nor to court subpoena, and any violation of the above will result in a report to the office of the Attorney General and subject to prosecution and penalties.

DEL. CODE ANN. tit. 24, § 3913 (2001): The Delaware Code recognizes various provider-client privileges, in which the patient can refuse to disclose and disallow others from disclosing communications he or she has had with the provider.

DEL. CODE ANN. tit. 29, § 10002 (2001): Personal or medical files belonging to a "public body," the disclosure of which would bring about an invasion of privacy, are not considered "public." These are thus not subject to the Freedom of Information Act and not available to the public.

DISTRICT OF COLUMBIA

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

*Statutes**Access*

D.C. CODE ANN. § 7-1201.03 (2001): If a mental health professional makes personal notes regarding a client, such personal notes shall not be maintained as part of the client's record. Notwithstanding any other provision of this chapter,

access to such personal notes shall be strictly and absolutely limited to the mental health professional and shall not be disclosed except to the degree that the personal notes or information contained therein are needed in litigation brought by the client against the mental health professional.

D.C. CODE ANN. § 7-1205.02 (2001): A mental health professional or mental health facility may limit the disclosure of portions of a client's record to the client or client representative only if the mental health professional primarily responsible for the diagnosis or treatment of such client reasonably believes that such limitation is necessary to protect the client from a substantial risk of imminent psychological impairment or to protect the client or another individual from a substantial risk of imminent and serious physical injury. The mental health professional shall notify the client or client representative if the mental health professional does not grant complete access.

Disclosure

D.C. CODE ANN. § 7-1201.02(a) (2001): Except as specifically authorized by law, no mental health professional, mental health facility, data collector, or employee or agent thereof shall disclose or permit the disclosure of mental health information to any person, including an employer.

FLORIDA

Case Law

Acosta v. Richter, 671 So. 2d 149 (Fla. 1996): At issue in this case was whether FLA. STAT. ch. 455.241(2) barred the defense counsel in a medical negligence action from having ex parte conferences with a claimant's current treating physician. The Supreme Court of Florida held that FLA. STAT. ch. 455.241(2) barred such conferences, and "provided for a broad physician-patient privilege of confidentiality for a patient's medical information and a limited exception to the privilege for disclosure by a defendant physician in a medical negligence action in order for the physician to defend herself." The court's decision in this case has been codified as FLA. STAT. ch. 456.057(6).

Butterworth v. X Hosp., 763 So. 2d 467 (Fla. Dist. Ct. App. 2000): The court concluded that despite the broad power to issue investigative subpoenas regarding Medicaid fraud, the Attorney General was still required to comply with FLA. STAT. ch. 394.4615(2)(c), and show good cause for their release. In order to respect privacy rights of patients, the legislature intended that sensitive records regarding mental health treatment require at least a court to find good cause to release them.

Humana Med. Plan v. Fischman, 750 So. 2d 677 (Fla. Dist. Ct. App. 1999): Humana gave Dr. Fischman notice terminating the physician agreement between

them. Humana contacted Fischman to retrieve patients' medical records pursuant to the agreement. Fischman provided only those records for which he had received prior written consent from his patients. Humana filed a complaint seeking the return of the records. Fischman answered, seeking attorney's fees pursuant to the agreement. He also counterclaimed. The trial court entered summary judgment on the complaint in favor of Fischman, and awarded him attorney's fees and costs. On appeal, the court noted that Humana failed to remit to Fischman written authorizations from all his patients before demanding the release of their records. Thus, under statute, Fischman was not required to release the documents until he received those authorizations. The court also affirmed prevailing party fees on the counterclaim, because Humana's voluntary payment amounted to a confession of judgment entitling Fischman to such fees pursuant to the agreement.

Pierre v. Handi Van, 717 So. 2d 1115 (Fla. Dist. Ct. App. 1998): A workers' compensation statute requiring health care providers to disclose information did not permit an expert medical examiner to participate in an ex parte conference with an employer and an insurance carrier regarding the condition of a claimant.

Hospital Correspondence Corp. v. McRae, 682 So. 2d 1177 (Fla. Dist. Ct. App. 1996): Under Florida law, the maximum charge that the defendant, a hospital copying service, was permitted to charge the plaintiff patients for paper copies of their medical records was \$1.00 per page copied, regardless of the source used to store the records.

Statutes

Access

FLA. STAT. ch. 455.667 (2000): Health care practitioners must, upon request of a patient or their authorized representative, furnish in a timely manner, the patient's records or reports. If the information is a mental health record, a report of the examination may be provided instead of copies of the records, though copies must be provided in certain limited circumstances. Not more than the actual cost may be charged for such copying.

FLA. STAT. ch. 199.07 (2000): Although records held by state agencies are generally publicly available, there are several exceptions, including an exemption for medical information pertaining to officers or employees of an agency if the information would identify the individual.

Disclosure

FLA. STAT. ch. 381.026 (2000): Every patient who is provided health care services retains certain rights to privacy, which must be respected to the extent consistent with providing adequate medical care to the patient and with the efficient administration of the health care facility or provider's office.

FLA. STAT. ch. 394.4615 (2000): Providing for the confidentiality of mental

health records, this statute outlines the limited exceptions to when such records may be disclosed without the express and informed consent of the patient. FLA. STAT. ch. 490.0147 (2000) extends the above right of confidentiality to communications between a patient and her mental health provider, and FLA. STAT. ch. 456.059 (2000) extends this right to communications between psychiatrists and patients.

FLA. STAT. ch. 395.3025 (2000): Patient records held by a hospital are confidential and must not be disclosed without the consent of the person to whom they pertain, with only limited exception.

FLA. STAT. ch. 455.667 (2000): Generally, a patient's records may not be disclosed without the written authorization of the patient or their representative, nor may their medical condition be discussed with anyone other than the patient, their legal representative, or other practitioners and providers involved in the patient's care and treatment. Disclosure may be made without consent under certain limited circumstances.

FLA. STAT. ch. 456.057 (2000): Patient records may not be furnished to, and the medical condition of a patient may not be discussed with, any person other than the patient or the patient's legal representative or other health care practitioners and providers involved in the care or treatment of the patient, without the written authorization of the patient.

GEORGIA

Case Law

Payne v. Sherrer, 458 S.E.2d 916 (Ga. 1995): Payne sued Sherrer, an employer-appointed physician, for providing copies of his medical records to Payne's employer without his consent. In ruling against the plaintiff, the court cited GA. CODE ANN. § 24-9-40 (establishing the confidentiality of medical records under evidence law) but relied on the medical malpractice principle that patient-physician privity must exist before physicians are required to conform to a standard of conduct. When an employer retains a physician to examine an employee, no physician-patient relationship exists.

Southeastern Legal Found. v. Ledbetter, 400 S.E.2d 630 (Ga. 1991): Newspapers filed an action under the state Open Records Act against the Commissioner of the Department of Human Resources and the superintendent of hospitals seeking access to mental health records that directly or indirectly affected the release from custody of a person who allegedly shot people in a shopping mall. The court held that pursuant to GA. CODE ANN. § 37-3-166, mental health records were clinical records exempt from the Open Records Act.

Griffin-Spalding County Hosp. Auth. v. Radio Station WKEU, 241 S.E.2d 196 (Ga. 1978): WKEU filed a petition for mandamus against the Griffin-Spalding County

Hospital Authority alleging that its denial of access to records relating to its ambulance service constituted a violation of Georgia's "open records" law. The hospital authority argued that the records were medical records and that Georgia's open records law specifically excludes these materials from inspection by the public. The court ruled that the authority need not maintain two separate records, one with information the public may inspect, and one not accessible to the public. However, the court held that the open records law requires a custodian of public records to expunge any information that the public does not have a right to see. The hospital authority had a right to exact reasonable payment for these additional duties from the radio station before it released the information.

Mrozinski v. Pogue, 423 S.E.2d 405 (Ga. Ct. App. 1992): Pogue, a psychiatrist, treated Mrozinski's daughter for drug addiction and other mental health problems. Mrozinski and his daughter also participated in family therapy with Pogue, who gave health information to the attorney of Mrozinski's former wife for a custody suit at the request of the child. The information described Mrozinski's conduct during family therapy, including Pogue's criticisms of Mrozinski's interaction with his daughter. Citing GA. CODE ANN. § 37-3-166, limiting disclosure of clinical records of persons receiving hospital treatment for mental illness to a patient's attorney, the court noted that Pogue disclosed information to the wife's attorney, not the child's attorney. Similarly, GA. CODE ANN. § 37-7-166 permits disclosure of a substance abuser's record to a third-party attorney whom the patient designates in writing, but Mrozinski's daughter did not submit her request in writing. The court concluded that as the parent of the minor child, Mrozinski had standing to file suit for the unauthorized disclosure of his daughter's clinical records.

Statutes

Access

GA. CODE ANN. § 31-8-108(b)(6) (2001): Each resident of a long-term care facility shall be permitted to inspect and receive a copy of his or her medical records unless medically contraindicated. The facility may charge a reasonable fee for duplication that shall not exceed actual cost.

GA. CODE ANN. §§ 31-33-2(a)-(c) (2001): Upon written request from a patient, the provider having custody and control of the patient's record shall furnish a complete and current copy within a reasonable period of time to the patient, any provider designated by the patient, or any other person designated by the patient. If the provider reasonably determines that disclosure to the patient will be detrimental to the patient, the provider may refuse to furnish the record. However, upon such refusal, the patient's record shall, upon written request by the patient, be furnished to any other provider designated by the patient.

GA. CODE ANN. § 37-3-162(b) (2001): Each patient in a mental health facility

and each patient receiving services for mental illness has the right to participate in his or her care and treatment. Unless disclosure to the patient is determined by the chief medical officer or the patient's treating physician or psychologist to be detrimental to the patient, and unless a notation to that effect is made a part of the patient's record, the patient shall have reasonable access to review his or her medical file.

GA. CODE ANN. §§ 37-3-167(a)-(c) (2001): Except as provided in GA. CODE ANN. § 37-3-162, every mental health patient has the right to examine all medical records kept in the patient's name by the state or the facility where the patient was hospitalized or treated. Every patient has the right to request that any inaccurate information found in his or her record be corrected. Nothing in this section shall be construed to require the state to delete information or constrain the state from destroying patient records after a reasonable passage of time.

GA. CODE ANN. § 37-4-122(c) (2001): Each client in a facility and each person receiving services for mental retardation has the right to participate in his or her habilitation. Unless disclosure to the client is determined by the superintendent or person having charge of the client's habilitation to be detrimental to the client, and unless a notation to that effect is made a part of the client's record, the client shall have reasonable access to review his or her medical file.

GA. CODE ANN. § 37-7-162(b) (2001): Each patient in a facility and each person receiving services for substance drug abuse has the right to participate in his or her care and treatment. Unless disclosure to the patient is determined by the chief medical officer or the patient's treating physician or psychologist to be detrimental to the patient and unless a notation to that effect is made a part of the patient's record, the patient shall have reasonable access to review his or her medical file.

Disclosure

GA. CODE ANN. §§ 31-7-6(a), (c) (2001): Any hospital, health care facility, medical or skilled nursing home, or other organization rendering patient care may provide information, interviews, reports, statements, memoranda, or other data relating to the condition and treatment of any person to research groups approved by the medical staff of the institution involved, to governmental health agencies, medical associations and societies, or to any in-hospital medical staff committee, to be used in the course of any study for the purpose of reducing rates of morbidity or mortality. No liability shall arise against any person or organization for providing such information or material, or for releasing or publishing study findings and conclusions, or summaries thereof, to advance medical research or medical education, or to achieve the most effective use of health manpower and facilities. In all events the identity of any person whose condition or treatment has been studied pursuant to this section shall be confidential and shall not be revealed under any circumstances.

GA. CODE ANN. §§ 37-3-166(a), (c) (2001): A clinical record for each mental health patient shall be maintained. Authorized release of the record shall include, but not be limited to, examination of the original record, copies of all or any portion of the record, or disclosure of information from the record, except for matters privileged under state law. Any disclosure authorized by this section or any unauthorized disclosure of confidential or privileged patient information or communications shall not in any way abridge or destroy the confidential or privileged character thereof, except for the purpose for which such authorized disclosure is made. Any person making an authorized disclosure shall not be liable to the patient or any other person notwithstanding any contrary provision of state evidence laws.

GA. CODE ANN. §§ 37-4-125(a), (c) (2001): A clinical record for each mentally handicapped client shall be maintained. Authorized release of the record shall include, but not be limited to, examination of the original record, copies of all or any portion of the record, or disclosure of information from the record, except for matters privileged under state law. Any disclosure authorized by this section or any unauthorized disclosure of confidential or privileged client information or communications shall not in any way abridge or destroy the confidential or privileged character thereof, except for the purpose for which such authorized disclosure is made. Any person making an authorized disclosure shall not be liable to the client or any other person, notwithstanding any contrary provision of state evidence laws.

GA. CODE ANN. §§ 37-7-166(a), (c) (2001): A clinical record for each substance abuse patient shall be maintained. Authorized release of the record shall include but not be limited to examination of the original record, copies of all or any portion of the record, or disclosure of information from the record, except for matters privileged under state law. Any disclosure authorized by this section or any unauthorized disclosure of confidential or privileged patient information or communications shall not in any way abridge or destroy the confidential or privileged character thereof, except for the purpose for which such authorized disclosure is made. Any person making an authorized disclosure shall not be liable to the patient or any other person, notwithstanding any contrary provision of state evidence laws.

HAWAII

Case Law

Painting Indus. of Hawaii Mkt. Recovery Fund v. Alm, 746 P.2d 79 (Haw. 1987): The state constitutional right to privacy extends only to highly personal and intimate information such as medical, financial, educational, or employment records.

Statutes

No statutes dealing strictly with access or disclosure of medical records were found.

IDAHO

Case Law and Statutes

No court cases or statutes dealing strictly with access or disclosure of medical records were found.

ILLINOIS

Case Law

Burger v. Lutheran, 759 N.E.2d 533 (Ill. 2001): The plaintiff patient's medical malpractice suit against defendants, hospital, corporations, and physicians in the circuit court of Cook County, declared parts of 210 ILL. COMP. STAT. 85/6.17 unconstitutional. Upon appeal, the Illinois Supreme Court reversed the circuit court's decision that found parts of 210 ILL. COMP. STAT. 85/6.17(d),(e) violated patient privacy rights under the state constitution; and remanded the matter to the circuit court for further proceedings.

Kunkel v. Walton, 689 N.E.2d 1047 (Ill. 1997): The court found that requiring consent forms from injured parties authorizing the release of medical information is unconstitutional and an invasion of privacy.

Best v. Taylor, 689 N.E.2d 1057 (Ill. 1997): The court held that the state's discovery statutes mandating unlimited disclosure of a plaintiff's medical records, violated the Illinois Constitution. The Act was found to interfere with privacy rights in its mandatory disclosure of all medical information and records.

Statutes

Access

735 ILL. COMP. STAT. 5/8-2001 (West 2001): Every private and public hospital shall, upon the request of any patient who has been treated in such hospital, and after his or her discharge, permit the patient or his or her physician or authorized attorney to examine the hospital records kept in connection with the treatment of such patient, and permit copies of such records. A request for examination of the records shall be in writing and shall be delivered to the administrator of such hospital. The hospital has a maximum of sixty days to comply with the request.

735 ILL. COMP. STAT. 5/8-2003 (West 2001): Every physician and other health care practitioner shall, upon the request of any patient who has been treated by such physician or practitioner, permit such patient's physician or authorized

attorney to examine and copy the patient's records. Such a request for examining and copying the records shall be in writing and shall be delivered to such physician or practitioner. The physician or practitioner has a maximum of sixty days to comply with the request and shall be reimbursed by the person requesting such records.

740 ILL. COMP. STAT. 110/4 (West 2001): Upon request, the parent or guardian of a recipient under twelve years of age, the recipient, the guardian of the recipient, or the attorney of the recipient of mental health services is entitled to inspect and copy his or her records.

Disclosure

410 ILL. COMP. STAT. 50/3 (2001): Each patient has a right to privacy and confidentiality in health care. Each physician, health care provider, health services corporation, and insurance company shall refrain from disclosing the nature or details of services provided to patients, except that such information may be disclosed to the patient; the party making treatment decisions if the patient is incapable of making decisions regarding the health services provided; those parties directly involved with providing treatment to the patient or processing the payment for that treatment; those parties responsible for peer review, utilization review, and quality assurance; and those parties required to be notified due to abuse or a notifiable condition.

INDIANA

Case Law

Terre Haute Reg'l Hosp. v. Trueblood, 600 N.E.2d 1358 (Ind. 1992): The patient filed an action against a hospital and the hospital's parent corporation alleging that the hospital's staff physician performed two unnecessary surgeries on the patient's neck and back. During discovery, the patient sought the records of non-party patients. The trial court entered an order, which permitted the patient's attorney and expert to inspect the medical records. On appeal, the intermediate appellate court held that the trial court's order constituted an abuse of discretion and vacated the discovery order. On review, the supreme court vacated the decision of the intermediate appellate court. The supreme court held that when all the information regarding the identities of the non-party patients had been redacted from the records, production of the medical records did not violate the physician-patient privilege. The court held that where adequate safeguards exist to protect the identity and confidentiality of the non-party patient, the trial court may allow the discovery of the non-party patient medical records even where the patient has not waived the physician-patient privilege.

Canfield v. Sandock, 563 N.E.2d 526 (Ind. 1990): The court affirmed the decision of the trial court and found that medical information, which is unrelated

to the medical condition and irrelevant to the issue in litigation, remains privileged, and therefore protected from discovery.

Andreatta v. Hunley, 714 N.E.2d 1154 (Ind. Ct. App. 1999): When a patient who is a party to a lawsuit places his or her physical condition at issue, the patient has implicitly waived the physician-patient privilege as to that condition. However, once the physician-patient privilege has been invoked, the burden is upon the party claiming it to prove his entitlement to protection. The bare assertion of a claim of privilege will not suffice to block discovery of the information sought by the discovery request.

Statutes

Access

IND. CODE § 16-39-1-1 (2001): On written request and with reasonable notice, a provider shall supply to the patient the health records possessed by the provider.

IND. CODE § 16-39-2-4 (2001): A patient is entitled to inspect and copy the patient's own mental health record. However, if the provider that is responsible for the patient's mental health records determines for good medical cause, upon the advice of a physician, that the information requested under this section is detrimental to the physical or mental health of the patient, or is likely to cause the patient to harm the patient or another person, the provider may withhold the information from the patient.

IND. CODE § 27-13-31-4 (2001): A health maintenance organization is entitled to access treatment records and other information pertaining to the diagnosis, treatment, and health status of any enrollee during the period of time the enrollee is covered by the health maintenance organization.

Disclosure

IND. CODE § 16-14-1.6-8 (2001): This statute provides that information obtained and maintained in the course of providing services to a patient is confidential and can be disclosed only with the consent of the patient. However, records reflecting the cost of care and maintenance are not confidential and may be disclosed without the consent of the patient, to the extent necessary to obtain payment for services rendered or other benefits to which the patient or client may be entitled.

IND. CODE § 16-39-1-5 (2001): A provider may withhold information from a patient that is judged to be detrimental to the health of the patient or likely to cause the patient to harm self or other.

