



## Privacy, Confidentiality, or Both?

Leslie P. Francis, Jay A. Jacobson, Charles B. Smith, Margaret P. Battin

Privacy and confidentiality are often confused, although they capture significantly different ideas. In this brief essay, we first present a standard view about privacy and confidentiality and then challenge this view. Because many questions about the use of health information come to the fore—including two of the most publicized contemporary examples: the use of de-identified data in quality improvement activities and the use of health data in surveillance against emerging infections or bioterrorism—clarification about privacy and confidentiality, what they mean and why they matter, is critical.

In discussions of these issues, privacy and confidentiality typically appear as twinned concepts. As with human twins, they appear in order: privacy first, confidentiality second. *Privacy* protects access to the person, guarding him or her from bodily touching, intimacy, or direct exposure to view. Privacy in this sense might also extend to guarding objects associated with the person from view: diaries, suitcases, and other personal spaces, for example, as Michael Selgelid and Matthew Liao have pointed out (2007). Whether or not intrusions into such spaces are invasions of privacy comparable to invasions of the body are not relevant to our discussion here. *Confidentiality* is about passing on information: sharing academic, financial, or health records without permission. In this prioritization, privacy may be thought to be the more important value, with direct access (such as intrusion into bodily space) seen as a worse affront than unauthorized informational spread. Or, protecting confidentiality may be seen as a means to protecting privacy, with safeguards against informational spread seen as a way of protecting people against having the information garnered in the first place. But surveillance for endemic

and epidemic infectious disease (including surveillance for reportable sexually transmitted diseases and for outbreaks of new infections such as avian influenza or SARS) in particular challenges whether privacy should be regarded as the superior twin or whether what it is important to protect about how personal information is gathered and transferred may vary with the circumstances (Francis, 2008).

A rough cut on the distinction between privacy and confidentiality starts with confidentiality. Confidentiality is about expectations of control over information about a person after the information has been gleaned. Confidentiality is violated if medical records are shared with employers without consent, if bank records are forwarded to potential mortgage companies, or if tax returns are leaked to the press. Privacy, it seems, is about something closer: invasions of the body, personal space, or liberty. Privacy is *invaded*, and confidentiality is *breached*. Surely, it would seem, the physical body of a person (and perhaps his or her personal items and spaces) is more important to the person than the information. Invasions are worse than breaches, and privacy, thus, would be the superior twin.

But the impressive contemporary confusion of these two ideas in the Health Insurance Portability and Accountability Act (HIPAA) regulations casts doubt on this easy conclusion. These massive recent efforts in U.S. federal law to protect patients' health information (called privacy protections) have resulted in an elaborate set of standards for protecting the "privacy" of patients' medical records (U.S. Department of Health and Human Services, 2008). But health records are not the person, although they certainly may contain important personal information (Terry & Francis, 2007). Why the confusion? Congress and the Department of Health and Human

Services may have been inarticulate or may have called upon a grander-sounding value (privacy) to justify HIPAA's extensive regulatory regime. Neither hypothesis captures the fact that invoking "privacy" to protect health records does not seem strange, at least to the non-legally-trained ear and to some philosophical ears as well (Parent, 1983). Perhaps access to medical records really does feel a lot like access to the person: the records may describe someone's physical being in great detail, making him or her easy to visualize (consider "obese white male"). Or perhaps the idea is that medical records are dangerously revealing pieces of information (such as "HIV positive" or "dementia of the Alzheimer's type").

Infectious disease examples, however, urge contextualizing the picture of privacy as the superior twin. Invasions of privacy and breaches of confidentiality are

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# Ask Not What You Can Do for ASBH, Ask What ASBH Can Do for You

Tod S. Chambers



I suspect that many on the ASBH Board of Directors have grown tired of my unending requests for timelines and deliverables. Keeping academics on a schedule is not so much like herding cats as like herding cats through a field of catnip. We like to explore the ins and outs of every issue; timelines—and in particular deadlines for milestones—can seem counter to our very being. So I have developed sympathy for those poor editors to whom I have lied to for years about when the final draft would arrive.

But *deliverables* sounds like some odd business term, something we should be as suspect if I started rambling on using such business speak as “mind share,” “six sigma,” and “SMART objectives.” Didn’t we go into academia to escape these things? I use the term simply to remind the board that we must always ask, “What does one get for being a part of ASBH?” For a number of years, the answer to this question was quite vague. It is what I put on my CV to indicate that I am a member of a professional association. Or, well, it provides a discount on those costly annual meetings. This seems to me at least to be a very low expectation, and I think that the organization owes its members those things that only gathering together all those concerned with issues in bioethics and medical humanities can bring about. So let me talk about some of the deliverables that you should be receiving in the near future.