IND. CODE § 16-39-5-3 (2001): This statute allows the owners of the original health records (health care providers) to use these without specific written authorization of the patient and for legitimate business purposes that include submission of claims for payment from third parties; collection of accounts; litigation defense; quality assurance; peer review; and scientific, statistical, and

educational purposes. The provider is obligated to protect the confidentiality of the health record at all times and disclose the identity of the patient only when disclosure is essential to the provider's business use or to quality assurance and peer review.

IOWA

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Disclosure

IOWA CODE § 22.7 (2) (2001): Medical records, hospital records, and professional counselor records of the condition, diagnosis, care, or treatment of a patient or former patient that are maintained by a public entity maintain their status as confidential records and are not open to public inspection unless otherwise ordered by a court.

IOWA CODE § 228.2 (2001): Mental health professionals, mental health facilities, data collectors, and their respective employees and agents are prohibited from disclosing (or permitting the disclosure of) mental health information without the written authorization of the client.

IOWA CODE § 228.8 (2001): Mental health professionals and mental health facilities may disclose mental health information to family members without the client's authorization when specific conditions are met. Disclosure of mental health information without the client's consent is also permitted to initiate or complete civil commitment proceedings; to file requisite reports for the funding of local community health services; and to meet other statutory requirements.

KANSAS

Case Law

Burroughs v. Thomas, 937 P.2d 12 (Kan. Ct. App. 1997): The county coroner argued that his underlying investigative materials should not be disclosed under the Kansas Open Records Act on the proposition that these materials constituted medical records that could not be revealed by Kansas statute. The court agreed that they were medical records not subject to public disclosure.

*Statutes**Disclosure*

KAN. STAT. ANN. § 21-3853 (2000): Entities holding medical records must turn them over to the attorney general within the context of the attorney general's Medicaid fraud investigations. Anyone turning such information over shall not be liable for a breach of confidentiality.

KAN. STAT. ANN. § 38-1513 (2000): When the health or condition of a child who is a ward of the state requires it, a court may consent to the performing and furnishing of hospital, medical, surgical, or dental treatment or procedures, including the release and inspection of medical or dental records.

KAN. STAT. ANN. § 38-1609 (2000): The medical records of juvenile offenders shall be privileged and shall only be disclosed in limited situations, including whether such disclosure is ordered by a court and when the juvenile has given written consent.

KAN. STAT. ANN. § 40-22a09 (2000): Utilization review organizations must have written procedures for assuring that patient specific information obtained during a utilization review is kept confidential in accordance with state and federal law, and that the information is used only for the purposes of the utilization review, quality assurance, discharge planning, and catastrophic case management.

KAN. STAT. ANN. § 40-22a10 (2000): Medical records exchanged between health care provider or patient and utilization review organization shall not be subject to release, subpoena, or admissible into evidence in judicial or administrative proceedings other than in limited situations.

KAN. STAT. ANN. § 45-221 (2000): Unless specifically required by statute, no public agency shall be required to disclose the medical, psychiatric, psychological, or alcoholism or drug dependency treatment records that pertain to identifiable patients.

KAN. STAT. ANN. § 59-2979 (2000): Treatment or medical records that are in possession of a court or treatment facility (of mentally ill patients) shall not be disclosed unless, among other exceptions, (1) there is consent of the patient or his guardian; (2) the head of a facility determines that disclosure is necessary for the treatment of the patient; or (3) there is a court order.

KAN. STAT. ANN. §§ 65-5601, 65-5602, 65-5603 (2000): A patient of a community health center, community facility for the mentally retarded, psychiatric hospital, or state institution for the mentally retarded may prevent personnel at those facilities from disclosing that he has been, or is currently, receiving treatment, or from disclosing any confidential communications made for the purposes of diagnosis or treatment. Disclosure without the patient's consent is permitted only in limited situations such as to protect a person who has been threatened with substantial physical harm by the patient and for the purposes of

involuntary commitment proceedings.

KENTUCKY

Case Law

Geary v. Schroering, 979 S.W.2d 134 (Ky. Ct. App. 1998): A woman filed suit seeking damages resulting from an accident in which she was involved. The trial court ordered her to sign a blank medical authorization. The court held that this was inappropriate and that pertinent medical information should have been discovered by taking subpoenas and depositions.

Hardin County v. Hardin Mem'l Hosp., 894 S.W.2d 151 (Ky. Ct. App. 1995): An attorney in a personal injury action subpoenaed medical treatment records during discovery. The records were furnished at a cost of \$1.00 per page. The party seeking the documents contested the cost as unreasonable. The lower court found that the rate was reasonable. The court of appeals reversed and remanded for further consideration.

Statutes

Access

KY. REV. STAT. ANN. § 422.317 (Michie 2001): Upon a patient's written request, a health care provider or hospital must provide, without charge to the patient, a copy of the patient's medical record. The provider or hospital may charge up to \$1.00 per page for the second copy.

Disclosure

KY. REV. STAT. ANN. § 17.574 (Michie 2001): With certain exceptions, state and local detention or correctional facilities, hospitals, and other institutions shall forward (among other things) medical records, including psychological records and the treatment record, of sex offenders to be discharged or paroled to an approved provider for review prior to the release or discharge for consideration in making recommendations to the sentencing court.

KY. REV. STAT. ANN. § 200.490 (Michie 2001): Medical records of children in the care of the Commission for Children with Special Health Care Needs shall be confidential and shall not be disclosed without the consent of a parent or guardian or other select individuals except where such disclosure may be necessary to provide additional services to the children through other medical, welfare, or service agencies and institutions.

KY. REV. STAT. ANN. § 304.17 A-555 (Michie 2001): This statute recognizes a patient's right of privacy in the content of his or her record and communications with a health care provider with respect to mental health or chemical dependency. Insurers are limited in the information they can get from the provider, and no

third party to whom disclosure is made may redisclose the information.

KY. REV. STAT. ANN. § 422.315 (Michie 2001): A patient may ask to prohibit or limit the use of his medical records.

LOUISIANA

Case Law

Speer v. Whitecloud, 744 So. 2d 1283 (La. 1999): Speer sought records of a 1994 study published by Dr. Whitecloud that concerned spinal pedicle screw devices for a medical malpractice suit. Whitecloud countered that, under LA. REV. STAT. ANN. § 13:3715.1, a subpoena, court order, or patient consent was required for medical record release. Because the plaintiff desired only the model numbers and manufacturers of the pedicle screws, the supreme court affirmed the trial court ruling that discovery did not invade physician-patient privilege once personal identifying information was removed.

Davis v. American Home Products Corp., 727 So. 2d 647 (La. Ct. App. 1999): The plaintiffs claimed that Norplant contraception caused injuries. In communications with the defendant, they presented a report from a Texas medical expert alleging that his institution evaluated patients with complications due to Norplant. The defendant wished to examine the medical records, with identifiable information removed, of these patients. The court of appeals reversed the decision of the trial court and pronounced the records not discoverable due to the absence of a statutory exception, of permission from the non-party patients, and of a contradictory hearing with the non-party patients.

Lugar v. Baton Rouge Gen. Med. Ctr., 696 So. 2d 652 (La. Ct. App. 1997): The plaintiff signed multiple authorization forms allowing his insurance company, who was also his employer, access to his medical records. After being fired, the plaintiff filed suit against the hospital, contending its negligence, and that of its employees, in regards to releasing his confidential medical information. Ruling that the hospital rightfully released information allowed by the authorization form and that no reasonable evidence existed for the plaintiff's claim of tampering, the court of appeals affirmed the trial court's ruling in favor of the defendant.

Farr v. Riscorp, 714 So. 2d 20 (La. Ct. App. 1996): The plaintiff was injured in an industrial workplace accident and filed for workers' compensation. The medical case manager discussed the employee's medical situation with the treating physician, although the employee had previously signed a standard medical authorization with the provisions for medical discussions and opinions scratched from the form. Because the employee filed a workers' compensation claim, the court of appeals affirmed the trial court's decision that the case manager did not violate physician-patient privilege and was immune from tort.

Goldstein v. St. Paul Fire & Marine Ins. Co., 665 So. 2d 1267 (La. Ct. App. 1995):

The decedent was attacked by a fellow patient at a residential nursing facility and subsequently died from exacerbations, brought about by injuries sustained in the attack, of pre-existing conditions. Her executor requested documents concerning her attacker from the nursing home insured by the named insurance company. The insurer claimed that such records fell under the purview of physician-patient privilege, as the nursing facility acted as health care provider. The court of appeals affirmed the trial court ruling that the privilege existed only to patient and not provider, and thus the non-party patient's records were discoverable.

Jo Ellen Smith Psychiatric Hosp. v. Harrell, 546 So. 2d 886 (La. Ct. App. 1989): An employee of Smith Psychiatric Hospital had erroneously sent a Blue Cross Provider Register that listed confidential information of thirty-nine patients when the family of one patient requested information about its bill. Fearing disclosure of its record to others, the family proposed to contact the other thirty-eight patients to check upon the situation. The hospital then filed for an injunction, which was denied. Claiming the family's proposal to contact the others to investigate the possibility of a claim against the hospital would infringe on the privacy of the patients and that they would suffer irreparable harm, the hospital appealed. Believing that the patient's right to investigate for possible litigation did not outweigh the privacy of the other patients and that the irreparable harm would occur, the court of appeals reversed the trial court's decision.

Statutes

Access

LA. REV. STAT. ANN. § 40:1299.96 (West 2001): A health care provider will furnish each patient, upon request of the patient, a copy of any information related to the patient that has been provided to any company, agency, or person. But the provider may deny access if he or she concludes that knowledge from the records would be harmful to the patient or any other person. The provisions of this statute do not apply to providers who examine a patient at the request of any state or federal agency in charge of assistance or entitlement programs under the Social Security Act. No prohibition exists on records retained by the Social Security Administration, unless contrary to state or federal law or regulation.

LA. REV. STAT. ANN. § 40:2144 (West 2001): Upon receipt of a request in writing signed and dated by the person initiating the request, a hospital is required to, except for good cause shown, such as medical contraindication, furnish medical records as soon as practicable and upon payment of the reasonable cost of so providing.

Disclosure

LA. REV. STAT. ANN. § 13:3715.1 (West 2001): A health care provider shall disclose medical or hospital records of a patient who is party to litigation pursuant to a subpoena. Additionally, a court shall issue an order of a patient's record,

regardless of whether the patient is party to litigation only after contradictory hearing with the patient and a court finding that release is proper. But no health care provider is required to grant access to photographs of alleged victims of child sexual abuse unless court-ordered for counsel or expert evaluation of medical diagnosis of child sexual abuse.

LA. REV. STAT. ANN. § 44:7 (West 2001): The charts, records, documents, and other memoranda by the physicians, surgeons, psychiatrists, nurses, and employees in the public hospitals, mental health centers, or schools of Louisiana are exempt from the laws granting access to public records and are confidential.

MAINE

Case Law

Bailan v. Board of Licensure in Med., 722 A.2d 364 (Me. 1999): Dr. Bailan was fined by a medical board for failure to release psychiatric records to his patient's doctors. Bailan testified that he did not release the records because he required that the patient's signature be witnessed and attested to by someone from the requesting physician's office, the witness sign the medical release form, and the physician make a specific request to Bailan. The court agreed with Bailan that the board erred in fining him because they failed to reveal or introduce into evidence the standards of professional ethics Bailan was alleged to have violated.

Guy Gannett Publ'g Co. v. University of Maine, 555 A.2d 470 (Me. 1989): The court found that a portion of the settlement agreement between the University and a former coach relating to medical information was properly kept from disclosure because the information fell within the definition of "medical information," and thus was exempt from disclosure under the state Freedom of Access Act.

Statutes

Access

ME. REV. STAT. ANN. tit. 22, § 1711 (West 2000): Within a reasonable time of receiving a written authorization, a health care practitioner must release copies of all treatment records of a patient or a summary containing all the relevant information in the treatment records, to the patient. The practitioner may impose a reasonable charge for the copies or the report supplied, not exceeding the costs incurred by the practitioner. If the practitioner believes that the release of the records to the patient would be detrimental to the health of the patient, he must advise the patient that the records or summary will be made available to an authorized representative of the patient upon presentation of a written authorization by the patient. The copies must be provided to the representative

within a reasonable time. Similar rules apply to hospitals.

ME. REV. STAT. ANN. tit. 24-A, § 2211 (West 2000): A person has the right to have any factual error in his medical records corrected and to have any misrepresented or misleading entry amended or deleted in accordance with certain procedures.

Disclosure

ME. REV. STAT. ANN. tit. 22, § 1711 (West 2000): Disclosure without an individual's authorization is permitted in a number of circumstances such as to other health care practitioners and facilities within and outside the original office, to practice or organizational affiliates, to quality or peer reviewers, to certain family or household members unless specifically prohibited by the individual, to third parties who face a direct threat, when directed by a court, and to persons conducting scientific research. Health care practitioners and facilities are expressly prohibited from disclosing health care information for the purpose of marketing or sales without written or oral authorization for the disclosure.

ME. REV. STAT. ANN. tit. 22, § 8707 (West 2000): Privileged medical information provided by hospitals and health care providers concerning patient treatment and its associated costs to the Health Data Organization shall be treated as confidential and shall not be available to the public.

MARYLAND

Case Law

Warner v. Lerner, 705 A.2d 1169 (Md. 1998): Warner was a patient of Dr. Schirmer, a urologist. Dr. Lerner was also a urologist at the same hospital, and he was sued by Kelly. Kelly retained Dr. Schirmer as an expert. In an attempt to discredit Dr. Schirmer, Dr. Lerner obtained plaintiff Warner's urological record from the hospital and made it public by discussing it in a binding mediation. The lower courts found that Dr. Lerner's conduct did not violate Warner's rights. The court of appeals reversed, finding no authority in the statute for allowing such disclosure of confidential information.

Davis v. Johns Hopkins Hosp., 622 A.2d 128 (Md. 1993): Plaintiffs asked for compensatory and punitive damages against a hospital for not producing their medical records in a timely manner as required by state law. The court found that the mere failure to produce records is not enough to constitute a violation of the law unless there was evidence of intent on the part of the hospital not to produce the records in a timely fashion. The court found that in this case there was no such evidence and thus dismissal was warranted.

Shady Grove Psychiatric Hosp. v. State, 736 A.2d 1168 (Md. Ct. Spec. App. 1999): The court of appeals found that the trial court erred when it ordered a hospital to

comply with a subpoena. Even though the information requested in the subpoena did not relate to the health care of a patient, the wording of the subpoena was such that the information could not be disclosed without acknowledging that a medical record of the patient existed. The court held that was enough to invoke the rule that a health care provider cannot disclose a medical record without proof that the agency to which it is released has procedures for ensuring the confidentiality of the record. Since there was no proof of such procedures here, the subpoena should not have been enforced.

Dr. K. v. State Bd. of Physician Quality Assurance, 632 A.2d 453 (Md. Ct. Spec. App. 1993): The State Board of Quality Assurance had an interest in reviewing the medical records of a patient in a hearing on an allegation that a doctor was having a romantic relationship with the patient. The patient argued that the Board did not have a right to inspect her medical records. The court held that the patient's privacy interest was outweighed by the Board's need to investigate doctors, and thus the release of the records was appropriate.

Statutes

Access

MD. CODE ANN., HEALTH-GEN. I § 4-304 (2001): A health care provider shall allow a person to receive a copy of his mental health record or to see a copy of his medical records unless there is some physiological or psychiatric information that might be injurious to the patient, in which case the provider shall follow certain specified procedures. A person may request a change to be made in their medical records. The person may be charged for the costs of retrieving and copying the records. Such charges shall not exceed certain statutorily determined amounts.

MD. CODE ANN., HEALTH-GEN. I § 5-711 (2001): A local department that is investigating allegations of child abuse or neglect can get access to the child's medical records from the physician.

Disclosure

MD. CODE ANN., HEALTH-GEN. I § 4-209 (2001): Medical records of inmates shall remain confidential and shall only be disclosed to certain law enforcement, correctional facilities personnel, or other listed authorities with the further restriction that such records shall only be used for certain circumscribed purposes.

MD. CODE ANN., HEALTH-GEN. I § 4-303 (2001): A health care provider can disclose medical records when the person has consented to such disclosure.

MD. CODE ANN., HEALTH-GEN. I § 4-305 (2001): A health care provider may disclose certain information without the consent of the person in certain limited situations, including (1) to certain limited persons for the purpose of offering, providing, evaluating, or seeking payment for health care to patients or recipients by the provider, to provider's legal counsel, or to provider's insurer; (2) to persons for educational and research purposes, for evaluation and management of health

care systems, and for accreditation purposes where such recipients agree not to redisclose the information; (3) to another provider for the purposes of treating the patient; (4) when disclosure is necessary in the case of an emergency; and (5) to family members of the patient in certain limited situations.

MD. CODE ANN., HEALTH-GEN. I § 4-306 (2001): A health care provider shall disclose medical records without authorization of the patient under limited circumstances, including (1) to certain authorities where there is suspicion of child abuse or neglect; (2) to health professional and disciplinary licensing boards; and (3) to an insurer or legal counsel when there is a civil claim related to the records.

MD. CODE ANN., HEALTH-GEN. I § 4-308 (2001): A health care provider who in good faith discloses or does not disclose medical records is not liable in any cause of action arising from the disclosure or nondisclosure of such records.

MD. CODE ANN., HEALTH-GEN. I § 4-309 (2001): If a health care provider refuses to disclose records within a reasonable time when the disclosure has been requested by a person in interest, the provider is liable for actual damages. Refusal cannot be based on refusal to pay for health care services rendered.

MD. CODE ANN., CTS. & JUD. PROC. § 9-109 (2001): There is a patient-psychologist privilege that allows the patient and/or provider to refuse disclosure of medical information except in certain situations, such as where disclosure is necessary to place the patient in a mental illness facility, a patient puts his mental illness at issue in a court proceeding, or when there is a malpractice claim made by the patient.

MD. CODE ANN., STATE GOV'T § 10-617 (2001): This statute excludes from state open disclosure laws certain public records that contain medical or psychological information about an individual, other than an autopsy report of a medical examiner.

MASSACHUSETTS

Case Law

Mitchell v. Subramanya, 538 N.E.2d 319 (Mass. 1989): A plaintiff alleged that the defendant physician wrongfully refused to provide the plaintiff with her medical record. The court partially affirmed an earlier judgment for a suit brought against the physician, which held that evidence fell short of demonstrating that the doctor had furnished an incomplete or inaccurate summary of the medical record. In compliance with a regulation from the Board of Registration of Medicine, discretion was given to the doctor as to whether to provide the patient with her entire medical record in his possession, or a summary.

Statutes

Access

MASS. GEN. LAWS ch. 111, § 70 (2001): A patient or an authorized representative has the right to review the patient's hospital records. Upon request, a copy must be provided after payment of a reasonable fee.

MASS. GEN. LAWS ch. 112, § 12CC (2001): Health care providers must grant a patient access to his or her medical records. Upon request, a copy of the medical records must be provided after payment of a reasonable fee.

Disclosure

MASS. GEN. LAWS ch. 111, § 70E (2001): Records of hospitals licensed to the department of public health are confidential to the extent provided by law. Hospitals are allowed to give third-party reimbursers the permission to inspect and copy records relating to diagnosis, treatment, or other services provided to any person for which coverage, benefit, or reimbursement is claimed if the policy or certificate under which the claim is made provides that such access to records is permitted. Hospital records can be disclosed without patient authorization in any peer-review or utilization procedures.