First, for those who work as odd liminal figures in medical schools, an ongoing concern has been tenure and promotion. Our medical school colleagues often seem happy to have us around (at least to be able to say that there is someone who takes care of that morality and meaning stuff) but when it comes to questions of tenure and promotion, they seem unable to understand our CVs. In collaboration with the Association of Bioethics Program Directors, a report (which should be largely credited to Jonathan Moreno) will be forthcoming that provides explanation and criteria for granting promotion and tenure to bioethics and medical humanities scholars

in medical academic institutions. Related to this issue is one about what are appropriate salary rates for those in our fields. Toby Schonfeld has been instrumental in creating a salary survey that will begin in the spring and will be able to provide an ongoing tracking of this issue. A second edition of the guideline *Publishing Without Perishing*, spearheaded by Steve Latham, will be published soon. And finally, we will begin the construction of an ongoing project to provide online encyclopedias of bioethics (directed by Glenn McGee) and medical humanities (directed by Catherine Belling). These wikis will be open and editable to all members of ASBH, and we expect that they will be a resource as much for the scholarly community as for interested laypeople.

For those engaged in ethics consultation, the society is presently entering into a second phase of developing a code of ethics. Ken Kipnis has begun a formal project that, once he is able to secure funding, will allow him to determine what kind of moral guidelines are needed. Anita Tarzian is in charge of the second edition of the *Core Competencies for Health Care Ethics Consultation*. The *ASBH Learner’s Guide*, providing guidance for advanced training in consultation, will be available this fall, and although many have dedicated long hours to this new guide, the society owes special thanks to Sue Rubin and Mark Aulisio.

For those who have long disparaged the lack of political activism, we wish to reopen the issue of “taking stands” but with a difference. There has been a danger in seeing this issue in a simple binary of “yes, ASBH takes stands” or “no, it does not.” We wish to encourage creativity in thinking about this issue. We want our members to think of alternatives beyond this simple binary. Toward this end, the organization will soon send an invitation to participate in a forum to foster new ideas and new approaches to this issue. It is our hope that new ways of thinking can be brought forth and critically examined.

Although I have been discussing the importance of services to our members,

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# ASBH 10th Annual Meeting: Future Tense

Elisa Gordon and Jason Robert, Program Planning Committee Cochairs

Mark your calendars for the 10th Annual Meeting of the American Society for Bioethics and Humanities, October 23–26, 2008, in Cleveland, OH! Since the 2007 meeting in Washington DC, the Program Planning Committee has been hard at work to build a conference program that meets the needs and interests of ASBH members. We are planning a series of preconference workshops, conference panels, and paper and poster sessions exploring the past, present, and future of medical humanities and bioethics. The theme for 2008 is Future Tense. As we look back on the first 10 years and ahead to the next 10 years of the ASBH, we invite you to think about the many meanings one might extrapolate from this phrase and to address such questions as

- What new issues will face bioethics and medical humanities?
- What recurring and unresolved issues will continue to demand our attention?
- What moral assumptions have yet to be empirically examined?

- How accurate have our predictions about the moral dilemmas surrounding new technology been and how can we do better?
- How does science fiction provide models of and models for our current concerns about the future?
- What is the future of narrative medicine?
- What is the future of graduate education in bioethics and medical humanities?
- How will clinical ethics consultation evaluation and core competencies evolve?
- What is the future of ASBH?

Our plenary speakers will touch on these questions and raise many others for discussion and deliberation. Psychiatrist, novelist, and playwright Dr. Stephen Bergman (Samuel Shem), author of *The House of God*, will open the conference on Thursday. Professor Dorothy Roberts of Northwestern University School of Law will speak on Friday, and Dr. David Korn, senior vice president for biomedical and health sciences research



at the Association of American Medical Colleges, will speak on Saturday. These plenary speakers will address past, present, and future themes in bioethics and medical humanities and, we expect, provoke reflection and debate about where we have been and where we are headed.

We are very excited about the ASBH 10th Annual Meeting. The Program Planning Committee is working with colleagues in Cleveland to prepare a variety of extracurricular activities, and we look forward to welcoming you to a stellar and engaging program this fall. ■

## Please Join Us as We “Return to *The House of God*”

### (W)rites of Passage ... A Journey Through Resident Medical Education, 1978–2008

Don't miss this special symposium! Help us recognize the 30th anniversary of Samuel Shem's *The House of God*, October 22–23, just before the ASBH 10th Annual Meeting in Cleveland. “Return to *The House of God: (W)rites of Passage ... A Journey Through Resident Medical Education, 1978–2008*” is sponsored by the Center for Literature, Medicine, and Biomedical Humanities of Hiram College and the Division of Medicine of the Cleveland Clinic. Stephen Bergman (Samuel Shem) himself will introduce the symposium and will bring with him some of his fellow interns who were the models for characters in the novel. Joining them will be top physician and nurse writers, leading medical humanities scholars, and resident educators. Presenters include Larry Smith and Keith Armitage (national leaders in resident education); Suzanne Poirier, Howard Brody, Howard Markel, and Stephanie Brown Clark (noteworthy contributors to scholarship in the medical humanities); and

outstanding writers Martin Winckler, Jay Baruch, and Abigail Zuger. Our presenters will address the following questions:

- What impact did *The House of God* have on medical residency programs? What has been happening in medical residency since the novel's publication? What problems and issues still remain? How do medical educators use the book?
- What is iconic about *The House of God*? Why have more than 2 million people in many different countries read the book? In what ways is it still relevant today?
- What are the relationships between medical education and literature? How does writing reflect, complement, and criticize medical training and practice? How has *The House of God* served physician and nurse writers in their dual careers?