MASS. GEN. LAWS ch. 112, § 12G (2001): Medical records and information are included in a person's statutory right of privacy. Statutory exceptions exist where physicians and hospitals may disclose medical information of a patient without his or her consent when establishing eligibility for, or entitlement to, government benefits in connection with mandatory health department reports, or as required by any law.

MICHIGAN

Case Law

In re Petition of Attorney Gen., 369 N.W.2d 826 (Mich. 1985): The contents of a hospital's peer-review committee proceedings (likely to include patient medical records) are confidential.

Gaertner v. State, 187 N.W.2d 429 (Mich. 1971): A state hospital may not lawfully deny the guardian of an incompetent minor access to his or her records, for confidentiality purposes, because the physician-patient privilege belongs to the patient. The guardian can legally act for his or her mentally incompetent ward who cannot act for himself or herself.

Scott v. Ford Hosp., 501 N.W.2d 259 (Mich. Ct. App. 1993): Under MICH. COMP. LAWS § 600.2157, a defendant health care provider can only release a deceased patient's medical records to his or her estate's personal representative. Such a rule is necessary to protect the physician-patient privilege.

Popp v. Crittenton Hosp., 449 N.W.2d 678 (Mich. Ct. App. 1989): The physician-

patient privilege precludes a hospital from releasing medical records of a nonparty. The privilege prohibits the disclosure of even the names of patients not involved in the litigation.

Gallagher v. Detroit-Macomb Hosp. Ass'n, 431 N.W.2d 90 (Mich. Ct. App. 1988): Pursuant to the Michigan Public Health Code, a hospital can invoke its privilege to exempt from court subpoena information and records compiled in furtherance of improving health care and reducing morbidity and mortality.

Dierickx v. Cottage Hosp., 393 N.W.2d 564 (Mich. Ct. App. 1986): A parent holds the right to assert the physician-patient privilege on behalf of his or her minor child. Though requested medical records may be relevant to a hospital's theory of a child's genetically transmitted defect, such records are privileged and not subject to discovery.

Statutes

Access

MICH. COMP. LAWS § 333.20201(2)(b) (2001): A patient is entitled to inspect or receive, for a reasonable fee, a copy of his or her medical records. A third party shall not be given a copy of the patient's medical records without the patient's prior authorization.

MICH. COMP. LAWS § 333.22210(3)(k)(vi) (2001): A patient in a short-term nursing care program, or a person who the patient has authorized in writing, may, after submitting a written request to the hospital, inspect and copy his or her medical records. The hospital shall make the records available for inspection and copying within seven days of receiving the patient's (or other authorized individual's) written request.

Disclosure

MICH. COMP. LAWS § 15.243(1)(b) (2001): A public body may exempt from disclosure as public records information subject to the physician-patient privilege and medical records concerning an individual if the individual's identity would be revealed by their disclosure.

MICH. COMP. LAWS § 330.1750(3) (2001): Hospitals cannot disclose the fact that a patient was examined, treated, or underwent any diagnosis unless such medical information is relevant to the health care provider's insurer's rights and liabilities.

MICH. COMP. LAWS § 331.531(1) (2001): A person, organization, or entity may provide to a review entity information relating to the physical and/or psychological condition of a person, the necessity, appropriateness, or quality of health care rendered to a person, or the qualifications, competence, or performance of a health care provider.

MICH. COMP. LAWS § 333.20175(1) (2001): Health facilities shall keep and maintain full and complete records for each patient. Departmental officers and

employees shall respect the confidentiality of a patient's clinical records and shall not disclose the contents of records in a manner identifying an individual except pursuant to court order.

MICH. COMP. LAWS § 600.2157 (2001): An authorized physician shall not disclose any medical information that he or she acquired in attending to a patient if such information was necessary to enable him or her to prescribe for the patient as a physician.

MINNESOTA

Case Law

Koudsi v. Hennepin County Med. Ctr., 317 N.W.2d 705 (Minn. 1982): The plaintiff brought an action against the hospital for an alleged violation of her statutory right to privacy. The court held that communication over telephone by the hospital's patient information operator of information concerning the plaintiff's discharge and the fact that she had given birth did not involve "medical records" within the meaning of the state Patients' Bill of Rights. Furthermore, the hospital, despite having notice of the plaintiff's desire that the birth not be disclosed to anyone, was not limited in its "use and dissemination" of such information to that necessary for administration and management of programs specifically authorized or mandated by the legislature, local governing body, or federal government.

Swarthout v. Mutual Serv. Life Ins., 632 N.W.2d 741 (Minn. Ct. App. 2001): In a suit arising over the purchase of life insurance, the court held that MINN. STAT. § 144.355 (prohibiting the unauthorized release of medical information) does not require the existence of a patient-physician relationship.

Day v. Miner, No. C3-97-1944, 1998 Minn. App. LEXIS 634 (Minn. Ct. App. June 2, 1998): Dr. Day was convicted of fourth-degree criminal sexual conduct. As a result, he was referred to the University of Minnesota's Program in Human Sexuality, where he began treatment with Dr. Miner. During treatment, Day made written requests to review his medical records. Miner denied the requests, stating by letter that such review would be "counter-therapeutic." Day subsequently sued Miner under MINN. STAT. § 144.355 for denying him access to his medical records and for releasing private medical data to the Minnesota Board of Medical Practice (the Board). The court held that the denial complied with the statute and that when Day entered a stipulation with the Board to regain his license upon completion of treatment, he provided informed consent for release of information to the Board.

*Statutes**Access*

MINN. STAT. § 144.335(2)(b) (2001): Except as provided in paragraph (e), upon a patient's written request, a provider, at a reasonable cost to the patient, shall promptly furnish to the patient (1) copies of the patient's health record, including but not limited to laboratory reports, x-rays, prescriptions, and other technical information used in assessing the patient's health condition, or (2) the pertinent portion of the record relating to a condition specified by the patient.

MINN. STAT. § 144.335(2)(c) (2001): If a provider reasonably determines that requested information is detrimental to the patient, or is likely to cause the patient to inflict self harm, or to harm another, the provider may withhold the information from the patient and may supply the information to an appropriate third party or to another provider. The other provider or third party may release the information to the patient.

MINN. STAT. § 144.335(2)(d) (2001): A provider shall release information upon written request unless, prior to the request, the provider has designated and described a specific basis for withholding the information.

Disclosure

MINN. STAT. § 144.335(3) (2001): A patient's health record, including but not limited to laboratory reports, x-rays, prescriptions, and other technical information used in assessing the patient's condition, or the pertinent portion of the record relating to a specific condition, or a summary of the record, shall promptly be furnished to another provider upon the written request of the patient.

MINN. STAT. § 144.335(3)(a) (2001): A provider, or a person who receives health records from a provider, may not release a patient's health records without a signed and dated consent from the patient or the patient's legally authorized representative unless the release is specifically authorized by law.

MINN. STAT. § 144.335(3)(b) (2001): This subdivision does not prohibit the release of health records (1) for a medical emergency when the provider is unable to obtain the patient's consent due to the patient's condition or the nature of the medical emergency, or (2) to other providers within related health care entities when necessary for the current treatment of the patient.

MINN. STAT. § 144.335(3)(e) (2001): A person who negligently or intentionally releases a health record in violation of this subdivision, forges a signature on a consent form, obtains under false pretenses the consent form or health records of another person, or without the person's consent alters a consent form, is liable to the patient for compensatory damages caused by an unauthorized release, plus costs and reasonable attorney's fees.

MINN. STAT. § 144.335(3)(f) (2001): Upon the written request of a spouse,

parent, child, or sibling of a patient being evaluated for or diagnosed with mental illness, a provider shall inquire of a patient whether the patient wishes to authorize a specific individual to receive information regarding the patient's current and proposed course of treatment. If the patient so authorizes, the provider shall communicate to the designated individual the patient's current and proposed course of treatment.

MINN. STAT. § 144.651(16) (2001): Patients and residents of health care facilities shall be assured confidential treatment of their personal and medical records, and may approve or refuse their release to any individual outside the facility. Residents shall be notified when personal records are requested by any individual outside the facility and may select someone to accompany them when the records or information are the subject of a personal interview.

MISSISSIPPI

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Access

MISS. CODE ANN. § 41-9-65 (2001): Hospital records constitute hospital property subject to reasonable access. With payment of a reasonable charge for such a service and with good cause, a patient, heirs, representatives, or attending medical personnel may have reasonable access.

MISS. CODE ANN. § 41-21-102 (7) (2001): Unless disclosure is determined to be detrimental to the physical or mental health of the patient, and unless notation to that effect is made in the patient's record, a patient has the right of access to his medical records.

Disclosure

MISS. CODE ANN. § 13-1-21 (2001): All communications made to a physician, osteopath, dentist, hospital, nurse, pharmacist, podiatrist, optometrist, or chiropractor by a patient or a person seeking professional advice are privileged and generally may not be disclosed.

MISS. CODE ANN. § 41-9-67 (2001): Hospital records are not public records.

MISS. CODE ANN. § 41-41-11 (2001): A patient's medical records may be disclosed to others when the patient has waived the medical privilege or has consented to such disclosure.

MISSOURI

Case Law

State ex rel. Wilfong v. Schaeperkoetter, 933 S.W.2d 407 (Mo. 1996): A mother and natural guardian previously sued the treating physician and medical center for alleged injuries from their refusal to provide timely medical care to her child with a genetic disorder. During discovery, the mother was ordered by the court to sign authorizations for defendant's attorneys as to all of her other children but applied for a writ of prohibition that was denied by the court of appeals. The Supreme Court of Missouri issued the writ of prohibition, ruling that the non-party siblings did not personally place their medical conditions at issue and that the mother could not waive the other children's privilege.

State ex rel. Lester E. Cox Med. Ctr. v. Keet, 678 S.W.2d 813 (Mo. 1984): A woman filed a malpractice suit against treating physicians and the medical center for the death of her husband who died from a post-surgical bacterial infection. Writs in prohibition were previously granted to the treating physicians and medical center regarding the release of medical records of any patient at the medical center who had developed a bacteriological infection subsequent to surgery and disclosure of the reason for hospitalization of any patient who was in the same ward with the decedent. The Supreme Court of Missouri ruled to quash the preliminary writs of prohibition, enabling the respondent to conduct in camera examinations of the records sought with identifying information removed.

Fierstein v. DePaul Health Ctr., 949 S.W.2d 90 (Mo. Ct. App. 1997): In a child custody case, the court of appeals found that a physician had a duty of confidentiality not to disclose medical information, including medical records obtained during the patient's treatment under MO. REV. STAT. § 630.140.

Wear v. Walker, 800 S.W.2d 99 (Mo. Ct. App. 1990): Previously, a woman filed an action against a group of physicians who refused to furnish her with a copy of her medical records upon request, and the circuit court moved to dismiss the case citing MO. REV. STAT. § 191.227. The court of appeals reversed the original ruling and remanded the case for a new trial stating that MO. REV. STAT. § 191.227 does not seek to eliminate the right of access completely, but merely to limit it.

Statutes*Access*

MO. REV. STAT. § 191.227 (2000): All physicians and hospitals, upon written request of a patient, guardian, or legal representative of a patient, must furnish a copy of the patient's medical record. Nevertheless, the provider has the right to limit access consistent with the patient's condition and sound therapeutic treatment.

MO. REV. STAT. § 630.110 (2000): Persons admitted to mental health facilities

and mental health programs are entitled to access to their mental and medical records.

Disclosure

MO. REV. STAT. § 630.140 (2000): Medical records held by a health care facility will be kept confidential and disclosed only with the authorization of the patient, pursuant to an order of a court or administrative agency, to a representing attorney, or to a county board or other qualified personnel excluding patient identifiers.

MONTANA

Case Law

Huether v. District Court, 4 P.3d 1193 (Mont. 2000): The petitioner filed a wrongful death action against the defendant hospital and requested that the defendant produce any incident reports regarding the care and treatment of the decedent while a patient at the hospital. The defendant objected to the request on the grounds that these documents were not subject to discovery under statutes providing for the confidentiality of in-hospital medical staff committees. The supreme court held that documents were discoverable to the extent that they were relevant to the decedent's hospital care and treatment. However, documents related solely to the training, supervision, or discipline of the medical staff were not discoverable.

Bowen v. Super Valu Stores, 745 P.2d 330 (Mont. 1987): On appeal from the worker's compensation court, the supreme court found that the insurer was entitled to confidential health care information as it related to the injured employee's claim for compensation. The employee had a duty to file all reasonable information with the insurer and the worker's compensation court.

Statutes

Access

MONT. CODE ANN. § 50-16-502 (2001): Health care information is personal and sensitive information that if improperly used or released may do significant harm to a patient's interests in privacy and health care or other interests. Patients need access to their own health care information as a matter of fairness, to enable them to make informed decisions about their health care and to correct inaccurate or incomplete information about themselves.

MONT. CODE ANN. § 50-16-541 (2001): Upon receipt of a written request from a patient to examine or copy all or part of the patient's recorded health care information, a health care provider, as promptly as required under the circumstances, but no later than ten days after receiving the request, shall (1) make the information available to the patient for examination, without charge,

during regular business hours, or (2) provide a copy, if requested, to the patient or inform the patient if the information does not exist or cannot be found.

MONT. CODE ANN. § 50-16-542 (2001): A health care provider may deny access to health care information by a patient if the provider concludes that the knowledge of the health care information could be injurious to the health of the patient, lead to the patient's identification of an individual who provided the information in confidence, or could reasonably be expected to cause danger to the life or safety of any individual.

Disclosure

MONT. CODE ANN. § 50-16-202 (2001): A health care facility and its agents and employees may provide medical records or other health care information relating to the condition and treatment of any patient in the health care facility to any utilization review, peer review, medical ethics review, quality assurance, or quality improvement committee of the health care facility.

MONT. CODE ANN. § 50-16-525 (2001): Health care providers may not release health care information about a patient to any other person without the patient's written authorization.

MONT. CODE ANN. § 50-16-526 (2001): A patient may authorize a health care provider to disclose the patient's health care information. A health care provider shall honor an authorization and, if requested, provide a copy of the recorded health care information unless the health care provider denies the patient access to health care information.

MONT. CODE ANN. § 50-16-529 (2001): A health care provider may disclose health care information about a patient without the patient's authorization, to the extent a recipient needs to know the information. The disclosure can be made to a person who is providing health care to the patient; to any other person who requires health care information for health care education; to provide planning, quality assurance, peer review, or administrative, legal, financial, or actuarial services to the health care provider; for assisting the health care provider (or successors of the health care provider) in the delivery of health care; or to a third-party health care payer who requires health care information.

NEBRASKA

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

*Statutes**Access*

NEB. REV. STAT. §§ 20-164(1)-(2) (2001): To protect the legal rights of a mentally ill individual or with respect to matters that occur within ninety days after the discharge date of such an individual from a mental health facility, the protection and advocacy system shall be granted access to the records of (a) any mentally ill individual who is a client of the protection and advocacy system if such individual or the legal guardian, conservator, or other legal representative of such individual has authorized the protection and advocacy system to have such access; and (b) any mentally ill individual (1) who by reason of the mental or physical condition is unable to authorize the protection and advocacy system to have such access; (2) who does not have a legal guardian, conservator, or other legal representative, or for whom the legal guardian is this state; and (3) with respect to whom a complaint has been received by the protection and advocacy system or with respect to whom there is probable cause to believe that such individual has been subject to injury or deprivation with regard to his or her health, safety, welfare, rights, or level of care. The protection and advocacy system may not disclose information from such records to the mentally ill individual who is the subject of the information if disclosure would be detrimental to such individual's health.

NEB. REV. STAT. §§ 71-8403(1)-(4) (2001): A patient may request a copy of his or her medical records or may request to examine them. Access to medical records shall be provided upon written request, except that mental health records may be withheld if any treating physician, psychologist, or mental health practitioner determines in his or her professional opinion that release of the records would not be in the best interest of the patient. Upon receiving a written request for a copy, the health care provider shall comply within thirty days. Upon receiving a written request to examine medical records, the provider shall as promptly as required under the circumstances, but no later than ten days after receiving the request (a) make the medical records available for examination during regular business hours; (b) inform the patient if the records do not exist or cannot be found; (c) if the provider does not maintain the records, inform the patient of the name and address of the provider who maintains such records, if known; or (d) if unusual circumstances have delayed handling the request, inform the patient in writing of the reasons for the delay and the earliest date, not later than twenty-one days after receiving the request, when the records will be available for examination. A provider shall not be required to disclose confidential information in any medical record concerning another patient or family member who has not consented to the release of the record.

NEB. REV. STAT. § 71-8404 (2001): For medical records provided under NEB. REV. STAT. § 71-8403 (2001) to a patient or his or her authorized representative, a

provider may charge no more than \$20.00 as a handling fee and no more than \$0.50 per page as a copying fee. A provider may charge for the reasonable cost of all duplications of medical records that cannot routinely be copied or duplicated on a standard photocopy machine. A provider may charge an amount necessary to cover the cost of labor and materials for furnishing a copy of an x-ray or similar special medical record. If the provider does not have the ability to reproduce x-rays or other records requested, the person making the request may arrange, at his or her expense, for the reproduction of such records.

NEB. REV. STAT. §§ 71-8505(1)-(4) (2001): Prior to an initial telehealth consultation, a telehealth care practitioner shall ensure that the patient receive (1) a written statement that all existing confidentiality protections apply to the telehealth consultation; (2) a written statement that the patient shall have access to all medical information resulting from the telehealth consultation as provided by law for patient access to his or her medical records; and (3) a written statement that dissemination of any patient-identifiable images or information from the telehealth consultation to researchers or other entities shall not occur without the written consent of the patient.

Disclosure

NEB. REV. STAT. § 71-1335(1) (2001): No mental health practitioner shall disclose any information he or she may have acquired from any person consulting him or her in his or her professional capacity except with the written consent of the person or, in the case of death or disability, of the person's personal representative, any other person authorized to sue on behalf of the person, or the beneficiary of an insurance policy on the person's life, health, or physical condition. When more than one person in a family receives therapy conjointly, each such family member who is legally competent to execute a waiver shall agree to the waiver. Without such a waiver from each family member, a practitioner shall not disclose information received from any family member who received therapy conjointly.

NEB. REV. STAT. § 71-5185 (2001): No patient data received or recorded by an emergency medical service or an out-of-hospital emergency care provider shall be divulged, made public, or released except to the receiving health care facility, to the state for statistical purposes, or upon the written authorization of the patient. For purposes of this section, patient data means any data received or recorded as part of the records maintenance requirements of the Emergency Medical Services Act.

NEB. REV. STAT. § 71-8406 (2001): A provider who transfers or submits information in good faith to a patient's medical record shall not be liable in damages to the patient or any other person for the disclosure of such medical records.

NEB. REV. STAT. § 81-674 (2001): Any private or public entity, individual, or

approved researcher who wrongfully discloses confidential data obtained from state medical records and health information registries, or uses such information with the intent to deceive, shall be guilty of a misdemeanor for each offense.