The symposium begins at 1 pm on Wednesday, October 22 will take place the first day at the Louis Stokes Wing of the

Cleveland Public Library just a short walk from the Renaissance Cleveland Hotel. Wednesday's session will be capped by dinner and a performance of the award-winning off-Broadway play about the founding of Alcoholics Anonymous, *Bill W. and Dr. Bob*, written by Bergman and his wife Janet Surrey. The symposium will continue on Thursday, October 23 at the Renaissance Cleveland Hotel. Those who choose to attend Thursday only should register through ASBH because the Thursday morning portion of the “Return to *The House of God*” symposium is also serving as a preconference session of the ASBH 10th Annual Meeting. The cost of the full symposium is \$90 for ASBH members, \$50 for full-time students and residents, and \$120 for nonmembers.

The symposium is presented with generous support from Wish, Cope, and Life Foundation and the Division of Medicine of the Cleveland Clinic. To register for the full symposium and for more information, please visit <http://litmed.hiram.edu>. ■

How do you use the texts and methods of the humanities disciplines in your teaching of medical humanities, bioethics, or any other healthcare courses? We would like to share your ideas in *ASBH Exchange*. Send a concrete description of a particular class or exercise that you have found effective to Johanna Shapiro at [jfshapiro@hs.uci.edu](mailto:jfshapiro@hs.uci.edu).

### Write Brain Left Brain, or How I Learned to Stop Worrying and Love Writing

Audrey Shafer

According to studies of the lateralization of brain function, including a paper cunningly subtitled “A meta-analytic tale of two hemispheres” (Hull & Vaid, 2007), the view that the left brain handles language, analysis, and the to-do list of daily life while the right brain serves as a font of creativity and imaginative fancy fails to convey the complex interplay between structures throughout the brain that are engaged when we talk, write, or even think about language. The act of writing, hence, becomes not only a tool for engaging both the analytic and the creative processes required for complex activity, such as the practice of medicine\*, but also a metaphor for the unification of the at times clichéd dualism invoked to explicate medicine (such as the art of medicine, the science of medicine).

Furthermore, writing is both an act of reflection on what one has already experienced as well as an act of exploration: a leap into uncharted, unknown, and sometimes scary territory. When you sit down to write, you don't fully know what will emerge on the paper or screen. The “free write” is a time to turn off that carping nag of an internal editor who critiques your every word as too dull, too naughty, too nice, or just not right—even before the word is allowed onto the page (Greenberg, 1990). And yet writing cannot end with the free write. The careful, iterative process of editing, identifying the shine of gem-like phrases and girding those gems, is as important a part of the creative process as the initial spill of words.

Ah, you ask, could this backwards and forwards process, mingling of known and unknown, combination of imaginative leaps and attention to detail be related to medicine? Of course. I daresay a number of occupations and pursuits encompass these traits as well (parenting, teaching, and research leap to mind). Basically, the skills you hone in the practice of writing translate, in some fashion, to other endeavors, including medicine, which demand high level function and coordination between multiple loci in the brain.

But there's more. Writing is usually considered a solitary act. You are, after all, communing with your own brain. Yet the power of exposure and the possibility for community-building that the sharing or publishing of writing affords can be extraordinary (Shapiro, Kasman, & Shafer, 2006). Sharing writing in a workshop, course, or other protected environment enables the acknowledgement of vulnerability, fallibility, ambiguity, and other emotionally charged but frequently neglected components of being human in a domain (such as medicine) that expects perfection. A writing group, in contrast to a morbidity and mortality conference for instance, almost inevitably fosters feelings of reciprocity and witnessing, which in turn

create a precious kind of intimacy. Such experiences of truly being known and knowing others tend to be rare in a medical community, which so frequently is bound by hierarchy, restricted self-presentation, and other divisions. For these and other reasons, writing has been advocated for medical students and trainees (e.g., during anatomy, clerkships, residency) and practitioners of all types and experiences (Reisman, Hansen, & Rastegar, 2006). Workshops may be associated with a medical institution or conference or independently advertised yet geared for those in medicine.

Publishing or public readings are also forms of sharing and, therefore, exposure. Web publishing formats, such as blogs, provide even more methods to publicly express various aspects of the medical and illness experiences. Years ago, after a reading of my poem, “Monday Morning,” a work in which I mention my naked toddler son (Shafer, 1992), I noted that he had grown to dislike the poem because of his lack of attire. “He shouldn't be upset,” Kathryn Montgomery later advised me. “It's you who are truly naked in the poem.”

The therapeutic benefit of writing has been advocated and used for various populations, including prisoners, victims of domestic violence, the unemployed, and, of course, patients (see, for example, the work of James W. Pennebaker, PhD). In addition to the advantages of community and support noted previously, research suggests that the act of writing itself produces a range of healing outcomes even if no feedback about the writing is provided (Smyth, Stone, Hurewitz, & Kaell, 1999).

Finally, I have a confession. The subtitle of this piece, “How I learned to stop worrying and love writing,” is an utter falsehood. Having just seen the film *The Diving Bell and the Butterfly* last night, I feel small saying this, but here it is: writing remains painful. Birthing is arduous. And sometimes I am easily distracted. My time Websurfing while I should have been writing this piece included visiting images of Homer Simpson's X ray of his mini brain, learning that the koala has peculiarly tiny cerebral hemispheres, and drooling over my sister's summer rental property in Nag's Head. Joshua Spanogle, a physician and mystery thriller author, has said his apartment is never cleaner than when he is working on a writing project. Maybe someday I will stop worrying, but it hasn't happened yet. I do, however, acknowledge the need, the joy, and even the love. I am fortunate to also feel the same about my practice: I worry about each case, and I also love what I do. The last thing you want is a complacent anesthesiologist.

Writing, as well as the study of what writing and medicine mean, is a vital component of medical humanities. Fledgling writers need nurturing; writing groups or courses require support. Medical schools and training programs can encourage the human side of medicine by fostering writing. So pull out a piece of paper and your favorite pen or open a new, blank document on your computer screen. I urge you: write. ■

\*The term *medicine* is used here to denote the practice of patient care, including doctoring, nursing, and therapy.

Audrey Shafer, MD, is a professor of anesthesia for the Stanford University School of Medicine; staff anesthesiologist for the Veterans Affairs Palo Alto Health Care System; and director of the Arts, Humanities, and Medicine Program for Stanford Center for Biomedical Ethics. She is the author of *The Mailbox*, a novel about posttraumatic stress disorder in Vietnam veterans.

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# A Bibliographic Tour

Les Rothenberg

Because of space limitations, “A Bibliographic Tour” will be a listing rather than a review but will include e-mail addresses to facilitate reprint requests. Suggestions of your own work or that of others, as well as suggestions for improving the column, are enthusiastically solicited. Please contact Les Rothenberg by e-mail at Les.S.Rothenberg@kp.org. An alphabetized list of all references in this and past columns can be found on the ASBH Web site at [www.asbh.org/exchange/biblio.htm](http://www.asbh.org/exchange/biblio.htm).

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## Supreme Court's FDA Decision Highlights Little Understood Issue of Preemption

Jennifer S. Bard, JD MPH

Although having a JD along with a PhD is as near a thing as there is to a golden ticket for a bioethicist who wants to get a teaching job, I still stand by my belief that 3 years of law school is tremendous overkill for people who just want to understand the legal issues arising in the study of bioethics and the practice of medicine.

Most of the legal concepts that come up in cases involving medical issues—right to refuse treatment, right to privacy, right to die (or, more accurately, lack thereof)—are based on interpretations of the Bill of Rights and can be understood by anyone who actually sits down and reads the landmark cases. There are, however, exceptions. The recent Supreme Court decision in *Riegel v. Medtronic* is one. The decision prohibits individuals injured by a medical device from seeking damages in state court, which is the only way individuals can get compensation for personal injuries. The Supreme Court has a pending decision on a similar question. *Wyeth v. Levine* involves prescription drugs and raises some of the most complicated and nonintuitive Constitutional doctrines. These doctrines are not in the glamorous Bill of Rights but rather right in the heart of the Constitution that establishes the balance of powers between the federal government and the individual states.

A good argument can be made that the impetus for adopting our Constitution was the need to preserve the bonds between a loose confederation of former British colonies that had banded together to throw off their oppressor. While under British rule, each colony existed independently of the others, and none of them were interested in giving up their new freedom. It took 10 years of struggle before there was agreement that there could be no United States of America without a strong central government. The compromise was one that allowed the states to govern everything within their borders that did not cause harm to those living in other states.

The balance of power between the states and the federal government is discussed throughout the Constitution.

Article I, Section 8 gives Congress the “power to regulate commerce among the several states.” This bland statement, known as the Commerce Clause, gave the federal government the power to prevent individual states from favoring themselves in matters of trade. Article VI declares that laws and treaties made by the federal government shall be the “supreme law of the land.” On its face, those provisions seem to establish the federal government as the final authority. However, these provisions are interpreted within the context of each state retaining all powers to regulate matters within its boundaries, so long as the regulation is consistent with the fair and efficient operation of the country as a whole. This always had special meaning in areas of health and safety, which are viewed as issues that fall under what is described as the “police power”—the power to regulate safety within the borders of the individual states.