NEVADA

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Access

NEV. REV. STAT. §§ 163A.B.363(1)-(3), (7) (2001): Health care providers and all persons who own or operate an ambulance in Nevada shall make a patient's health care records available for inspection by the patient or a representative with written authorization from the patient. The records must be made available at a place convenient for inspection, and inspection must be permitted at all reasonable office hours and for a reasonable length of time. If the records are located outside the state, the provider shall make them available within ten working days after the request. The provider shall also furnish a copy of the records to each patient or authorized representative who requests them and pays the actual cost of postage, if any, the costs of making the copy, not to exceed \$0.60 per page for photocopies, and a reasonable cost for copies of x-ray photographs and other health care records produced by similar processes. No administrative fee or additional service fee of any kind may be charged for furnishing such a copy. Health care providers or owners or operators of ambulances, their agents, and their employees are immune from any civil action or consequential damages for any disclosures made in accordance with the provisions of this section.

NEV. REV. STAT. §§ 443.504(1)-(2) (2001): A mental health patient must be permitted to inspect his or her records and kept informed of his or her clinical status and progress at reasonable intervals, not longer than three months, in a manner appropriate to the clinical condition. Unless a psychiatrist has made an entry to the patient's record to the contrary, the patient must be given a copy of his or her records at any time upon notice to the administrative officer of the facility and payment of costs to reproduce records.

Disclosure

NEV. REV. STAT. § 433A.360(1) (2001): Clinical mental health records cannot be released except (a) to physicians, attorneys, and social agencies authorized in writing by the patient, his or her guardian, or his or her attorney; (b) to persons authorized by a court of competent jurisdiction; (c) to qualified facility staff, an employee of the facility, or a staff member of a Nevada agency when the

administrator deems it necessary for proper care; (d) for statistical and evaluative purposes if the identity of the patient is protected; (e) to make a claim for insurance benefits with the written consent of the patient or his or her guardian; (f) to any staff member of a Nevada agency; or (g) for transfer to another facility.

NEV. REV. STAT. § 443.482(8) (2001): Each mental health or mentally handicapped patient admitted for evaluation, treatment, or training has the right to designate a person who must be kept informed by the facility of the patient's medical and mental condition, if the client signs a release allowing the facility to provide such information. Patients have a right to deny access to their medical records to any person other than a member of the facility staff or related medical personnel, a person who obtains a waiver by the patient, or a person who obtains a court order.

NEV. REV. STAT. § 449.720(4) (2001): Every patient of a medical facility, dependent care facility, or individual residential care facility has the right to privacy concerning his or her program of medical care. Discussions of a patient's care, consultation with other persons concerning the patient, examinations or treatments, and all communications and records concerning the patient are confidential except for personal injury suits, state efforts to collect and analyze data, forwarding medical records upon transfer of a patient, and activities related to "healing arts" occupations.

NEW HAMPSHIRE

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Access

N.H. REV. STAT. ANN. § 151:21(X) (2001): Medical information contained in medical records at any licensed facility shall be deemed the property of the patient. The patient shall be entitled to a copy of such records upon request. The charge for copying medical records shall not exceed \$15.00 for the first thirty pages or \$0.50 per page, whichever is greater, provided that copies of filmed records such as radiograms, x-rays, and sonograms shall be copied at a reasonable cost.

Disclosure

N.H. REV. STAT. ANN. §§ 135-C:19-a(I)-(II) (2001): Notwithstanding other provisions, a community mental health center or state facility providing services to seriously or chronically mentally ill clients may disclose information regarding diagnosis, admission to or discharge from a treatment facility, functional

assessment, the name of the medicine prescribed, the side effects of any medication prescribed, behavioral or physical manifestations that would result from failure of the patient to take such prescribed medication, treatment plans and goals, and behavioral management strategies to a family member or other person, if such family member or person lives with the client or provides direct care to the client. The mental health center or facility shall provide a written notice to the patient that shall include the name of the person requesting the information, the specific information requested, and the reason for the request. Prior to disclosure, the mental health center or facility shall request the patient's consent in writing. If consent cannot be obtained, the patient shall be informed of the reason for the intended disclosure, the specific information to be released, and the person or persons to whom the disclosure is to be made.

N.H. REV. STAT. ANN. § 151:21(X) (2001): Patients shall be ensured confidential treatment of all information contained in their personal and clinical records, including that stored in an automatic data bank. A patient's written consent shall be required for the release of information to anyone not otherwise authorized by law to receive it.

N.H. REV. STAT. ANN. §§ 151:30(I)-(II) (2001): Any person aggrieved by a hospital or sanitarium's failure to abide by the provisions of N.H. REV. STAT. ANN. § 151 may seek equitable relief from the superior court, which shall have original jurisdiction. A facility violating N.H. REV. STAT. ANN. § 151 will be liable in the sum of \$50.00 for each violation per day or part of a day, or for all damages proximately caused by the violations, whichever is greater.

N.H. REV. STAT. ANN. § 329:26 (2001): The confidential relations and communications between a physician or surgeon and a patient are placed on the same basis as those provided by law between attorney and client. Except as otherwise provided by law, no such physician or surgeon shall be required to disclose such privileged communications. Confidential relations and communications between a patient and any person working under the supervision of a physician or surgeon that are customary and necessary for diagnosis and treatment are privileged to the same extent.

N.H. REV. STAT. ANN. §§ 332-I:1(I)-(III) (2001): Medical information contained in medical records in the possession of any health care provider shall be deemed the property of the patient. Release or use of patient-identifiable medical information for sales or marketing of services or products is prohibited without written authorization.

NEW JERSEY

Case Law

Boldt v. Correspondence Mgmt., 726 A.2d 975 (N.J. Super. Ct. App. Div. 1999):

Plaintiff patients sued the defendants, doctors and the medical record copying service, for overcharging plaintiffs for copies of medical records under N.J. ADMIN. CODE tit. 8 § 43G-15.3(d) and tit. 13 § 35-6.5(c)(4). Defendants moved for summary judgment, claiming that the complaint should have been addressed to the state board of medical doctors. The trial court granted summary judgment, but the appellate court reversed and remanded the decision because there was an issue of fact as to the meaning of "actual costs" used in the regulation governing copying of medical records.

Estate of Behringer v. Med. Ctr. at Princeton, 592 A.2d 1251 (N.J. Super. Ct. Law Div. 1991): The estate of a surgeon who died of AIDS brought an action against the hospital seeking damages for the breach of the hospital's duty to maintain confidentiality of the plaintiff's diagnosis. The defendant hospital denied any breach of confidentiality, but the trial court granted a judgment in favor of the plaintiff because the potential harm from non-consensual disclosure was substantial.

In re J.C.G., 366 A.2d 733 (N.J. Hudson County Ct. Law Div. 1976): A parent who applied for the involuntary civil commitment of her thirteen year-old daughter requested, through counsel, that the Trenton Psychiatric Hospital release her daughter's hospital records. The court denied the request, concluding that the parent failed to advance any evidence that the disclosure would be used directly or indirectly for the benefit of the patient.

Statutes

Access

N.J. STAT. ANN. § 26:2H-12.8(g) (West 2001): A patient has the right to access his or her medical records pertaining to his or her treatment from the hospital upon request within a reasonable cost unless the patient's physician has stated in writing that access by the patient is not advisable.

Disclosure

N.J. STAT. ANN. § 26:2H-12.8(g) (West 2001): Every person admitted to a general hospital has a right to privacy and confidentiality of all records kept pertaining to the person's treatment, except as otherwise provided by law or third-party payment contracts.

N.J. STAT. ANN. § 30:4-24.3 (West 2001): To protect the institutionalized mentally ill, all certificates, applications, records, and reports made in conjunction with any person presently or formerly receiving services in a non-correctional institution must be kept confidential and may not be disclosed by any person without the consent of the patient, except in limited circumstances.

NEW MEXICO

Case Law

Pina v. Espinoza, 29 P.3d 1062 (N.M. Ct. App. 2001): The plaintiff, an injured woman, appealed a court decision that was made when she filed a personal injury action against a driver she claimed was responsible for hitting her car and causing her subsequent injury. The lower court requested a blanket release of her medical records for the trial, but the appellate court found that this was an abuse of discretion, and the case was remanded.

Lara v. City of Albuquerque, 971 P.2d 846 (N.M. Ct. App. 1998): The city filed a motion to compel the plaintiff, a city employee, to provide a signed medical release allowing the city to access his drug test results and other treatment records. The plaintiff refused to offer his medical records, asserting the psychotherapist-patient privilege and rules of confidentiality, and the appellate court found for the plaintiff on those grounds.

Eckhardt v. Charter Hosp. of Albuquerque, 953 P.2d 722 (N.M. Ct. App. 1997): The lower courts dismissed the claim that a hospital employee wrongfully disclosed confidential records to the patient's husband. The appellate court reversed, finding that the patient's wrongful disclosure claim was viable because the employee improperly disclosed information about the plaintiff.

New Mexico v. Roper, 921 P.2d 322 (N.M. Ct. App. 1996): The district court suppressed the results of the defendant's blood tests after the defendant was charged with operating a vehicle under the influence of alcohol and causing great bodily injury while driving under the influence of alcohol. The state appealed, but the appellate court affirmed the decision of the lower court, stating that the results of the defendant's blood tests constituted a confidential communication.

New Mexico v. Gonzales, 912 P.2d 297 (N.M. Ct. App. 1996): The victim claimed that the defendant had sexually assaulted her, and the defendant claimed that they had consensual sex. The defendant wanted dismissal of the charges since the prosecution would not produce the victim's medical records for camera view. The lower court found that because the victim's medical releases were signed in favor of the prosecution, this terminated the confidentiality of the records and waived the physician-psychotherapist privilege of New Mexico. The appellate court affirmed the trial court's dismissal of the charges against the defendant.

Statutes*Access*

N.M. STAT. ANN. § 14-6-3 (Michie 2001): Health care providers must provide a patient, a former patient, or an authorized representative of such a patient, who is applying for or appealing denial for benefits based on social security disability, with a copy of that patient's medical records. The health care provider may charge

a fee to the requestor for such a copy.

N.M. STAT. ANN. § 32A-6-15 (Michie 2001): A child has a right to access confidential information about himself, and to make copies of information about himself, unless the physician or health professional believes and notes in the child's medical record that disclosure is not in the best interest of the child. Except as otherwise provided in the Children's Mental Health and Developmental Disabilities Act, no person shall, without the authorization of the child, disclose confidential information that would enable an acquainted person to recognize the child. When a child fourteen years or older is incapable of consenting to disclosure, the person seeking authorization shall petition the court for appointment of a treatment guardian to decide for the child. Authorization for disclosure is not necessary when the request is from a mental health or disability professional; when it is necessary to protect or treat the child; or when the disclosure is to a paying insurer. No disclosure authorization is effective unless it is in writing, signed, and contains a copy of the child's right to copy the information.

N.M. STAT. ANN. § 43-1-19 (Michie 2001): A client has a right of access to confidential information about himself and has the right to make copies of any information, except if the physician, mental health, or disabilities professional believes and notes in the record that disclosure is not in the best interest of the client. In that case, a client may petition the court for access.

Disclosure

N.M. STAT. ANN. § 14-6-1 (Michie 2001): All health information that relates to and identifies specific individuals as patients is strictly confidential and shall not be a matter of public record or accessible to the public even though the information is in the custody of, or contained in the records of, a governmental agency or its agent, a state educational institution, a duly organized state or county association of licensed physicians or dentists, a licensed health facility, or staff committees of such facilities.

N.M. STAT. ANN. § 43-1-19 (Michie 2001): Without the authorization of the client, no person shall disclose any confidential information from which the client may be recognized, except when this information is requested by a mental health or developmental disability professional or a primary caregiver of the client; disclosure is necessary to protect against a clear and substantial risk of "imminent serious physical injury or death" of the client or another; or disclosure is to a contracted insurer obligated to pay any part of the expenses. No authorization shall be effective unless it is in writing, signed, and contains a statement of the client's right to examine and copy the information to be disclosed.

N.M. STAT. ANN. § 59A-46-27 (Michie 2001): Records pertaining to physical or mental examinations and medical treatment of persons confined to any institution cannot undergo public inspection.

NEW YORK

Case Law

McCrossan v. Buffalo Heart Group, 695 N.Y.S.2d 852 (N.Y. App. Div. 1999): The court held that, where a patient authorized a third party to receive a copy of her medical records, the provider could charge the authorized party no more than \$0.75 per page as proscribed by N.Y. PUB. HEALTH LAW § 18(2)(e), even though the designated party is not a "qualified person" as defined in the statute.

Rabinowitz v. Hammons, 644 N.Y.S.2d 726 (N.Y. App. Div. 1996): The court held that § 18's requirement for patient authorization of disclosure exempts medical records held by state and local officials from public disclosure under the Freedom of Information Law.

Doe v. Roe, 599 N.Y.S.2d 350 (N.Y. App. Div. 1993): The court considered whether the defendant-physician's disclosure of the patient plaintiff's HIV status to a Pennsylvania court, in violation of N.Y. PUB. HEALTH LAW § 2782, was grounds for a private civil suit, and with what types of remedy. The defendant doctor had mailed the patient's records, which included HIV status, to comply with a subpoena for the patient's worker's compensation suit. The court found the suit viable and the defendant liable for both compensatory and punitive damages. In addition, the court found the defendant's oral agreement to keep the information confidential to be grounds for a breach of contract claim.

Calabrese v. PHF Life Ins. Co., 594 N.Y.S.2d 1016 (N.Y. App. Div. 1993): In reviewing a motion filed by the plaintiff doctor to quash, based on N.Y. PUB. HEALTH LAW § 4504, a subpoena issued by defendant insurance company for the plaintiff's patients' records, the court upheld the subpoena but ordered the patient records produced in redacted form, "deleting the patients' names and addresses and any other identifying information to comport with. . .doctor-patient privilege."

Rosen v. Arden Hill Hosp., 622 N.Y.S.2d 663 (N.Y. Sup. Ct. 1993): The court considered whether the defendant-hospital's disclosure that the plaintiff had undergone a procedure violated his right to confidentiality under N.Y. PUB. HEALTH LAW § 2803-c. The defendant performed a test on the plaintiff and his two infant sons to confirm paternity. The sons' mother, from whom the plaintiff was divorced, called the defendant and inquired whether plaintiff had made payment for a paternity test. Defendant informed her that payment had been made for such a test, thereby revealing that it had occurred. The court held that since she, as guardian of the children, had a legal right under N.Y. PUB. HEALTH LAW § 18 to any records concerning tests and procedures involving her children; and since it would be impossible to reveal that a paternity test had been administered on the children without revealing its administration on the plaintiff-father; the defendant-hospital's disclosure was appropriate under law.

*Statutes**Access*

N.Y. PUB. HEALTH LAW § 18(2)(a)-(2)(c) (McKinney 2001): Upon written request, a health care provider must grant, within ten days, the opportunity to inspect a patient's non-excluded medical records to the patient; to a minor patient's parent or legal guardian (except where such access would be detrimental to the minor); to a "qualified person," which includes any properly identified subject or guardian appointed pursuant to article eighty-one of the mental hygiene law; to a guardian of an infant; or to a representing attorney; and, where the patient has been found incompetent, to the committee appointed for the patient's protection.

N.Y. PUB. HEALTH LAW § 18(2)(d)-(2)(i) (McKinney 2001): Upon request, a provider must furnish a copy of non-excluded records to a qualified person within a reasonable time. A provider may impose a reasonable charge for access not to exceed the costs incurred by the provider. For copies of medical records, the charge may not exceed \$0.75 per page. Access to medical records may not be denied solely because of inability to pay. For inspections, a provider may place reasonable limitations on the time, place, and frequency of inspection; and may provide a copy instead if inspection is limited by space.

N.Y. PUB. HEALTH LAW § 18(3)(a)-(f) (McKinney 2001): A provider may refuse access to medical records only when (1) the provider has determined that identifiable harm would befall a patient as a result of disclosure or (2) when those medical records contain privileged and confidential physician notation. Where a provider has denied access to a patient's records, it may provide a summary of denied records. In the event of a denial of access, the qualified person shall be informed by the provider of the decision, and of the qualified person's right to obtain, without cost, a review of the denial by the appropriate medical record access review committee.

N.Y. PUB. HEALTH LAW § 18(9) (McKinney 2001): Any agreement to waive the right to access one's patient records as described in this statute is unenforceable and void as against public policy.

N.Y. MENTAL HYG. § 33.16 (McKinney 2001): Mental health records are subject to rules similar to those set forth in PUB. HEALTH LAW § 18, with the following differences. Qualified person status is extended to include the parent, spouse, or child of certain adult patients. There is no disclosure exemption for confidential physician notation.

Disclosure

N.Y. PUB. HEALTH LAW § 18(6) (McKinney 2001): Whenever a health care provider discloses patient information to a person or entity other than the subject of such information or to other qualified persons, a copy of the subject's

authorization, or the name and address of such third party shall be placed or noted in the chart. The disclosure should be limited to information necessary in light of the reason for disclosure. If a provider must disclose patient information to a person or entity other than the relevant patient as authorized by law, the provider shall notify the patient.

N.Y. PUB. HEALTH LAW § 2803-c (McKinney 2001): Hospital patients have the right to confidentiality in the treatment of personal and medical records. A statement of this right (and other patient rights and responsibilities) must be both given to patients and conspicuously posted in each hospital.

NORTH CAROLINA

Case Law

Lavelle v. Guilford Area Mental Illness, 456 S.E.2d 827 (N.C. 1995): The court held that mental health facilities are required to disclose confidential information to a patient's attorney upon the patient's request without restrictions.

Baugh v. Woodward, 287 S.E.2d 412 (N.C. Ct. App. 1982): In a class action on behalf of all prisoners, the plaintiff demanded that the Department of Correction provide each prisoner who had undergone psychiatric or psychological treatment while in prison with direct access to their mental health records pursuant to principles now codified in N.C. GEN. STAT. § 122C-53 (2001). The court ruled that prison-operated mental health facilities did not qualify as facilities subsumed by statute; that no prisoner would be allowed access to their mental health records even if treatment was received after transfer to a facility operated by the Department of Human Resources, so as to avoid equal protection problems; and that prisoners had no property rights in mental health records generated while in prison, and thus, no legitimate claim of entitlement protected by procedural due process.

Statutes

Access

N.C. GEN. STAT. § 90-85.35 (2001): Pharmacists employed in health care facilities shall have access to patient records maintained by those facilities when necessary for them to provide pharmaceutical services.

N.C. GEN. STAT. §§ 122C-53(c), (d) (2001): Upon request, a client of a mental health, developmental disability, or substance abuse facility shall have access to confidential information in his or her record except information that would be injurious to the client's well being as determined by the attending physician or, if there is none, by the facility director or his or her designee. The legally responsible person of a client has the same right. If the attending physician or facility director or his or her designee has refused to provide information, the

client or legally responsible person may request that the information be sent to a physician or psychologist of his or her choice.

Disclosure

N.C. GEN. STAT. § 90-412(a) (2001): Notwithstanding any other provision of law, any health care provider or facility licensed, certified, or registered under state law, or any unit of state or local government, may create and maintain medical records in an electronic format. The health care provider, facility, or governmental unit shall not be required to maintain a separate paper copy of the electronic medical record; however, when a consent to treatment or authorization to disclose medical record information is contained in a paper writing, the writing shall be preserved in a durable medium, and its existence and location shall be noted in the electronic record.

N.C. GEN. STAT. § 90-412(c) (2001): The usual legal rights and responsibilities, including those regarding access to and disclosure of medical records, apply to records created or maintained in electronic form to the same extent as they apply to medical records embodied in paper or other media.

N.C. GEN. STAT. § 122C-53(a) (2001): A mental health, developmental disability, or substance abuse facility may disclose confidential information if the client or his or her legally responsible person consents in writing to the release of the information to a specified person. This release is valid for a specified length of time and is subject to revocation by the consenting individual.