So what is the difference between striking down a state law based on the dormant commerce clause versus the pre-emption doctrine? In effect, nothing. Both doctrines allow the federal government to substitute its judgment for that of any individual state. The two doctrines, however, are based on very different theoretical foundations. The Supremacy Clause is an expression of doctrine with no practical information about how it is to be implemented. The Supreme Court usually treats pre-emption cases as issues of routine statutory construction usually involving the same two questions: (1) whether the federal government has an existing, conflicting law and (2) even if there is no actual conflict, is it more efficient or effective for the issue to be regulated through the federal government.

In contrast, the Supreme Court has always viewed the Commerce Clause, which for reasons to be explained, is usually described as the Dormant Commerce Clause, as not just a rule but an actual Constitutional doctrine. The most traditional application of the rule was when a state wanted to impose standards on a product, such as butter, that effectively banned imports from other states. During the New Deal, the Supreme Court

expanded the Commerce Clause to include not just goods that actually traveled from state to state but also those that “affected” interstate commerce. During the 1960s the concept of affecting commerce was broadened so that the Supreme Court used the Commerce Clause to uphold antidiscrimination laws that prevented individual hotels and restaurants from refusing to serve African-Americans. It seemed as if almost anything the federal government wanted to do for the “greater good” could be justified by the Commerce Clause.

The “joke” about the Dormant Commerce Clause in law school was that it was, indeed, the sleepest area of the Constitution and the least likely to cause trouble on an exam or in real life. This was because the Supreme Court almost always found that the federal government had a good reason for what it was doing and would uphold the federal law based on the Commerce Clause. Well, good-bye to all that! In 1995 the Supreme Court in *United States v. Lopez* held that the Federal Gun-Free School Zones Law was unconstitutional because it interfered with state sovereignty. The trend continued in 2000 when the Supreme Court held that the Violence Against Women Act also interfered with state sovereignty and was unconstitutional. The view of lawyers who follow this (and law students who get tested on it) was, “OK, you’re the Supreme Court. We’ll do it your way.” The balance of power has tipped back to the states ... except apparently it hasn’t. In 2006 while evaluating the constitutionality of California’s Medical Marijuana Act, the Supreme Court in *Gonzalez v. Raich* held that federal drug enforcement laws trumped California’s decision to make marijuana available for medical reasons because—and I’m not kidding—California’s laws could affect the national market for marijuana. Moreover, in *Gonzalez v. Oregon*, a case often wrongly understood as upholding the rights of states to allow assisted suicide, the Supreme Court actually affirmed the power of the federal Congress to ban assisted suicide through its regulation of prescription drugs. The frustration is increased by the fact that in

every decision (from Lopez to Gonzalez) the majority of the Supreme Court has insisted, in the face of reality, that they have made no changes whatsoever to the historical interpretations of the Commerce Clause.

So what about Medical Devices? Well, here the Supreme Court goes again, except this time the issue is pre-emption. Before the passage of the Medical Device Act of 1976 (the MDA) the Food and Drug Administration (FDA) did not set standards for the safety or efficacy of medical devices, and states stepped up to fill in the void. The inevitable development of conflicting standards made difficulties for manufacturers, and they were able to persuade Congress that medical devices were like prescription drugs, and only the FDA should be able to approve or disapprove their sale.

The dispute before the Supreme Court in Medtronic was whether when the federal government took over regulation, it took away from patients injured by medical devices the right to seek compensation for injury in state courts. In an eight to one decision, the Supreme Court held Congress' giving the FDA sole power to regulate medical devices, creating the presumption that once the FDA approves a medical device, it is rendered perfect and, therefore, legally incapable

of causing harm if manufactured and used appropriately. At a time when no one (including the pharmaceutical industry) has any confidence that the underfunded and understaffed FDA is in any way capable of fulfilling its regulatory responsibilities, the Supreme Court has rendered it infallible.

So strongly worded is the Supreme Court's argument that were it not for Justice Ruth Bader Ginsberg's "The Emperor Has No Clothes" dissent it would be hard for a layperson to appreciate how extraordinary this decision is. She explains that the reason why no one in the 30 years since the passing of the MDA imagined that the MDA took away this right was that if this were true then "consumers injured by devices that receive FDA approval but nevertheless prove unsafe" would have no means whatsoever to seek compensation.

There is every indication that Riegel is just the first step in establishing the infallibility of the FDA. The Supreme Court has agreed to hear a second case this term. This will give the Supreme Court the opportunity to find that patients injured because of a faulty drug label also lack the ability to seek compensation because once the FDA has exercised its authority to approve a drug label the information on that label is immune from further scrutiny.

You don't have to be a lawyer to see the two-point basis for this decision. First, it is appropriate for the federal government to step in and prevent a state from establishing safety standards for medical devices implanted in its citizens. Second, should those devices prove to be unsafe, the companies are immune to lawsuits. This is an example of the kind of results-oriented decisions on health and safety issues that have been gushing out of the current, self-described "strict constructionist" court.

It would take some serious book time, however, to understand why the Supreme Court made this decision and how it adds further uncertainty and unpredictability to how the court will resolve issues of abortion, assisted reproductive technology, and assisted suicide, which it may well decide to take up in the near future. Is this a fruitful use of valuable time? Probably not—unless you are looking for a hard-money, summers-off teaching position. ■■

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## ASBH Annual Meetings: Save the Dates



## Privacy, Confidentiality, or Both? *continued from page 1*

both of moral concern. Sometimes we prevent the invasion because our primary concern is the breach. Sometimes we prevent the breach from concern it will lead to invasions. In some contexts we protect privacy to protect confidentiality rather than the reverse (Kipnis, 2006).

Invasion of privacy evokes military images: serious risks to bodily integrity, such as torture or sustained surveillance and threats. Where diagnoses of infectious diseases are concerned, however, many invasions seem de-coupled from threats to physical security. With a required sputum sample to test for tuberculosis, the body isn't intruded upon; all that is required is a cough and a spit. The sample, even if demanded without consent, may increase physical security in the form of appropriate health care—if health care is available. Moreover, effective surveillance activities may enhance protection of everyone; a consideration for even the person required to give the anonymous sample. When readily accessible bodily samples (spit, hair, sweat) are gathered, physical security isn't on the line. Even with a blood sample, what is done with the information the sample provides may be far more threatening to physical security than the procedure to obtain it. People diagnosed with widely feared infectious diseases have been beaten, imprisoned, or worse. In these cases, security isn't threatened by the initial access: it's the failure of confidentiality about what was found. Confidentiality, not privacy, is the superior twin. We protect against the original access because we fear that we will be unable to protect against the information coming to light, not because of harm in obtaining the information.

Some of the most frightening images of invasions of privacy are the use of coercion to extract motives or thoughts or the no-longer-science-fictional use of brain imaging devices to obtain information about mental states. Even in the United States, where liberty seems especially threatened, the problem may lie not with access per se, but with the information gathered and how it is shared. An infectious disease analogy would be anonymous remote sensing of body temperatures as a means of gauging infection rates in a population. The idea that someone knows that another person is feverish is discomforting—but will it affect how the person goes about living, chilling liberty any more than the physical

sensation of being feverish already does? Will the knowledge that there is a fever-sensor effect whether the person with a cold stays home or goes to work? Chills may come, of course—literally as well as figuratively—but the figurative ones are most likely if identity is known, the person is watched, and contacts are traced. The knowledge that sensing is occurring may lead people with fevers to think twice about how their behavior affects others. But this is to encourage the person to think in an enriched way about illness, to think about the effects of what he or she is doing on others, rather than to restrict his or her liberty in a coercive manner. Limits to individual liberty are unlikely to come from sensing anonymous data and storing it in a data bank, so long as the data are fully anonymous even if the data are used for such health policy purposes as influenza vaccine distribution. Indeed, from the individual patient perspective it might be a good thing if knowledge that there has been a general rise in human body temperatures in a given region led to increases in the supply of antiviral drugs delivered to that region. If linkage is the problem, confidentiality is the driving value; we protect privacy because we cannot be sure that the fever will not be linked to an identifiable individual after it has been detected.

Privacy is also important to intimacy, in addition to security and liberty. Without control over invasions of the body, it may be difficult to establish intimate relationships. In part through controlled and selective disclosure of information, people become friends or lovers (Scanlon, 1975). Here, too, with infectious disease it is arguable that the principal focus is confidentiality, not whether information has been obtained, but whether and how it gets passed along to others. Consider diagnostic medical tests for sexually transmitted diseases: the fact that one person's physician can perform a needle stick or take a cheek swab to obtain the sample for a diagnosis of HIV doesn't control a sexual partner's decision to share or not to share HIV-status information within a relationship. What matters to intimacy is whether the disclosure is made and whether it comes from the person, the physician, or a public health officer tracing sexual contacts. To be sure, learning one's HIV status can affect intimate relationships, but whether one learns this information is not a matter of access but of whether

choices about what is done with the information are respected. Someone might choose to keep information confidential even from themselves (as with those who decide not to receive results of HIV testing, genetic testing, or amniocentesis in pregnancy). Some people might want to bar access to the information in the first place from concern that the information will be inadvertently revealed, that they will be tempted to ask, or that they will live in horror of the thought that someone knows but they do not. It may be far less plausible to live in horror of the fact that there are information bytes about body temperature or sputum sample biology that came originally from access to the person but that they are in no way at this point linked or linkable in a data bank somewhere.

Nonetheless, there might be horror at the thought that one has contributed information to a data bank being put to nefarious purposes, such as racial targeting or ethnic cleansing. Collections of health data have been put to awful usage: consider the image of overall social health as it functioned in the eugenics movement as a reason for sterilizing supposedly "defective" members of the population. The corrective, however, lies in moral constraints on how data banks are used, not on the existence of the banks themselves. Of course, when there is a realistic possibility of the misuse of data banks, refusal to share information with them, even anonymously, should remain a possibility for patients.