N.C. GEN. STAT. § 122C-53(b) (2001): A mental health, developmental disability, or substance abuse facility may disclose the fact of admission or discharge of a client to the client's next of kin whenever the responsible professional determines that the disclosure is in the best interest of the client.

N.C. GEN. STAT. § 122C-55(a) (2001): Any area or state facility or the psychiatric service of the University of North Carolina Hospitals at Chapel Hill may share confidential information regarding any mental health, developmental disability, or substance abuse patient of that facility with one another when necessary to coordinate appropriate and effective care, treatment, or habilitation and when failure to share this information would be detrimental to the patient. Consent is not required, and the information may be furnished despite objection by the patient.

N.C. GEN. STAT. § 122C-55(b) (2001): A facility, physician, or other individual responsible for evaluation, management, supervision, or treatment of respondents examined or committed for outpatient mental health, developmental disability, or substance abuse treatment may request, receive, and disclose confidential information to the extent necessary to enable them to fulfill their responsibilities.

N.C. GEN. STAT. § 122C-55(c) (2001): When requested, a facility may furnish confidential information to the Department of Correction regarding any client of that facility when the inmate has been determined by the department to be in

need of treatment for mental illness, developmental disabilities, or substance abuse. The department may furnish a facility with confidential information in its possession about treatment that the department has provided to any present or former inmate if the inmate is presently seeking treatment from the requesting facility or if the inmate has been involuntarily committed to the requesting facility. The consent of the client or inmate shall not be required for this information to be furnished and the information shall be furnished despite objection by the client or inmate. Confidential information disclosed pursuant to this subsection is restricted from further disclosure.

N.C. GEN. STAT. § 122C-55(e) (2001): A responsible professional may exchange confidential information with a physician or other health care provider who is providing emergency medical services to a mental health, developmental disability, or substance abuse client. Disclosure of the information is limited to that necessary to meet the emergency as determined by the responsible professional.

N.C. GEN. STAT. § 122C-55(f) (2001): A mental health, developmental disability, or substance abuse facility may disclose confidential information to a provider of support services whenever the facility has entered into a written agreement with a person to provide support services and the agreement includes a provision in which the provider of support services acknowledges that in receiving, storing, processing, or otherwise dealing with any confidential information, he or she will safeguard and not further disclose the information.

N.C. GEN. STAT. § 122C-55(h) (2001): Within a mental health, developmental disability, or substance abuse facility, employees, students, consultants, or volunteers involved in the care, treatment, or habilitation of a client may exchange confidential information as needed for the purpose of carrying out their responsibility in serving the client.

N.C. GEN. STAT. § 122C-55(i) (2001): Upon specific request, a responsible professional of a mental health, developmental disability, or substance abuse facility may release confidential information to the physician or psychologist who referred the client.

N.C. GEN. STAT. § 122C-55(j) (2001): Upon request of the next of kin or other family member who has a legitimate role in the therapeutic services offered, or other person designated by a mental health, developmental disability, or substance abuse client or his or her legally responsible person, the responsible professional shall provide the next of kin or other family member or the designee with notification of the client's diagnosis, prognosis, prescribed medications, medication dosage, medication side effects, and progress, provided that the client or legally responsible person has consented in writing, or the client has consented orally in the presence of a witness selected by the client.

N.C. GEN. STAT. § 122C-55(k) (2001): Notwithstanding N.C. GEN. STAT. § 122C-53(b) (2001) or provisions governing transfer of clients between twenty-four-

hour facilities, upon request of the next of kin or other family member who has a legitimate role in the therapeutic services offered to a client of a mental health, developmental disability, or substance abuse facility, or other person designated by the client or his or her legally responsible person, the responsible professional shall provide the next of kin, family member, or designee notification of the client's admission, transfer, decision to leave against medical advice, discharge, and referrals and appointment information for treatment after discharge, after notification to the client that this information has been requested.

N.C. GEN. STAT. § 122C-55(1) (2001): In response to a written request of the next of kin or other family member who has a legitimate role in the treatment of a mental health, developmental disability, or substance abuse client, or other person designated by the client, for additional information not provided for in N.C. GEN. STAT. §§ 122C-55(j), (k) (2001), and when such written request identifies the intended use for this information, the responsible professional shall, in a timely manner (1) provide the information based upon the responsible professional's determination that it will be to the client's therapeutic benefit, and provided that the client or his legally responsible person has consented in writing to the release; (2) refuse to provide the information based upon the responsible professional's determination that it would be detrimental to the therapeutic relationship between client and professional; or (3) refuse to provide the information based upon the responsible professional's determination that the next of kin or family member or designee does not have a legitimate need for the information.

N.C. GEN. STAT. § 131E-97(a) (2001): Medical records compiled and maintained by health care facilities in connection with the admission, treatment, and discharge of individual patients are not public records.

N.C. GEN. STAT. § 131E-98 (2001): Notwithstanding any other provision of law, a hospital does not breach patient confidentiality by providing the Department of Correction with medical records of inmates who receive medical treatment at the hospital while in the custody of the department.

NORTH DAKOTA

Case Law

Theven v. Job Serv. N.D., 488 N.W.2d 48 (N.D. 1992): A clerk in the medical records department of a hospital discovered her husband's misfiled lab report while cleaning out records. The clerk removed the report and placed it in her desk, where a co-worker discovered it and reported the clerk to a supervisor. The clerk was subsequently fired for a breach of confidentiality, which the court upheld.

Jane H. v. Rothe, 488 N.W.2d 879 (N.D. 1992): Jane H. sued her doctors for medical malpractice, alleging that they negligently performed gynecological

surgery. Jane H. petitioned the court for a supervisory writ directing the trial court to vacate a discovery order that compelled her to disclose her chemical dependency treatment records. The trial court found that the three facilities where Jane received treatment are covered by acts that restrict the disclosure of a patient's records about drug and alcohol abuse treatment at federally assisted facilities. The court concluded that an in camera inspection should be conducted before ordering even limited disclosure of treatment records that are privileged under federal law. The petition was granted, and the court ordered to vacate the discovery order and remand for further proceedings.

Statutes

Disclosure

N.D. CENT. CODE § 23-16-09 (2001): In the case of hospitals and related institutions providing maternity care, no agent of the state department of health or of any board of health, nor the licensee under the provisions of this chapter, may disclose the contents of case records of such institution except in a judicial proceeding, to certain health or social agencies, or to persons who have a direct impact on the well being of the patient or her infant.

Ohio

Case Law

McCleary v. Roberts, 725 N.E.2d 1144 (Ohio 2000): The court held that names, addresses, phone numbers, family information, and medical records of children in a city's database are exempt from public disclosure under the state Public Records Act because they do not meet the definition of "records."

Biddle v. Warren Gen. Hosp., 715 N.E.2d 518 (Ohio 1999): The court found that in Ohio, an independent tort exists for the unauthorized, unprivileged disclosure to a third party of non-public medical information that a hospital or physician learns within the physician-patient relationship. The court also noted a common law duty of disclosure of information concerning public health or safety to third persons and other situations where certain countervailing interests outweigh the patient's interest in confidentiality. Finally, the court held that a consent to the release of medical information must be fairly specific in terms of to whom the disclosure is made.

Levias v. United Airlines, 500 N.E.2d 370 (Ohio Ct. App. 1985): A flight attendant brought an action against her employer airline claiming an invasion of privacy for the disclosure of confidential medical data. The evidence showed that she had directed her physician to supply the airline's medical examiner with certain confidential medical information. The examiner used this information to authorize a waiver of weight limits imposed on certain employees. The examiner

released the information to the flight supervisor who then repeatedly contacted the plaintiff to discuss her medical condition with her. The court held that the employer and its examiner could be liable for unauthorized disclosure of medical records because the persons to whom it was disclosed had no "need to know" it.

Thompson v. Eiler, No. C-990634, 2000 Ohio App. LEXIS 2895 (Ohio Ct. App. June 30, 2000): A worker who files a worker's compensation claim waives her physician-patient privilege and allows for the release of medical records.

Peeples v. Department of Corrections, No. 95API03-337, 1995 Ohio App. LEXIS 4491 (Ohio Ct. App. Oct. 12, 1995): Where an inmate fails to file a request for his medical records jointly with his attorney or physician, Ohio law states that such a request may be denied.

Ebsch v. Tanpnaichitr, 611 N.E.2d 430 (Ohio Ct. App. 1992): Where a doctor refused to release medical records of a patient without first receiving payment for his medical services, there was no violation of law because there was no legal duty under Ohio statute or common law to transfer, upon request, the medical records of a patient, and that there was no evidence of damages resulting from the delay in the release of the information.

Statutes

Access

OHIO REV. CODE ANN. § 1347.08 (Anderson 2001): A state or local agency that maintains health information about an individual must let the individual know about the existence of that information, allow the person to inspect those records, and inform the person about the uses of the information. The information shall not be disclosed to the person if a physician, psychiatrist, or psychologist determines that disclosure will have an adverse effect on the individual.

OHIO REV. CODE ANN. § 3701.74 (Anderson 2001): Within a reasonable amount of time after receiving a written request from a former patient, a hospital must provide patient access to, or a copy of, her hospital records. If the physician determines that such disclosure would have an adverse effect on the patient, the hospital must provide the record to a physician designated by the patient. If the hospital fails to furnish the requested records, the patient may bring a civil action to enforce her right of access.

OHIO REV. CODE ANN. § 4113.23 (Anderson 2001): No employer or physician, other than a provider that contracts with the employer to provide medical information pertaining to employees, shall refuse upon written request of an employee to furnish to the employee or their designated representative a copy of any medical report pertaining to the employee.

OHIO REV. CODE ANN. § 5119.61 (Anderson 2001): The recipient of services provided through local boards of alcohol, drug addiction, and mental health services has the right to access his own medical and mental health records unless

access is restricted for clear treatment reasons.

OHIO REV. CODE ANN. § 5120.21 (Anderson 2001): An inmate may obtain a copy of his or her medical record if he or she signs a written request together with a written request of an attorney or licensed physician. Such a record will be made available to the physician or attorney. A reasonable fee may be charged for copying. If the physician concludes that revealing the medical record to the inmate will result in medical harm to the inmate, such disclosure shall be withheld. The records shall be made available to an attorney or physician not more than once in every twelve months.

OHIO REV. CODE ANN. § 5122.31 (Anderson 2001): A mental health patient who has been institutionalized pursuant to a court order has a right to access his own psychiatric and medical records unless access is specifically restricted in a patient's treatment plan for treatment-related reasons.

Disclosure

OHIO REV. CODE ANN. § 149.43 (Anderson 2001): Medical records maintained by any public office are specifically excluded from the definition of "public records" that must be made available to the public under the state's open records law.

OHIO REV. CODE ANN. § 2305.24 (Anderson 2001): Records and information made available to a hospital's quality assurance or utilization review committee retain their confidentiality and may be used by members of the committee only in the exercise of their functions as members of the committee.

OKLAHOMA

Case Law

Bettis v. Brown, 819 P.2d 1381 (Okla. Ct. App. 1991): A private right of action was available for a dentist's breach of the statutory duty to provide the requested medical records to a patient pursuant to OKLA. STAT. tit. 76, §§ 19-20, which governs health care providers in general.

McFeely v. Tredway, 816 P.2d 575 (Okla. Ct. App. 1990): OKLA. STAT. tit. 76, § 19, providing that any patient of a doctor, hospital, or other medical institution has a right to access information contained in his or her medical records upon request, does not provide any implied private right of action against attorneys of doctors, hospitals, or other medical institutions when records are not so provided.

Statutes

Access

OKLA. STAT. tit. 36, §§ 6804(A), (D), (E) (2001): Prior to the delivery of health care via telemedicine, the health care practitioner who is in physical

contact with the patient shall have the ultimate authority over the care of the patient and shall obtain informed consent from the patient. The informed consent shall include a statement that (1) all existing confidentiality protections apply; (2) patient access to all medical information transmitted during a telemedicine interaction is guaranteed, and that copies of this information are available at stated costs, which shall not exceed the direct cost of providing the copies; and (3) a statement that dissemination to researchers or other entities or persons external to the patient-practitioner relationship of any patient-identifiable images or other patient-identifiable information from the telemedicine interaction shall not occur without the written consent of the patient.

OKLA. STAT. tit. 76, § 19(A) (2001): Any person who is or has been a patient of a doctor, hospital, or other medical institution has a right upon request to access information contained in his or her medical records, including any x-ray or other photograph or image. A patient shall receive copies of all records upon request and upon tender of the expense of the copies. The cost of each copy, not including any x-ray or other photograph or image, shall not exceed \$0.25 per page. The cost of each x-ray or other photograph or image shall not exceed \$5.00 or the actual cost of reproduction, whichever is less. Physician, hospitals, or other medical professionals and institutions may charge for the actual cost of mailing the requested medical records, but may not charge a fee for searching, retrieving, reviewing, and preparing medical records. In the case of psychological or psychiatric records, a patient shall not be entitled to copies unless access to the records is consented to by the treating physician or practitioner or is ordered by a court of competent jurisdiction upon a finding that it is in the best interests of the patient. However, the patient may be provided access to information contained in the records, as provided in OKLA. STAT. tit. 43A, § 1-109 (2001), which specifically addresses mental health records and communications. A patient or his or her guardian may authorize the release of the psychiatric or psychological records to the patient's attorney, a third-party payer, or a governmental entity. The execution of an authorization shall not be construed to authorize the patient personal access to the records or information.

OKLA. STAT. tit. 76, § 20 (2001): Any person refusing to furnish records required is guilty of a misdemeanor.

OREGON

Case Law

In re Compensation of Coman, 960 P.2d 383 (Or. 1998): The court acknowledged that the medical records of inmates are confidential under Oregon law, but that they should have been disclosed here where a worker at the prison needed those records to show that he had contracted tuberculosis while working

at the prison facility.

Calley v. Olsen, 532 P.2d 230 (Or. 1975): The beneficiary under a life insurance policy sought disclosure of the medical records of the deceased in an attempt to determine what caused his death. The court, interpreting Oregon statutory law, found that the beneficiary had the right to waive any doctor-patient privilege in order to take, by deposition, the testimony of the treating doctor, but that this terminated the privilege. The court also held that once a patient has waived his privilege as to one doctor, he cannot then exclude the testimony of other doctors.

Nielson v. Bryson, 477 P.2d 714 (Or. 1970): The plaintiff in a personal injury case argued that his medical records should not be disclosed and that such disclosure would violate Oregon law. The court agreed that there was no express or implied consent to release that information and that since such release was not specifically provided for in the statute, the release was not permissible. The court held that such statutes were not unconstitutional under Oregon law.

In re Mershon, 772 P.2d 440 (Or. Ct. App. 1989): The Workers Compensation Board may force a claimant to disclose medical information related to his own claim in its evaluation process.

Statutes

Access

ORE. REV. STAT. § 179.505 (1999): Copies of medical records can be released to the patient within five days of a request. Disclosure may be denied when it is determined that such disclosure would result in the grave detriment to the treatment of the patient. Also, psychiatric information may be withheld by the Department of Corrections in certain situations with any such denials being documented and placed in the patient's records. The provider may be reimbursed by the patient for reasonable costs associated with producing the documents upon the patient's request.

ORE. REV. STAT. § 192.525 (1999): A health care provider must disclose a patient's medical records upon the receipt of a medical release. Any records withheld must be identified as being withheld. Records that are injurious to the patient may be held back as long as the patient is notified that certain records are not being disclosed for this reason. The provider may charge a reasonable fee for producing the records.

Disclosure

ORE. REV. STAT. § 109.650 (1999): A hospital or physician may advise a parent or legal guardian of a patient of the care, diagnosis, treatment, or need for treatment, without the consent of the patient and the doctor. The hospital or physician will not be liable for advising the parents or legal guardians of the minor without his or her consent.

ORE. REV. STAT. § 109.680 (1999): A physician, psychologist, or nurse practitioner may advise the parents or legal guardians of a minor of diagnosis or treatment whenever the disclosure is clinically appropriate and will serve the best interests of the minor's treatment because the minor's condition has deteriorated or the risk of suicide has become such that inpatient treatment is necessary, or the minor requires detoxification treatment. No liability shall attach to such disclosures.

ORE. REV. STAT. § 179.505 (1999): Medical records, such as case histories, clinical records, x-rays, treatment charts, and other forms of patient medical information maintained by a health care provider shall not be subject to inspection. The records may be released if there is informed consent on the part of the patient or a legal guardian in writing directing that such records may be released. Such records may be released without consent to any person (1) to the extent that there is a medical emergency; (2) at the discretion of the responsible officer of the provider, or to persons engaged in scientific research, program evaluation, peer review, and fiscal results; and (3) to governmental agencies when necessary to secure compensation for services rendered to the patient. When the identity of the individual is disclosed, the provider shall prepare a record of such and put it into the patient's permanent records. Records may also be disclosed to certain agencies when there has been a claim of constitutionally inadequate medical care. If any information obtained by the provider is deemed to reveal a clear and immediate danger to others, such information may be reported to appropriate authorities. The prohibitions against disclosure of medical records apply irrespective of whether the patient is still being treated by a given provider. Anyone who is given access to the medical records may not disclose the information to anyone else.

ORE. REV. STAT. § 192.502 (1999): Information of a personal nature such as that kept in a medical file that is maintained by a government agency is generally exempt from public inspection if the disclosure of the information would constitute an unreasonable invasion of privacy, unless the public interest, by clear and convincing evidence, requires disclosure.

ORE. REV. STAT. § 332.061 (1999): Any school board hearing at which the medical records of a student are discussed shall be conducted in a private session.

PENNSYLVANIA

Case Law

Commonwealth v. Moore, 584 A.2d 936 (Pa. 1991): The district attorney petitioned for access to the health department's medical records of a man charged with rape, statutory rape, indecent assault, and corruption of minors. The medical records contained information on treatment of gonorrhea, which occurred prior

to being charged with sexual misconduct offenses. The superior court granted the district attorney's petition for access to confidential information regarding whether the accused received treatment for gonorrhea, but the supreme court reversed.

Department of Military & Veteran Affairs v. Civil Serv. Comm'n, 719 A.2d 1134 (Pa. Commw. Ct. 1998): The court found that a civil service physician was removed without just cause from employment for his disclosure of confidential medical records to his attorneys for the purposes of an agency investigation because the disclosure did not negatively touch upon his competency or job performance.

Hunt v. Pennsylvania Dep't of Corrections, 698 A.2d 147 (Pa. Commw. Ct. 1997): Medical and mental health records of a deceased prisoner were not public records subject to disclosure under Pennsylvania's Right-to-Know Act because protection from disclosure under statute does not end with the deceased's death.

Arbster v. Unemployment Compensation Bd. of Review, 690 A.2d 805 (Pa. Commw. Ct. 1997): The claimant was properly denied unemployment benefits because her willful violation of her employer's policy against unauthorized access to computerized medical records constituted willful misconduct.

Doe v. Workmen's Compensation Appeal Bd., 653 A.2d 715 (Pa. Commw. Ct. 1995): Petitioner filed a claim for workmen's compensation benefits against his employer for alleged clinical and situational depression. The court affirmed the Workmen's Compensation Appeal Board's decision that dismissed petitioner's complaint on the ground that he refused to disclose medical information regarding his status as HIV positive to his employer in its defense of his claim. The court held that medical information could be disclosed in civil matters brought by a patient for damages on account of personal injuries. Where a party places his physical or mental condition in issue, the privacy right against disclosing private medical information was waived.