Another very serious risk even of entirely anonymous surveillance is that the data will reveal sufficient information about groups to result in stigmatization. Suppose, for example, that fully anonymous data are collected in a region of the country that is associated with a particular racial or ethnic group. Or suppose that the surveillance takes place at a border where immigrants of a particular ethnicity are known to cross. In such cases, information about the prevalence of an infectious condition might be a flash point for prejudice against new immigrants (Stern & Stern, 2002). The cursory examination on Ellis Island of steerage passengers seeking to enter the United States—first and second class passengers were excluded from the examination, perhaps on the theory that if they could pay for expensive passage they might be insulated from illness—played a role in natives' objections to immigrants

(National Park Service, U.S. Department of the Interior, 2006). Similar concerns about immigrants into the United States who return to Mexico with HIV acquired while away also fuel stigmatization (Lacey, 2007). Or consider contemporary fears of SARS or avian influenza: quarantines of entire regions or societies are surely imaginable.

These concerns—misuse and stigmatization—are very real concerns about the use of anonymized data. But there are ways to protect against them without insisting on individual informed consent (Dubler, Blustein, Bhalla, & Bernard, 2007). One important caution is to insist that any surveillance activities be openly disclosed and publicized. Another is to require that community-wide surveillance only be entered into after public discussion and authorization, a kind of community consent. If these protections are absent, the risks of misuse of surveillance would remain real, and even the anonymous collection of data would be morally problematic.

A final difficulty about collecting data without identifiers or using data that have been de-identified is that it may not be possible to preserve anonymity. The temptation may be to try to re-identify patients for treatment or preventive reasons. New York City, for example, has reportedly used surveillance data about diabetic patients to try to improve patients' health (Mariner, 2007). It may not be possible to preserve anonymity and have the information continue to be of any scientific use. These are empirical issues that we cannot fully settle here. Some surveillance activities, such as the collection of anonymous blood samples in pregnant women to monitor HIV prevalence (Dondero, Pappaioanou, & Curran, 1988), have yielded useful information without any threat to identification, but other activities may not.

Suppose, for example, that the Centers for Disease Control and Prevention (CDC) seeks comprehensive data about the prevalence (proportion in a population) or the incidence (numbers of new cases in a given time period) of a particular condition. These data can be critical to estimating lifetime risks to members of the population of developing a disease at a given point in time. They can be enormously useful in public health planning, in actuarial calculations of insurance rates, in efforts to assess the efficacy or costs of treatment, or in efforts to judge the relative efficacy of social interventions such as public-interest

advertising campaigns. To be informative about either prevalence or incidence, data sets need not contain any identifying information; they can be fully anonymized (Dyer, 1999). However, data must be collected from individuals. Privacy must be invaded in order to collect the data (whether consensually or not), but confidentiality need not be breached for the data to be informative for the CDC.

Because of infectious diseases' often rapid propagation patterns and capacity for transmission throughout a population, these issues are especially crucial in this area of health concerns. For example, infectious-disease researchers might want to know whether mutations of viral strains are appearing in a population. Samples from infected patients will be needed to study virus characteristics. Identifying patient information will be unnecessary; however, if there are very few patients with the infection in question, confidentiality may be difficult to protect. Examples might be monitoring of people with a given infectious condition to see whether resistant or more lethal strains are appearing in the population. When resistant HIV appeared in New York City, identifying information about the patient at issue was not made known, at least publicly (Bhattacharya, 2005). However, sufficiently informative descriptions appeared in the press to raise serious questions about whether his confidentiality was in fact being protected—whether respect for him as an actual victim and vector was adequately provided (Associated Press 2005).

These are all cases in which the information in question is potentially life-saving for many people. They are also cases in which collecting the information requires bodily invasion of the type that is considered a clear violation of privacy: disease diagnosis or samples of other bodily material such as saliva or blood. If we object to collection of the information because we take privacy to be the primary value, we risk never getting the information at all. As a public policy matter, therefore, it may be important to distinguish privacy and confidentiality and to be careful in assessing whether our objection is to access or to information becoming inappropriately shared. ■

*This essay draws from Margaret P. Battin, Leslie P. Francis, Jay A. Jacobson, Charles B. Smith, The Patient as Victim and Vector: Ethics and Infectious Disease, New York: Oxford University Press, forthcoming 2008.*

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## Literature and Medicine

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## ASBH-Endorsed Meetings

### Ethical Dilemmas in Research Involving Children—Damned Whether You Do or Don't

April 29, 2008  
SUNY Downstate Medical Center in Brooklyn, NY  
718/270-2752

### Ethical Challenges in Surgical Innovation

May 8-9, 2008  
Cleveland Clinic in Cleveland, OH  
216/445-7417

### SEEING MAKING HEALING: Art, the Arts, and Creativity in Medicine and the Medical Humanities

The 6th Annual Meeting of the Pennsylvania Medical Humanities Consortium  
May 13-14, 2008  
Carnegie Museum of Art, Pittsburgh  
412/647-5700

### The 4th Annual Pediatric Bioethics Conference

**Predicting Our Future: Genetic Testing in Children and Their Families**  
July 25-26, 2008  
Bell Harbor International Conference Center, Seattle  
206/987-7825

### Return to *The House of God: (W)rites of Passage ... A Journey Through Resident Medical Education 1978-2008*

October 22-23, 2008  
Cleveland, OH  
330/569-5380  
<http://litmed.hiram.edu>  
[joerightta@hiram.edu](mailto:joerightta@hiram.edu)

### Emerging Infectious Diseases: Ethics, Law, and Professional Obligation

November 6-8, 2008  
Institute for the Medical Humanities, University of Texas Medical Branch Galveston, TX  
409/772-9386

# The Bioethics Program

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**Randolph Steinhagen, MD**, Mount Sinai School of Medicine

**Ilene F. Willets, PhD**, Mount Sinai School of Medicine

## Letter from the President

*continued from page 2*

I do believe that we have a duty to serve those who work within our realm and those for whom medical humanities or bioethics is a “part-time” activity. In particular, many of us feel that there seems little formal training for those appointed to ethics committees. For this reason, the ASBH Board of Directors has asked David Doukas to examine the various ways in which a form of educational outreach can occur for those serving on ethics committees.

I believe it is obvious that all of these activities, these services, depend upon a large number of individuals that have dedicated their expertise, time, and

energy with no expectation of compensation and often with no expectation of acknowledgment. I hope in outlining the various “things” one gets for one’s membership in ASBH, I have acknowledged our debt to our members.

But this should not stop any member from demanding more from this society. The society exists only to the degree by which it serves the needs of its members. ■■

*Tod S. Chambers, PhD, is an associate professor of medical humanities and bioethics at Northwestern University, Chicago.*

## ASBH Meet-the-Professor Program

The ASBH Meet-the-Professor Program gives students and early-career scholars an opportunity to meet with distinguished faculty in bioethics and the medical humanities during the annual meeting. This year’s mentoring breakfast will be held 7:30–8:45 am, Friday, October 24, 2008, in Cleveland, OH.

Students will be assigned to mentors on the basis of the area of interest selected on the registration form: arts, literature, and cultural studies; clinical ethics; education; empirical research; history; law; philosophy; policy and public health; religious studies; research ethics; or social science. Students are responsible for sending biographical information or a curriculum vitae to the mentor before the meeting so that time spent on introductions during the session can be minimized.

There is no additional fee for the mentoring session, but advance registration is required. Additional information and a registration form will be included in the ASBH 10th Annual Meeting registration confirmation letter. ■■

### MASTER of ARTS in BIOETHICS

#### University of Pittsburgh

Designed for clinicians, lawyers, and students of the humanities and social sciences, this interdisciplinary program emphasizes the philosophical foundation of bioethics and offers opportunities for clinical experience and in-depth research. This program of the Center for Bioethics and Health Law and the School of Arts and Sciences allows students to combine study in ethical theory, philosophy and history of medicine, cultural and gender studies, health law, public health, and social sciences. Students may complete coursework, including clinical practica, in one calendar year. A thesis is required. Joint JD/MA and MD/MA programs are available. Applications are considered on a rolling basis, beginning **February 1** until **August 1** or until the class is filled. Financial assistance may be available to highly qualified applicants who apply early. For information and application materials, contact: Director of Admissions, Center for Bioethics and Health Law, Suite 300, Medical Arts Building, 3708 Fifth Avenue, Pittsburgh, PA 15213; [bioethic@pitt.edu](mailto:bioethic@pitt.edu); 412-647-5700; see also [www.pitt.edu/~bioethic](http://www.pitt.edu/~bioethic).

### *Early-Career Scholars: Support for Travel to the ASBH 10th Annual Meeting*

The ASBH Early-Career Scholars Program offers support to early-career scholars and students for travel to the ASBH 10th Annual Meeting. For information and an application form, visit the ASBH Web site at [www.asbh.org](http://www.asbh.org) or contact Amy Claver at [aclaver@connect2amc.com](mailto:aclaver@connect2amc.com). The deadline for receipt of applications is **August 22, 2008**.

## ASBH Exchange Regrets

The Winter 2008 issue of *ASBH Exchange* featured the article “Callousness, Legalism, and Clinical Moral Perception” by Christy A. Rentmeester. An attempt at gender-neutral pronoun use was made by altering the original manuscript, which used both pronouns “she” and “he.” However, “he” was mistakenly printed in all places. The *ASBH Exchange* staff apologizes. The error has been corrected in the online version available at [www.asbh.org](http://www.asbh.org).

Building clinical ethics capacity, bettering patient care

## Are you responsible for ethics programs in your organization? Do you need support?



### Clinical Ethics Summer Institute CESI 2008

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