Rost v. State Bd. of Psychology, 659 A.2d 626 (Pa. Commw. Ct. 1995): The State Board of Psychology's order that reprimanded a psychologist for releasing client records pursuant to a subpoena was proper, as her ethical duty of confidentiality required that she first seek the client's consent or professional legal advice.

MacMillen v. Lock Haven Hosp., 548 A.2d 706 (Pa. Commw. Ct. 1988): The city could not be held liable for the former police chief's actions violating a police officer's privacy in obtaining the officer's confidential hospital records simply on the basis of vicarious liability or respondeat superior.

Statutes

Access

42 PA. CONS. STAT. § 6155 (2001): A patient or his designee, including his attorney, has the right to access and copy his medical records maintained by a health care provider or a health care facility without the use of a subpoena.

Disclosure

35 PA. CONS. STAT. § 449.10 (2001): The Health Care Containment Council, charged with the collection of health data for the purposes of developing competitive health care services at low cost, shall not release any data, and no entity or person shall be allowed to gain access to any of the council's raw data that could reasonably be expected to reveal the identity of the individual patient. A person who knowingly releases council data to an unauthorized person violates the patient's confidentiality and is guilty of a misdemeanor punishable by fine, imprisonment, or both. An unauthorized person who knowingly receives or possesses such data is guilty of a misdemeanor.

50 PA. CONS. STAT. §§ 7103, 7111 (2001): Documents concerning patients receiving inpatient mental health treatment and those receiving involuntary outpatient treatment are confidential and may not be released without the patient's consent except in very limited circumstances.

63 PA. CONS. STAT. § 12(b) (2001): Under the Medical Practice Act of 1985 concerning subpoena power, medical records may not be subpoenaed without the consent of the patient or without order of a court of competent jurisdiction. The court must indicate that the records are reasonably necessary for the investigation. The court may also place limitations on the subpoenas to prevent unnecessary intrusion into a patient's confidential information.

RHODE ISLAND

Case Law

Fiore v. Lynch, 637 A.2d 1052 (R.I. 1994): It was not an error to order that medical records be delivered to an employee retirement investigation committee in redacted form because the plaintiffs introduced their physical conditions in proceedings before the retirement board.

Trembley v. City of Cent. Falls, 480 A.2d 1359 (R.I. 1984): Confidential medical information does not include a medical report that a patient directly procures from his own physician and personally delivers to a third-party employer.

In re Bd. of Med. Review Investigation, 463 A.2d 1373 (R.I. 1983): Physician's records of patient treatment may be subpoenaed during the investigative stages of a board of medical review inquiry into alleged unprofessional conduct.

State v. Anthony, 440 A.2d 736 (R.I. 1982): Disclosure of the records of the department for children and their families is not prohibited in cases of known or suspected child abuse.

*Statutes**Access*

R.I. GEN. LAWS § 5-37.5-5 (2001): A patient has the right to request review and

revision of his confidential health care information in the possession of a third party when the third party has taken an adverse action based on that information. The patient does not have the right to review the records himself and must, instead, designate a physician to review them. The third party may require the patient to pay the third party for the actual costs incurred by the third party. The physician may disclose to the patient as much of the information as he deems appropriate. There are certain procedures whereby the patient may request that the third party amend or expunge any part of the record that he believes to be in error. If there is an unreasonable refusal to change the records, the patient has the right to apply to the district court to amend or expunge any part of his confidential health care information that he believes to be erroneous.

R.I. GEN. LAWS § 5-37-22 (2001): Upon written request, a physician must permit a patient to examine and copy the patient's confidential health care information or provide him a summary of the information, at the physician's option. The patient may be required to pay reasonable expenses incurred in connection with copying at the time the information is provided. If the patient is not satisfied with the summary, he may request the full record and such full record must be provided. Access may be denied if the physician believes that it would be injurious to the mental or physical health of the patient to disclose or provide information. In such a circumstance, the physician must provide the information to another physician designated by the patient.

R.I. GEN. LAWS § 5-37-25 (2001): A physician who does not comply with the rules for access to patient medical records is subject to fine, imprisonment, or both.

Disclosure

R.I. GEN. LAWS § 5-37.3-4 (2001): A patient's confidential health care information shall not be released or transferred without written consent of the patient. Information can be provided to the department of health in certain circumstances so that it may carry out its function. Violations of the confidentiality mandate subject the violators to actual and punitive damages, with an award of attorney's fees and capping the punishment at \$5,000 and six months in jail for each violation. No consent is necessary where the information is, for example, necessary for the treatment of the individual in a medical emergency; for the release to peer review and other professional boards; or for the release to personnel conducting research, management audits, financial audits, program evaluations, and the like.

R.I. GEN. LAWS § 23-17-19.1 (2001): Government agencies that license health care facilities may not disclose patient identifying information received through filed reports and inspections except in a proceeding involving the question of licensure.

R.I. GEN. LAWS § 40.1-5-26 (2001): Mental health records are confidential and

such records shall only be disclosed in limited circumstances without the consent of the patient.

SOUTH CAROLINA

Case Law

Brown v. Bi-Lo, Inc. 535 S.E.2d 445 (S.C. Ct. App. 2000): The court held that a physician does not breach the duty of confidentiality by providing an employer or the employer's representatives with medical information relevant to workers' compensation cases.

McCormick v. England, 494 S.E.2d 431 (S.C. Ct. App. 1997): The plaintiff claimed that her physician, who was treating both her and her husband, violated patient-physician confidentiality by revealing her mental health problems to her husband during divorce proceedings absent a court order. The court held that South Carolina would henceforth recognize a common law tort for breach of a physician's duty of confidentiality.

Doe v. North Greenville Hosp., 458 S.E.2d 439 (S.C. Ct. App. 1995): The plaintiff sued the defendant hospital for releasing the plaintiff's records to his insurer, which in turn disclosed information to the plaintiff's wife. The court held that the hospital, which initially released the plaintiff's records for reimbursement purposes, could not be held liable for the insurer's subsequent disclosure.

Statutes

Access

S.C. CODE ANN. § 42-15-95 (Law. Co-op. 2001): All existing information compiled by a health care facility or a health care provider pertaining directly to a workers' compensation claim must be provided to the insurance carrier, the employer, the employee, their attorneys, or the Workers' Compensation Commission within fourteen days after receipt of a written request.

S.C. CODE ANN. § 44-22-110 (Law. Co-op. 2001): A mental health patient or his or her guardian has access to the patient's medical records. Patients or guardians may be refused access to information provided by a third party under assurance that the information remains confidential and information determined by the attending physician to be detrimental to the patient's treatment regimen. The determination must be placed in the patient's records and must be considered part of the restricted information. Patients and guardians denied of access may appeal to the Director of the Department of Mental Health. The director of the residential program shall notify a patient or guardian of the right to appeal.

S.C. CODE ANN. § 44-115-30 (Law. Co-op. 2001): A patient or his or her legal representative has a right to receive a copy of the patient's medical record or have

the record transferred to another physician upon written request by the patient or representative.

S.C. CODE ANN. § 44-115-60 (Law. Co-op. 2001): Except as otherwise provided by law, a physician may refuse to release a copy of a patient's entire medical record and may furnish instead a summary or portion of the record when the physician has a reasonable belief that release of the information contained in the entire record would harm the patient or another person who has given information about the patient, or where the release is otherwise prohibited by law. However, a physician may not refuse to release the entire record or a portion thereof if the information is requested by a licensed attorney representing the patient, when the request is accompanied by a written authorization signed by the patient, the patient's legal guardian, or the patient's personal representative, for any reason, or by an insurance company with reference to an application for life or health insurance, or the payment and adjudication of claims relating to life and health insurance, or if the information is requested with reference to the payment or adjudication of personal injury claims.

S.C. CODE ANN. § 44-115-70 (Law. Co-op. 2001): Medical records may not be withheld because of an unpaid bill for medical services.

25 S.C. CODE ANN. REGS. 67-1301(A) (2001): A medical practitioner or treatment facility shall furnish upon request all medical information relevant to an employee's complaint of injury to the claimant, the employer, the employer's representative, or the Workers' Compensation Commission.

Disclosure

S.C. CODE ANN. § 44-115-20 (Law. Co-op. 2001): A physician is the owner of medical records in his or her possession that were made in treating a patient and of records transferred to him or her concerning prior treatment of a patient.

S.C. CODE ANN. § 44-115-40 (Law. Co-op. 2001): Except as otherwise provided by law, a physician shall not honor a request for the release of copies of medical records without receiving express written consent from a patient or person authorized by law to act on behalf of the patient.

S.C. CODE ANN. § 44-115-50 (Law. Co-op. 2001): A physician may rely on the representations of a health and life insurance carrier or administrator of health and life insurance claims that the authorization of a patient for release of medical records, or that of a person upon whose status the patient's claim depends, is on file with the carrier. A physician who in good faith releases medical information for claims processing relying on such representations is immune from any civil or criminal liability allegedly caused by the physician's compliance with a request to release information. A physician is not subject to disciplinary action for an alleged violation of law or regulation due to compliance with the request to release information.

S.C. CODE ANN. § 44-115-130 (Law. Co-op. 2001): A physician may not sell

medical records to someone other than a physician or osteopath licensed by the South Carolina State Board of Medical Examiners or a hospital licensed by the South Carolina Department of Health and Environmental Control. Exceptions to this prohibition may be granted and approved by the South Carolina State Board of Medical Examiners. Before a physician may sell medical records, he or she must cause to be published a public notice of his or her intention to sell the records in a newspaper of general circulation in his or her practice locale at least three times in the ninety days preceding sale. The notice shall advise patients that they may retrieve their records if they prefer that their records not be included in the sale.

S.C. CODE ANN. § 44-115-140 (Law. Co-op. 2001): A physician who in good faith releases medical records to a party pursuant to a written authorization from the patient or patient's representative is immune from civil or criminal liability allegedly caused by the physician's compliance with the request. A physician is not subject to disciplinary action for an alleged violation of law due to compliance with the request to release information.

SOUTH DAKOTA

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Access

S.D. CODIFIED LAWS § 27A-12-26.1 (Michie 2001): Upon request, patients have the right to access their mental health records. However, patients may be refused access to (1) information provided by a third party under assurance that such information remain confidential; and (2) specific material if the qualified mental health professional responsible for the mental health services concerned made a determination in writing that such access would be detrimental to the patient's health. However, such material may be disclosed to a similarly licensed, qualified mental health professional selected by the patient, and such professional may, in the exercise of professional judgment, provide the patient with access to any or all parts of such material or otherwise disclose the information.

S.D. CODIFIED LAWS § 34-12-15 (Michie 2001): A health care facility shall provide copies of all medical records, reports, and x-rays pertinent to the health of the patient, if available, to a discharged patient or the patient's designee upon receipt by the health care facility of a written request or a legible copy of a written request signed by the patient. The health care facility may require before delivery that the patient pay the actual reproduction and mailing expense. A health care facility, complying in good faith with the provisions of this section, may not be

held liable for any injury or damage proximately resulting from compliance with this section. This section does not apply to chemical dependency treatment facilities.

Disclosure

S.D. CODIFIED LAWS § 27A-12-25 (Michie 2001): A complete statistical and medical record shall be kept current for each patient receiving mental health services. The material in the record shall be confidential.

S.D. CODIFIED LAWS § 27A-12-29 (Michie 2001): Mental health information may be disclosed in the discretion of the holder of the record (1) as necessary or beneficial for a patient, or persons acting on behalf of the patient, to apply for patient benefits; (2) as necessary or beneficial for evaluation and accreditation; (3) as necessary or beneficial to train persons enrolled in an accredited course leading to a degree and qualification, certification, or registration as a qualified mental health professional, licensed practical nurse, registered nurse, psychologist, social worker, physical therapist, occupational therapist, laboratory technician, medical records professional, dietician, or other health care professional; or (4) upon request of the human services center, with disclosure of records limited to relevant medical and psychiatric records.

S.D. CODIFIED LAWS § 27A-12-30 (Michie 2001): Any release of information by the holder of a psychiatric patient's record shall be approved by the administrator or facility director holding the records. The record holder shall keep a record of any information released, to whom it was released, the date it was released, and the purpose for such release.

S.D. CODIFIED LAWS § 27A-12-31 (Michie 2001): If mental health information is disclosed, the patient's identity shall be protected and may not be disclosed unless it is germane to the authorized purpose for disclosure.

S.D. CODIFIED LAWS § 34-14-3 (Michie 2001): It is a Class 1 misdemeanor to disclose any information, records, reports, statements, notes, memoranda, or other data obtained for or contained in any medical study for the purpose of reducing morbidity or mortality, except that necessary for the purpose of the specific study.

TENNESSEE

Case Law

Pratt v. Smart Corp., 968 S.W.2d 868 (Tenn. Ct. App. 1997): A patient filed a class action case to recover a portion of the payment she had made to receive copies of her medical records claiming that under TENN. CODE ANN. § 68-11-301, the amount charged was unreasonable. The court held that the statute was intended to insure patient's access to their medical records and to protect them

from excessive charges. The case was remanded for further proceedings.

Statutes

Access

TENN. CODE ANN. § 63-2-101 (2001): A health care provider shall furnish to a patient or a patient's authorized representative a copy or summary of that patient's medical records within ten working days upon request in writing by the patient or such representative.

TENN. CODE ANN. § 68-11-304 (2001): Unless restricted by state or federal law or regulation, a hospital shall furnish to a patient or a patient's authorized representative such part or parts of such patient's hospital records without unreasonable delay upon request in writing by the patient or such representative. The party requesting the patient's records shall be responsible for the reasonable costs of copying and mailing the patient's records.

Disclosure

TENN. CODE ANN. § 10-7-504 (2001): The medical records of patients in state, county, and municipal hospitals and medical facilities, and of persons receiving medical treatment at the expense of the state, shall be treated as confidential and shall not be open to inspection by members of the public.

TENN. CODE ANN. § 33-3-104 (2001): Information about individuals receiving treatment or services for mental health problems or developmental disabilities are confidential. Such information may be disclosed only with the consent of a service recipient who is sixteen years of age or older; the conservator of a service recipient; the attorney in fact under a power of attorney of a service recipient; the parent or legal guardian of a service recipient who is a child; the service recipient's guardian ad litem, the treatment review committee for a service recipient who has been involuntarily committed; or the executor, administrator, or personal representative on behalf of a deceased service recipient. Disclosure without consent is permitted to carry out treatment or commitment of the individual upon court order, and for law enforcement purposes in very limited circumstances.

TENN. CODE ANN. § 63-1-117 (2001): Records of hospitals, laboratories, nursing homes, homes for the aged, ambulatory surgical treatment centers, home health agencies, home health services, and recuperation centers shall be made available for inspection and copying when requested by a duly authorized representative of the Division of Health Related Boards.

TENN. CODE ANN. § 63-2-101 (2001): Medical records are not public records and are confidential. Except for any statutorily required reporting to health or government authorities, and except for access by an interested third-party payer, the name, address, and other identifying information of a patient shall not be divulged, nor shall these be sold for any purpose.

TENN. CODE ANN. § 68-11-304 (2001): Hospital records are and shall remain

the property of the various hospitals, subject, however, to court order to produce them. Hospital records shall be made available when requested for inspection by a duly authorized representative of the Board or Department of Health. Except as otherwise provided by law, hospital records shall not constitute public records. Nothing in this section is intended to impair any privilege of confidentiality conferred by law on patients, their representatives, or their heirs.

TENN. CODE ANN. § 68-11-1502 (2001): Every patient entering and receiving care at a health care facility licensed by the board for licensing health care facilities shall have the expectation of and right to privacy for care received at such facility.

TENN. CODE ANN. § 68-11-1503 (2001): The name and address and other identifying information of a patient shall not be divulged except for any statutorily required reporting to health or government; access by an interested third-party payer or designee for the purpose of utilization review, case management, peer reviews, or other administrative functions; access by health care providers from whom the patient receives care; and, if the patient does not object, any directory information including only the name of the patient, the patient's general health status, and the patient's location and telephone number.

TEXAS

Case Law

Abrams v. Jones, 35 S.W.3d 620 (Tex. 2000): Because the minor daughter's psychologist testified that it would be harmful to her to release his detailed treatment notes, the trial court's order requiring him to release his notes to her father was reversed.

Vaughn v. Moulton, No. 14-95-01467-CV, 1997 Tex. App. LEXIS 1348 (Tex. App. Mar. 20, 1997): Because the disclosure of confidential medical records of a police officer by a police chief was not a discretionary act, but one prohibited by statute, the police chief was not entitled to summary judgment on the basis of official immunity.

Tobias v. Green Oaks Hosp., No. 05-95-01022-CV, 1996 Tex. App. LEXIS 3557 (Tex. App. Apr. 7, 1996): A hospital's release of medical records in response to a subpoena was valid, and the hospital was not required to investigate the validity of the subpoena or notify the appellant of the subpoena.

Moore v. Henry, 960 S.W.2d 82 (Tex. App. 1996): A prison medical records custodian had no mandatory duty under statutory law to comply with an inmate's medical record request, and therefore, the dismissal of the inmate's mandamus petition as frivolous was proper.

Beltway Cmty Hosp., Inc. v. Jones, No. B14-92-00881-CV, 1993 Tex. App. LEXIS 1687 (Tex. App. June 10, 1993): While in the care of the health corporation,

appellee patient suffered severe brain damage. The hospital was then sold to another health corporation. After the sale, the appellee brought an action requesting medical records from the purchasing corporation, which informed the appellee that the records were under review by the appellant and unavailable. After requesting records, the appellee received a set of records from both the purchasing corporation and the appellant. A comparison of the two sets revealed that pages were missing from the purchasing corporation's set, and a document dated the day of the injury had been altered to postdate the injury. The appellee requested and was granted a temporary injunction against the appellant. The court affirmed, holding that the evidence demonstrated the existence of a wrongful act, and that if further documents were lost or altered, the appellee would suffer irreparable harm. It was not error to enjoin the appellant rather than the purchasing corporation, because the appellant retained some control over the records, and was not responsible under the injunction if the purchasing corporation altered or destroyed records.

Cassingham v. Lutheran Sunburst Health Service, 748 S.W.2d 589 (Tex. App. 1988): Cassingham sued the hospital in question for allowing improper access to her medical records. Cassingham was involved in an assault, and had recently had her son abducted by her ex-husband. Her treating physician and psychiatrist recommended that she speak with someone from the non-profit group Missing and Exploited Children of Texas. The advocate from that group made notation in, and viewed, her medical records. The court ruled that the hospital acted in error.

Statutes

Access

TEX. HEALTH & SAFETY CODE ANN. § 241.152 (Vernon 2000): A hospital may only disclose health information to a patient or his or her authorized legal representative unless the hospital has written permission from the patient to do otherwise. The permission is valid for up to 180 days after it is given, and may be revoked by the patient or their authorized legal representative.

TEX. HEALTH & SAFETY CODE ANN. § 241.154 (Vernon 2000): A patient must be given access to and a copy of his hospital records within fifteen days after he has submitted a written authorization for disclosure and payment of a reasonable fee for retrieval of processing, copying, and mailing. The fees for retrieving, processing, copying, and mailing are specified by statute. However, a hospital may not charge a fee for a patient to examine his own health care information.

TEX. HEALTH & SAFETY CODE ANN. §§ 611.001, 611.008, 611.0045 (Vernon 2000): A person who consults a professional for diagnosis, evaluation, or treatment of any mental or emotional condition or disorder, including alcoholism or drug addiction, is entitled to have access to the content of the records made about him. Access to these records must be provided within a reasonable time and may charge

a reasonable fee. Access to a portion of the records may be denied if the professional determines that the release of that portion would be harmful to the patient. If so, the patient must be notified of such decision and a professional designated by the patient may then examine and copy the record.

TEX. HEALTH & SAFETY CODE ANN. § 611.005 (Vernon 2000): A patient who has been improperly denied access to his mental health records has the right to bring a civil action seeking injunctive relief and damages.

Disclosure

TEX. HEALTH & SAFETY CODE ANN. § 241.153 (Vernon 2000): Hospitals may disclose information without the patient's consent under a few select circumstances and/or to the following individuals: general directory information (unless the patient requests otherwise); a health care provider who is rendering care or being asked to render care or is being consulted (as in the case of a specialist); the transporting emergency medical services provider solely for the purpose of determining the patients disposition; a member of the clergy specified by the patient; an organ or tissue procurement organization for the purpose of inquiring about donation; an employee or agent of the hospital who is going to use the information for education or peer review; the American Red Cross and poison control centers as identified by law; for participation in an approved research project; to facilitate reimbursement; or to a HMO as required by federal law.

TEX. REV CIV. STAT. ANN. art. 4495, §5.08 (Vernon 2000): Patient medical records may not be disclosed without the written consent of a patient. A physician must furnish to a patient copies of medical records requested, or if he prefers, a summary of the record upon receipt of the patient's written consent for the release. The statute specifies what should be contained in the written authorization and how the physician should reply.

UTAH

Case Law

No court cases strictly dealing with access or disclosure of medical records were found.

Statutes

Access

UTAH CODE ANN. § 63-2-202 (2001): A governmental entity upon request can disclose a private record to the subject of the record, the parent or guardian of a minor who is the subject of the record, or the legal guardian of a legally incapacitated individual who is the subject of the record. In addition, an individual who has the power of attorney from the subject of the record, or an individual who

has a notarized release from the subject or legal representative that is not more than ninety days old, may also access the medical record.

UTAH CODE ANN. § 78-25-25 (2001): When an attorney of law is representing the interest of a patient, records in the custody of the hospital or health care provider shall be made available to him for examination and copying. The attorney must be authorized to do so by the patient, the guardian of the patient, or the personal representative of a deceased patient.

Disclosure

UTAH CODE ANN. § 26-25-1 (2001): A person, health facility, or organization may provide information from vital records, interviews, reports, statements, memoranda, or other data relating to the condition or treatment of a person if the information is being provided to the department and local health departments, the Division of Mental Health within the Department of Human Services, the scientific and health care research organizations affiliated with institutions of higher education, the Utah Medical Association, peer and professional review committees, professional societies and organizations, or a health facility's in-house staff. This information can be provided only for studies that are researching the reduction of mortality and morbidity and for the evaluation and improvement of health care.

UTAH CODE ANN. § 63-2-302 (2001): Records that contain data on an individual's medical history, diagnosis, condition, treatment, evaluation, or other similar medical history is considered to be a private record and not a public record.

VERMONT

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Access

VT. STAT. ANN. tit. 18, § 1852(7) (2001): All communications and records pertaining to a patient's care are confidential. Only medical personnel, or individuals under the supervision of medical personnel, directly treating the patient, or those persons monitoring the quality of that treatment, or researching the effectiveness of that treatment, shall have access to the patient's medical records. Others may have access to those records only with the patient's written authorization.

VT. STAT. ANN. tit. 18, § 9419 (2001): A records custodian may impose a

charge that is no more than a flat \$5.00 fee or no more than \$0.50 per page, whichever is greater, for providing copies of a patient's health care record. Health care records include all written and recorded health care information about a patient maintained by a custodian. A custodian may charge a fee, reasonably related to the associated costs, for providing copies of x-rays, films, models, disks, tapes, or other health care record information maintained in other formats.

VIRGINIA

Case Law

Fairfax Hosp. Sys., Inc. v. Curtis, 492 S.E.2d 642 (Va. 1997): The patient received prenatal care and gave birth to a son, who later died, at the hospital. The patient, as administrator of the estate, filed a notice of claim against the hospital and a nurse in the neonatal intensive care unit. The hospital provided her personal medical records to a nurse without her permission. The court held that the hospital owed a duty of reasonable care to the patient to preserve the confidentiality of information.

Pierce v. Caday, 422 S.E.2d 371 (Va. 1992): The physician was consulted regarding stress as a result of sexual harassment by another doctor at the hospital where the patient worked. One of the physician's employees disclosed the patient's confidential information to other workers at the hospital. The patient filed a motion for judgment against the physician for breach of contract. The physician filed a motion to dismiss on the basis that he was not given notice of the claim prior to the suit, and the motion failed to state a cause of action. The trial court dismissed the patient's action. The court affirmed because the patient's claim was one in tort not contract and the patient failed to give notice prior to filing suit as required by the Virginia Medical Malpractice Act.

Mansoor v. Favret, No. 00A84, 2001 Va. Cir. LEXIS 286 (Va. Cir. June 13, 2001): Defendant physician acted willfully or arbitrarily in failing to provide the medical records in question to the plaintiff in a timely manner. The doctor's failure to respond for nearly thirty-eight days to the initial request and twenty-three days to the second request violated the Virginia statute.

Green v. Richmond Dep't of Soc. Servs., 547 S.E.2d 548 (Va. App. 2001): The father, who was incarcerated and coming up for parole, petitioned the court for access to his daughter's medical, hospital, and other health records. This request was denied by the district court. The appeals court affirmed the denial because the daughter's therapist presented persuasive testimony that the father's access to the records would impair treatment his daughter was receiving.

S.R. v. INOVA Health Care Serv., No. 174290, 1999 Va. Cir. LEXIS 287 (Va. Cir. June 1, 1999): The plaintiff filed an amended motion for judgment claiming injury arising from various acts alleged to constitute invasions of plaintiff's privacy

when she sought treatment away from hospital co-workers. The plaintiff's claim was found cognizable for unauthorized disclosure of private patient information because plaintiff's medical condition was discussed without her consent.

Statutes

Access

VA. CODE ANN. § 2.2-3705 (Michie 2001): Medical and mental records may be personally reviewed by the subject of the record or a physician of that individual's choice. However, an individual may not personally review his or her mental health records if the treating physician has made a written statement that review of such records by the individual would be injurious to the person's physical or mental health or well being. The medical records of a person confined in a state or local correctional facility shall only be reviewed and shall not be copied by such administrator or chief medical officer. The information in the medical records of a person so confined shall continue to be confidential and shall not be disclosed by the administrator or chief medical officer of the facility to any person except the subject or except as provided by law.

VA. CODE ANN. § 20-124.6 (Michie 2001): Notwithstanding any other provision of law, neither parent, regardless of whether such parent has custody, shall be denied access to the academic, medical, hospital, or other health records of that parent's minor child unless otherwise ordered by the court for good cause.

VA. CODE ANN. § 32.1-40 (Michie 2001): Every practitioner of the healing arts and every person in charge of any medical care facility shall permit the Commissioner or his designee to examine and review any medical records that he has in his possession or to which he has access upon request of the Commissioner or his designee in the course of investigation, research or studies of diseases or deaths of public health importance. No such practitioner or person shall be liable in any action at law for permitting such examination and review.

VA. CODE ANN. § 32.1-138.13 (Michie 2001): Private review agents who have been granted a certificate of registration by the department shall have reasonable access to patient-specific medical records and information to the extent and in the manner authorized by regulation.

Disclosure

VA. CODE ANN. § 32.1-127.1:03 (Michie 2001): Patients have a right to privacy in the content of their medical records. No provider, or other person working in a health care setting, may disclose the records of a patient. Patient records shall not be removed from the premises where they are maintained without the approval of the provider, except in accordance with a court order, subpoena, or in accordance with the regulations relating to change of ownership of patient records promulgated by a health regulatory board. No person to whom disclosure of patient records was made by a patient or a provider shall redisclose or otherwise

reveal the records of a patient, beyond the purpose for which such disclosure was made, without first obtaining the patient's specific consent to such redisclosure.

VA. CODE ANN. § 54.1-2403.3 (Michie 2001): Medical records maintained by any health care provider as defined in § 32.1-127.1:03 shall be the property of such health care provider or, in the case of a health care provider employed by another health care provider, the property of the employer. Such health care provider shall release copies of any such medical records in compliance with § 32.1-127.1:03 or § 8.01-413, if the request is made for purposes of litigation, or as otherwise provided by state or federal law.

WASHINGTON

Case Law

Berger v. Sonneland, 26 P.3d 257 (Wash. 2001): The court found that there was a cause of action against a physician for unauthorized disclosure of a patient's confidential information to the patient's former husband.

Oliver v. Harborview Med. Ctr., 618 P.2d 76 (Wash. 1980): The court held that the medical records at a public hospital are public records, and that a patient's public hospital medical records are "public records" under the Public Disclosure Act.

Statutes

Access

WASH. REV. CODE § 70.02.005 (2001): To enable patients to make informed decisions about their health care and correct inaccurate or incomplete information about themselves, patients need access to their own health care information.

WASH. REV. CODE § 70.02.080 (2001): When a written request from a patient is received, a health care provider has to make recorded health information available during business hours and provide a copy if requested. The health care provider may charge a reasonable fee for providing the requested information.

Disclosure

WASH. REV. CODE § 42.17.310 (2001): Personal information in any files maintained for patients or clients of public institutions or public health agencies, or welfare recipients are exempt from public inspection and copying.

WASH. REV. CODE § 70.02.020 (2001): A health care provider may not disclose health care information about a patient to any other person without the patient's written authorization.

WASH. REV. CODE § 70.02.040 (2001): At any time, a patient may revoke in writing a disclosure authorization to a health care provider.

WASH. REV. CODE § 70.02.050 (2001): A health care provider may disclose health care information about a patient without the patient's authorization to the extent a recipient needs to know the information.

WASH. REV. CODE § 71.05.390 (2001): All information and records obtained, compiled, or maintained in the course of providing services to either voluntary or involuntary recipients of services at public or private agencies shall be confidential.

WASH. REV. CODE § 71.05.630 (2001): All treatment records will remain confidential. Disclosure will be limited to the portions of the records necessary to meet the medical emergency. Outside of health care professionals, treatment records may be released only to those designated in an informed written consent of the patient.

WEST VIRGINIA

Case Law

West Virginia Dep't of Health & Human Res. v. Clark, 543 S.E.2d (W. Va. 2000): Absent probable cause of abuse and neglect, a public agency did not have the right to review children's medical and school records, though they did have the right to interview the children.

West Virginia Advocates, Inc. v. Appalachian Cmty. Health Ctr., 447 S.E.2d 606 (W. Va. 1994): The court held that where a mentally disabled person's lawyer sought access to his medical records and such access was denied by such person's legal guardian, the granting of the mentally disabled person of a right to someone other than the guardian to access his records needed to be tested by the lower court to determine whether he was mentally capable of giving such authority.

Morris v. Consolidation Coal Co., 446 S.E.2d 648 (W. Va. 1994): When there is a worker's compensation claim, a physician may discuss the relevant medical information with the employer, but such a discussion must be limited to the injury itself and should not be an opening to discuss the worker's entire medical record. A patient has a cause of action for the breach of the duty of confidentiality against a physician who wrongfully divulges confidential information, and in certain circumstances, a patient has a cause of action against a third party that induces a physician to disclose confidential information.

Child Prot. Group v. Cline, 350 S.E.2d 541 (W. Va. 1986): After a school bus driver stopped a bus and lectured the school children on religion, the Child Protection Group sought the medical records of the bus driver. The court held that in deciding whether the public disclosure of medical information would constitute an unreasonable invasion of privacy, the court should adopt a five factor test: (1) whether disclosure would result in a substantial invasion of privacy and if so, how serious; (2) the extent or value of the public interest, and the purpose or object of the individuals seeking disclosure; (3) whether the information is

available from other sources; (4) whether the information was given with an expectation of confidentiality; and (5) whether it is possible to mould relief so as to limit the invasion of individual privacy.

Statutes

Access

W. VA. CODE § 16-29-1 (2001): Health care providers shall furnish patients copies of their medical records when asked to do so by the patient in writing subject to certain restrictions. These restrictions include denying parent's access to the medical records of their children when records might include evidence of services such as the provision of birth control pills; allowing for records to be subpoenaed; and exclusions relating to patients with HIV/AIDS.

W. VA. CODE § 16-29-1(a) (2001): In the case of records for psychiatric or psychological treatment, a summary of the record is to be made available to the patient or his authorized representative following termination of the treatment program. A reasonable fee may be charged unless the person is indigent and needs the records to support a claim or appeal under the Social Security Act. A patient may maintain a civil action to enforce these provisions, and if the health care provider is found to be in violation of the law, the patient may be awarded attorney's fees and costs incurred in the course of enforcement.

W. VA. CODE §§ 29B-1-3, 29B-1-4(2) (2001): A person has the right to inspect and copy his or her medical files maintained by a public body. Information is exempt from general disclosure if the public disclosure of the information would constitute an unreasonable invasion of privacy. If a person demonstrates that the public interest requires disclosure, such information may be disclosed.

W. VA. CODE §§ 29B-1-5, 29B-1-7 (2001): A person who is denied access to his medical records may maintain an action in equity for injunctive or declaratory relief and, if he prevails, is entitled to recover attorney's fees and court costs.

Disclosure

W. VA. CODE § 23-4-7 (2001): When an employee makes a filing for workers compensation, he or she is deemed to waive confidentiality as to the medical records generated in relation to the claim and therefore, the employer or its representative can contact the physician directly to discuss the worker's medical situation.

W. VA. CODE § 27-3-1 (2001): Communications and information obtained in the course of treatment and evaluation of a mental health patient will be confidential and may not be disclosed unless it is necessary to comply with a court order, to prevent the patient from injuring himself or another, or for treatment and internal review purposes.

W. VA. CODE § 27-3-2 (2001): Authorization for disclosure of confidential

information must be in writing, signed by the patient, and the patient must know that failure to provide authorization will not impact his right to obtain treatment.

W. VA. CODE § 27-5-9 (2001): Records of mentally ill patients shall be kept confidential and shall not be released unless they are ordered to be released by a court, the attorney of the patient requests them, or the patient or someone authorized to act on his behalf provides written authorization.

W. VA. CODE § 33-25A-26 (2001): Medical records obtained from a physician or a health maintenance organization shall be held confidential and shall not be disclosed except in limited situations, such as where it is necessary to facilitate the assessment of quality of care, when the enrollee consents to such disclosure, or pursuant to court order.

WISCONSIN

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Access

WISC. STAT. § 146.83 (2000): Upon receipt of informed consent, any patient may inspect his or her health care records held by a health care provider with reasonable notice and receive copies of those records at reasonable cost.

Disclosure

WISC. STAT. § 51.30 (2000): All records of an individual's treatment shall remain confidential and are privileged to the individual. Such records may only be released to the individual or other persons as designated by the informed written consent of the individual. Notwithstanding, treatment records may be released without informed written consent of the individual to the parents, children, or spouse of an individual who is or was a patient at an inpatient facility; to a law enforcement officer who is seeking to determine whether an individual is on unauthorized absence from the facility; and to mental health professionals who are providing treatment to the individual at the time that the information is released to others.

WISC. STAT. § 146.82 (2000): All patient health care records shall remain confidential and may only be released to the individual or other persons as designated by informed consent of the patient or of a person authorized by the patient. Notwithstanding this, patient health care records shall be released upon request without informed consent to a health care provider or any person acting under the supervision of a health care provider, including medical staff members,

employees, persons serving in training programs, or persons participating in volunteer programs.

WISC. STAT. § 905.04 (2000): A communication or information is "confidential" if it is not intended to be disclosed to third persons other than those present to further the interest of the patient in the consultation, examination, interview, diagnosis, or treatment of the patient, such as a physician, registered nurse, chiropractor, psychologist, social worker, marriage and family therapist, or professional counselor.

WYOMING

Case Law

No court cases dealing strictly with access or disclosure of medical records were found.

Statutes

Access

WYO. STAT. ANN. §§ 35-2-609(c),(d) (Michie 2001): The medical staff committees of any hospital shall have access to the records, data, and other information relating to the condition and treatment of patients. All reports, findings, proceedings, and data of medical staff committees shall be confidential and privileged.

WYO. STAT. ANN. §§ 35-2-611(a),(b) (Michie 2001): Upon receipt of a written request from a patient to examine or copy all or part of his or her health record, a hospital, as promptly as required under the circumstances, but no later than ten days after receiving the request shall (1) make the information available for examination during regular business hours and provide a copy, if requested, to the patient; (2) inform the patient if the information does not exist or cannot be found; (3) if the hospital does not maintain a record of the information, inform the patient and provide the name and address, if known, of the health care provider or facility that maintains the record; (4) if the information is in use, or unusual circumstances of delay occur in handling the request, inform the patient and specify in writing the reasons for delay and the earliest date, which shall not be later than twenty-one days after receiving the request, when the information will be available for examination or copying or when the request will be otherwise answered; or (5) deny the request, in whole or in part, under WYO. STAT. ANN. § 35-2-612 and so inform the patient. If a record of the particular health care information requested is not maintained by the hospital in the requested form, the hospital is not required to make the information available in the requested form. The hospital may charge a reasonable fee, not to exceed the hospital's actual cost, for providing the health care information and is not required to

permit examination or copying until the fee is paid.

WYO. STAT. ANN. §§ 35-2-612(a)-(c) (Michie 2001): A hospital may deny access to health care information by a patient if the hospital reasonably concludes that (1) knowledge of the health care information would pose an imminent threat to the life or safety of the patient; (2) knowledge could reasonably be expected to lead to the patient's identification of an individual who provided the information in confidence and under circumstances in which confidentiality was justified; (3) knowledge could reasonably be expected to pose an imminent threat to the life or safety of any individual; (4) the information is compiled and used solely for litigation, quality assurance, peer review, or administrative purposes; or (5) access to is otherwise prohibited by law. If a hospital denies a request, in whole or in part, because of danger to the patient or others, the hospital shall permit examination and copying of the record by a health care provider selected by the patient who is licensed, certified, or otherwise authorized by law to treat the patient.

Disclosure

WYO. STAT. ANN. §§ 25-10-122(a),(b) (Michie 2001): Records and reports that directly or indirectly identify a mental health patient, a former patient, or an individual for whom an application for hospitalization has been filed, shall be confidential and shall not be disclosed by any person unless the patient or, if he or she is a minor or incompetent, a parent or guardian consents. Patient records may be provided without consent by and between a mental health center, a state hospital, and other hospitals only for the purpose of facilitating referral treatment, admission, readmission, or transfer.

WYO. STAT. ANN. §§ 35-2-606(a),(b) (Michie 2001): Except as authorized in WYO. STAT. ANN. § 35-2-609, a hospital or an agent or employee of a hospital shall not disclose any health care information about a patient to any other person without the patient's written authorization. A hospital shall maintain, in conjunction with a patient's recorded health care information, a record of each person who has received or examined, in whole or in part, the recorded health care information during the preceding three years. The record of disclosure shall include the name, address, and institutional affiliation, if any, of each person receiving or examining the health care information, the date of receipt or examination, and, to the extent practicable, a description of the information disclosed.

WYO. STAT. ANN. §§ 35-2-607(a)-(c), (e)-(g) (Michie 2001): A patient may authorize a hospital to disclose his or her health care information. If requested, a hospital shall provide a copy of a patient's health record unless the hospital denies the patient access to health care information under WYO. STAT. ANN. § 35-2-612. A hospital may charge a reasonable fee not to exceed the hospital's actual cost for providing the health care information and is not required to honor an authorization until the fee is paid. To be valid, the authorization must be in

writing and dated and signed by the patient, identify the nature of the information to be disclosed, and identify the person to whom the information is to be disclosed. A hospital shall retain each authorization or revocation in conjunction with any health care information from which disclosures are made. Except for authorizations to provide information to third-party health care payors, an authorization shall not permit the release of information relating to future health care that the patient receives more than twelve months after the authorization is signed. An authorization is invalid after the expiration date contained in the authorization, which shall not exceed forty-eight months. If the authorization does not contain an expiration date, it expires twelve months after it is signed.

WYO. STAT. ANN. § 35-2-608 (Michie 2001): A patient may revoke an authorization to disclose health care information at any time unless disclosure is required to effectuate payments for health care that has been provided. A patient shall not maintain an action against the hospital for disclosures made in good faith reliance on an authorization if the hospital had no notice of the revocation of the authorization.

WYO. STAT. ANN. § 35-2-609(a) (Michie 2001): A hospital may disclose health care information about a patient without the patient's authorization to the extent that a recipient needs to know the information, if, among other things, the disclosure is (1) to a person providing health care to the patient; (2) to any other person who requires health care information for health care education, planning, quality assurance, peer review, or administrative, legal, financial, or actuarial services to the hospital, or to assist the hospital in the delivery of health care, and the hospital reasonably believes that the person will not use or disclose the information for any other purpose and will use reasonable care to protect the confidentiality of the information; or (3) to any health care provider who has previously provided health care to the patient to the extent necessary to provide health care to the patient, unless the patient has instructed the hospital not to make the disclosure.

Making a Place for Emotions in Medicine

Nancy R. Angoff, M.D., M.P.H., M.Ed.*

From Detached Concern to Empathy: Humanizing Medical Practice. By Jodi Halpern. Oxford: Oxford University Press, 2001. Pp. 188.

The practice of medicine is fraught with emotion. For patients, illness with its accompanying losses engenders fears, anxiety, anger, and suspicion. For physicians, there are many sources of emotion. Certainly the emergency room seethes with intensity with each trauma case, and in the operating room, tempers may flare or despair may reign if all does not go well. But even in the patient's room, physicians may find anger, hostility, sadness, or withdrawal. Yet physicians are taught to remain detached from participating in these emotions in order to maintain the objectivity thought to be crucial to accurate clinical decision-making.

In their often quoted essay entitled, *Training for 'Detached Concern' in Medical Students*, Renee Fox and Harold Lief discuss the successful acculturation and professional development of medical students as a journey to achieve what has been termed detached concern. It is a journey that exposes them to "emotion-laden" experiences, such as cutting into a cadaver for the first time. The student learns through objectifying and intellectualizing these experiences to distance himself from his initial pangs of anxiety and fear. This distancing, or detachment, when balanced with the appropriate amount of concern for the patient, has long been considered a recipe for empathy in the patient-physician relationship. As Fox and Lief note: "The empathic physician is sufficiently detached or objective in his attitude toward the patient to exercise sound medical judgment and keep his equanimity, yet he also has enough concern for the patient to give him sensitive, understanding care."¹

In her new book, *From Detached Concern to Empathy: Humanizing Medical Practice*,² Jodi Halpern presents a well-reasoned and philosophically grounded argument that moves us from comfortable acceptance of the ideal of clinical detachment towards an understanding of the therapeutic good of the use of emotions in medical practice to establish empathetic

* Nancy R. Angoff is Assistant Professor of Internal Medicine and Associate Dean for Student Affairs at the Yale University School of Medicine.

and healing clinical relationships. As Halpern points out, emotions are already present in the patient-physician relationship. We cannot deny that they are there even though physicians may be unaware of, or out of touch with, their emotions. But we can learn to recognize them and use them constructively in the service of empathy.

Halpern's concept of empathy is central to the development of her thesis. It is different from the dictionary definition or from what is frequently taught in medical schools. It is not a projection of one's personality onto another—it is not imagining oneself in another's shoes.³ Nor is it an intellectualized stance, or the opposite, sympathy, an over-identification with another's problems.⁴ Her view of clinical empathy is a process that requires the physician's awareness of her own affect, openness to being moved, curiosity about the patient's state, and ability to imagine how it feels for the patient to experience something. In achieving clinical empathy, the physician's own emotions are put to work. Halpern believes that:

[E]xperiencing emotion guides what one imagines about another's experience, and thus provides a direction and context for learning. ...[E]motions are not necessarily pre-programmed and static, but, rather, involve making new linkages. Here is where empathy depends upon specific properties of emotional reasoning—associative linking and moods that provide an organizing context.⁵

In Halpern's view, critical clinical decision-making and diagnosis depend not on emotional distance, but on emotional engagement that allows the physician to gain deeper understanding of, and insight into, the patient's experience of illness. In fact, clinical reasoning, the process whereby a physician applies medical evidence to the questions raised by the illness of a patient, depends as much on emotional reasoning utilizing empathy as on detached reasoning. As Halpern writes:

Empathy involves discerning aspects of a patient's emotional experiences that might otherwise go unrecognized. Empathic communication enables patients to talk about stigmatized issues that relate to their health that might otherwise never be disclosed, thus leading to a fuller understanding of patients' illness experiences, health habits, psychological needs, and social situations.⁶

Halpern received her medical and doctoral degrees from Yale University in 1989 and then completed training in psychiatry. Her dissertation in philosophy was entitled, *Beyond "Detached Concern": The Cognitive and Ethical Function of Emotions in Medical Practice*. In 1993 she

extended her thinking in an essay entitled, *Empathy: Using Resonance Emotions in the Service of Curiosity*.⁷ Her new book draws on these previous two works and expands her thesis.

Some of us have waited a long time for this book. Halpern shatters dogma and provides clarity that helps explain our confusion about “how to do” detached concern, a concept that does not ring true to our medical lives. She cites William Osler’s influence on physicians in this regard:

He believed that physicians needed sensitivity to patients’ emotional problems, yet he believed that practicing medicine required overarching detachment. His solution to these conflicting demands was to theorize that by neutralizing his own emotions, a physician could achieve special insight, that by not being moved or influenced emotionally by the patient, the physician could more precisely influence the patient therapeutically.⁸

Many medical students and physicians in training and practice today find that they have difficulty “neutralizing” their own emotions, and, in fact, do not wish to do so.⁹ This book is written for physicians such as these and for those who would like to learn how to make stronger connections to their patients based on empathy, regardless of whether their patients are well known to them over time or newly encountered.

We have come a long way from the days of William Osler and even from the medical training environment observed and written about by Fox and Lief. One influence on some physicians’ awareness of the place for emotion in medicine was the early AIDS epidemic when we could not avoid the reality of feelings of helplessness and despair—our own and that of our patients. As one article described it:

It was a time in which some patients and their care providers were united in a kind of immediate, naked solidarity. Many clinicians learned or relearned the critical importance of accompanying patients through life-threatening illness, when patients valued above all else from their physicians the commitment not to abandon them to their fate.¹⁰

Halpern notes:

The idea that accompanying patients in their suffering can be therapeutic leads to an alternative to the ideal of detached concern for patient-physician interactions. The visual metaphor of the ‘objective’ doctor standing before the patient and ‘seeing through’ her irrational emotions ought to be replaced with a paradigm in which the patient ‘makes use of’ the doctor’s nonretaliatory emotional presence to go through the necessarily irrational emotional phases of grieving.¹¹

Halpern begins the book with the case of a patient, Ms. G, who wants to be left alone and allowed to die because she sees no useful future for herself.¹² Halpern weaves this case and a few others throughout the book to bring to life the applicability of her hypothesis. The physicians caring for Ms. G. feel that they need to respect her as an autonomous agent with the capacity to understand her medical situation and accede to her wishes to stop dialysis treatment. Ms. G is a double amputee whose husband has left her finding her grotesque and no longer lovable. Ms. G now sees herself in these terms. Her disgust and anger are transmitted to her physicians who acknowledge as objective observers that she has a right to decide not to go on living. As the psychiatrist consulted by Ms. G's medical team to assure her mental capacity to make a decision that would lead to her death, Halpern was bothered by what she realized was perhaps excessive and inappropriate objectivity. The physicians caring for Ms. G were missing out on valuable and material data by sidestepping their emotions about Ms. G's plight as well as about their own plight.

In the first part of her book, Halpern traces the historical pathway that leads to the notion that objectivity on the part of physicians is the ideal, and that the way to achieve objectivity is by neutral emotional observation. This model is of the physician as observer who brings to bear her skills of scrutiny from watching the patient's moods unfold. Obviously this distancing can be problematic. Patients want an emotionally caring and engaged provider. In fact, Halpern points out, "Alleviating suffering occurs through, among other things, emotional communication. People often express their pain in such a way as to have an emotional effect on other people. By refusing to let patients affect them, physicians cut off communication."¹³

Halpern leads the reader to see that Ms. G's physicians have taken a stance of non-interference. Real respect for a person's autonomous decision-making capacity, however, requires that the physician empathize with the patient. She devotes a chapter to the development of this important theme. The weight placed by modern medical ethics on the principle of respect for persons and its attendant acknowledgment of the patient as an autonomous health care decision-maker, does not require the emotional disengagement of the physician. In fact, the physician has a moral duty to try to understand the motivations of his or her patient, motivations that may be steeped in emotion. As Eric Cassell eloquently points out, illness is a state of loss of control and of connectedness to the very sources of our identity.¹⁴ In this state, one has more need than ever for grounding relationships including that of patient-physician:

When one's identity and goals are stable, a person can be resilient and

emotionally independent and withstand social rejection or neglect without being seriously affected. However, when someone's entire sense of self is disrupted, as occurs with suffering and trauma, the impact of not being empathized with can be very severe.¹⁵

Through clinical empathy, Ms. G's physicians may have come to know that her view of herself as unlovable may have been shared by them, a factor in their ready acceptance of her decision. On the other hand, by eliciting her emotional story they may have come to know that her view of herself may have been subject to emotional shifts, shifts that may or may not have changed her mind about stopping dialysis. In either case, however, her physicians would have satisfied themselves that they had gone beyond an intellectual and objective understanding of her motivations to include understanding her vitally important emotional motivations. While we have an obligation to engage our patients empathetically, Halpern points out that we must also accept when they decide not to be so engaged.

Can physicians be taught how to practice clinical empathy and put it to use in emotional reasoning? In her final chapter, Halpern treats it as a skill that can be understood in its component parts and practiced and taught just like other clinical skills. The first step is acknowledging its place in the important goal of reducing suffering. Students come to medical school open to caring, curious about the lives of the people who will become their patients, ready to listen, and aware of their own vulnerability. Rather than training for detachment, medical educators must appreciate their students where they are and praise and reinforce their natural empathic powers. She says:

Teaching empathy, then, involves not only specific verbal and nonverbal skills, but also, and most importantly, a change in medical culture, from emphasizing premature knowing and certainty toward maintaining curiosity. Physicians who cultivate curiosity about others, sensitivity to their own emotional reactions, and an ongoing capacity to see the patient's situation, motives, and reactions as distinct from their own are likely to develop increasing empathic skills. The accuracy of empathy increases with effort.¹⁶

Nevertheless, as physicians and educators, we have a long way to go to fully understand our and our students' emotional development. Perhaps attention to the precepts of this book will help us in that regard.

Halpern also addresses the problem of physicians who find themselves, as she puts it, "caught emotionally 'in the morass of the patient's problems'"¹⁷ Rather than feeling overwhelmed, the physician can examine the emotions elicited by the patient's irrationality. The physician should

ask himself: What am I feeling? Why? How is this patient making me feel? What is driving this patient's anger, worry, fear, sadness? Some patients can only feel reassured by a physician who demonstrates sufficient attention to the patient's predicament. For the physician open to recognition of these feelings, Halpern views this experience as an opportunity for positive therapeutic insight and intervention. This view may be easier stated than carried out, but it is worth striving for.

A glaring omission of the book is its lack of attention to residency training. Halpern acknowledges that empathic connections cannot be rushed. Residency is a time when many physicians feel they lose their ability to remain curious, when time and work demands preclude the luxury of deep attention to patients beyond what it takes to get the job done quickly, and often superficially. In fact, it can be protective for residents to detach and not to delve into either their own emotional motivations or that of their patients. Many physicians complain that it is a time that changes them. Real acculturation to the ideal of detached concern may occur not as a student, but as a resident. The particular plight of the resident is mentioned only in the foreword written by John Lantos, a pediatrician.¹⁸ He notes the fulfillment experienced by those residents that he has worked with who allow themselves to enter into the life stories of their patients thereby gaining understanding of themselves and meaning and joy in their work. But how to overcome the pressures and time constraints, and why some residents can engage emotionally and not others, is not addressed. Perhaps what is needed are better role models such as Lantos and Halpern to validate this behavior and lead the way.

The book is beautifully and clearly written. Halpern is a philosopher as well as a physician, so its points are developed by extensive research into the works of Freud, Kant, Descartes, Heidegger, and others. It is only 165 pages, but it is dense and requires thoughtful attention. It is worth working through the book. As a physician who has never been able to reconcile the goals of caring with the concept of detachment, I have found in Halpern a long awaited voice of truth. This book cannot be passed off as some "touchy-feely" appeal. There is a growing core of physicians who not only do not wish to avoid emotions, but who recognize their validity as an important reality, one that we can know and use to help our patients make difficult medical decisions. In this way, we are also helping ourselves be better physicians. As Halpern says, "A physician who allows his patients to move him emotionally will enrich his own experience of doctoring."¹⁹

References

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2. JODI HALPERN, *FROM DETACHED CONCERN TO EMPATHY: HUMANIZING MEDICAL PRACTICE* (2001).

3. *Id.* at 83.

4. *Id.* at 68.

5. *Id.* at 91.

6. *Id.* at 94.

7. Jodi Halpern, *Empathy: Using Resonance Emotions in the Service of Curiosity*, in *EMPATHY AND THE PRACTICE OF MEDICINE* 160-73 (Howard Spiro et al. eds., 1993).

8. HALPERN, *supra* note 2, at 25.

9. See, e.g., FRANK H. BOEHM, *DOCTORS CRY, TOO* 15-17 (2001); Nancy R. Angoff, *Crying in the Curriculum*, 286 *JAMA* 1017-18 (2001).

10. Peter A. Selwyn & Robert Arnold, *From Fate to Tragedy: The Changing Meanings of Life, Death, and AIDS*, 129 *ANNALS INTERNAL MED.* 899-902 (1998).

11. HALPERN, *supra* note 2, at 144.

12. *Id.* at 1-10.

13. *Id.* at 123.

14. ERIC J. CASSELL, *THE HEALER'S ART: A NEW APPROACH TO THE DOCTOR-PATIENT RELATIONSHIP* (1985).

15. HALPERN, *supra* note 2, at 116.

16. *Id.* at 135.

17. *Id.* at 136.

18. John Lantos, *Foreword* to JODI HALPERN, *FROM DETACHED CONCERN TO EMPATHY: HUMANIZING MEDICAL PRACTICE*, at vii-ix (2001).

19. HALPERN, *supra* note 2, at 145.

BOOK NOTES

***A Few Months to Live: Different Paths to Life's End.* By Jana Staton et al. Washington: Georgetown University Press, 2001. Pp. 358.**

Documenting the end-of-life experiences of nine terminally ill individuals, this book focuses on how they and their caregivers understood the illnesses, coped with symptoms, and searched for meaning and spiritual growth. The accounts, presented largely in the subjects' own words, reveal the nine individuals as more than just patients by placing them in the contexts of their daily lives and relationships. Addressing such issues as palliative care, quality of life, financial hardship, grief and loss, and communications with medical personnel, the authors identify how families, professionals, and communities can respond to the challenges of terminal illness and the need to confront life's end.

***Body Bazaar: The Market for Human Tissue in the Biotechnology Age.* By Lori Andrews and Dorothy Nelkin. New York: Crown Publishers, 2001. Pp. 245.**

Valued as both a source of information and the raw material for commercial products, the tissues in a single human being can now attract millions of dollars, and with them new commercial uses for human blood and body tissue. Andrews and Nelkin illuminate this business of bodies, telling individual stories to show the profound psychological, social, and financial impacts of the commercialization of human tissue. They explore the problems of privacy and social control that arise with the extraction of information from the body, and the provocative questions of profit and property that follow the creation of marketable products from human bodies.

***Drug Addiction and Drug Policy: The Struggle to Control Dependence.* Edited by Philip B. Heymann and William N. Brownsberger. Cambridge: Harvard University Press, 2001. Pp. 288.**

This book is the culmination of five years of conversations among distinguished scholars in law, public policy, medicine, and biopsychology about the most difficult questions in drug policy and the study of addictions. The authors challenge the standard dichotomies that ask whether drug addicts have an illness or control their addiction; whether they should be treated as patients or as criminals. Instead, the authors argue, the real question is how coercion and support can be used together to steer addicts toward productive life.

***Ethics and Economics of Assisted Reproduction: The Cost of Longing.* By Maura A. Ryan. Washington: Georgetown University Press, 2001. Pp. 192.**

Drawing on concepts from medical ethics, feminist theory, and Roman Catholic social teaching, Ryan analyzes the economic, ethical, theological, and political dimensions of assisted reproduction. Ryan contends that only by ceasing to treat assisted reproduction as a consumer product can meaningful questions about medical appropriateness and social responsibility be raised. Arguing for some limits on access to reproductive technology, Ryan considers ways to assess the importance of assisted reproduction against other social and medical prerogatives, and where to draw the line in promoting fertility.

***Holding Health Care Accountable: Law and the New Medical Marketplace.* By E. Haavi Morreim. New York: Oxford University Press, 2001. Pp. 336.**

Health care in the United States and elsewhere has been rocked by economic upheaval, but tort and contract law have not kept pace. Physicians are still expected to deliver the same standard of care, regardless of whether it is paid for, while health plans face litigation for virtually any unfortunate outcome. This book offers a clear resolution. Part I explains why new economic realities have rendered prevailing malpractice and contract law largely anachronistic. Part II argues that we should focus first on "who should be doing what, for the best delivery of health care," and suggests new standards of liability. Part III shows that this approach, though novel, fits remarkably well with basic common law doctrines.

***The Human Embryo Research Debates: Bioethics in the Vortex of Controversy.* By Ronald M. Green. New York: Oxford University Press, 2001. Pp. 250.**

Embryo research holds out the promise of cures for many serious diseases such as diabetes and Alzheimer's, but it has met with powerful opposition. Drawing on his experience as a member of the National Institutes of Health's Human Embryo Research Panel, Green offers a first-hand account of the embryo research debates, reflecting on some of the philosophical challenges posed by embryo research. Among the questions he examines are: What is the impact of new biological information on our thinking about life's beginning? May parents risk injuring a child in order to have it? And what role should religion play in shaping biomedical policy?