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- [Cover Story](#)
- [In the News](#)
- [Special News Brief](#)
- [Ethics, Law and Public Policy](#)
- [In the Societies](#)
- [Announcements](#)

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Privacy: Report on the Privacy Policies and Practices of Health Web Sites

by Janlori Goldman, Zoe Hudson and Richard Smith

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Consumers can now obtain a widening array of health care information and transact a growing number of health services online—from accessing information about symptoms, possible diagnoses, and remedies for hundreds of diseases and ailments to comparing rates, and signing up for health insurance. While a growing number of consumers are taking advantage of these services, there are many outstanding concerns about the privacy of health information gathered on these sites.

A recent report issued by the California HealthCare Foundation studied the privacy policies and practices of twenty-one large health-related Web sites. The study found that while nineteen of the twenty-one Web sites studied had privacy policies, few met fair information practice principles. What's more, the information practices at many sites conflicted with the privacy policies. The following article is an excerpt from a recent report issued by the California HealthCare Foundation. The full report is available at <http://ehealth.chcf.org>.

The Explosion of Health Information on the Internet

Current estimates are that the Internet offers at least 17,000 different health care sites, underscoring the large and growing demand for access to health-related information and services online. Of the estimated 110 million Internet users, some 24.8 million U.S. adults have searched for health information on the Internet, with the number projected to grow to more than 30 million this year.

Health care Web sites have access to an unprecedented amount of personal information about consumers. The public's concerns about Internet privacy are significant, and heightened with regard to safeguarding their personal health information online. (1) A survey of 1,009 U.S. adults, released in January 2000 by the California HealthCare Foundation and the Internet Healthcare Coalition found that: (2)

- Seventy-five percent of people are concerned about health Web sites sharing information without their permission.
- A significant percentage of people would not engage in certain health-related activities because of their concerns about privacy and security: Forty percent of people would not give a doctor online access to their medical records, twenty-five percent would not buy or refill prescriptions, and sixteen percent would not register at sites.
- Seventeen percent of people don't even go online merely to seek health information due to their concerns over privacy.

The good news is that nearly eighty percent of people say that the existence of a privacy policy that provides them with

the ability to make choices about how and whether their information is shared has a positive impact on their willingness to engage in online health activities.

Privacy Policies and Practices of Health Web Sites

This report presents a profile of the policies and practices of 21 health-related Web sites.³ What are their policies about the privacy of that information? How easily can consumers find and understand them? Do they afford sufficient protection? And do the actual practices of the health sites reflect their stated policies?

To conduct the survey, we reviewed the privacy policies of each site and investigated whether their actual practices reflect their stated policies. The method of this investigation was (1) to review the stated privacy policies against a set of “fair information practice principles,” and (2) to behave like a typical consumer on each site and observe and capture what happened to the data that were submitted.

It should be pointed out that these privacy policies and these actual practices were those in force during the month of January 2000, when this research was conducted. Our intention in conducting and releasing this research is not to embarrass or single out particular health Web sites or to scare consumers away from getting valuable health information. Rather we aspire to alert consumers and the industry to an impending problem so the industry can address the problem before it becomes acute. In fact, since the release of the report, a number of Web sites have changed their privacy policies and practices.

These are the major findings of the investigative research:

1. Visitors to health Web sites are not anonymous, even if they think they are.

Most online users do not realize that information is being collected about their online activities without their knowledge. Through mechanisms such as cookies, profiling, banner ads, and clickstreams, sites are collecting information about individuals, often without their knowledge or consent. The privacy policies reviewed for this report generally either fail to mention profiling or talk about profiling in very vague terms.

2. Health Web sites recognize consumers' concern about the privacy of their personal health information and have made efforts to establish privacy policies; however, the policies fall short of truly safeguarding consumers.

Nineteen of the twenty-one Web sites studied post privacy policies. It is also encouraging that all of the Web sites posting privacy policies include some prohibition on disclosure of personal information to third parties or business partners. Sixteen Web sites also give users the right to opt in to or out of many specific disclosures such as e-mail newsletters, promotional mailings, and public listings.

Nevertheless, there are significant weaknesses in the policies. Privacy policies generally do not provide adequate notice about when and how the information is collected and by whom. Most strikingly, the policies do not address the collection of information by third-party ad networks and by business partners (such as content providers or co-branded services). Only eight sites provide users with access to the personal information that users submitted voluntarily. None of the Web sites we surveyed allow users to access data collected by third-party ad networks or banner advertisements.

3. There is inconsistency between the privacy policies and the actual practices of health Web sites.

Numerous examples of practices that appear to contradict the stated privacy policies were uncovered. For example, a number of sites purport to prohibit disclosure to third parties in their privacy policies. In an examination of the practices at these sites, however, we observed personally identifiable information being collected through the use of cookies and banner advertisements by third parties. There are also instances where personally identifiable data is transferred to third parties in direct violation of stated privacy policies.

4. Consumers are using health Web sites to better manage their health, but their personal health information may not be adequately protected.

Even with the best intentions, many sites do not have adequate security in place to protect consumer information from

the casual hacker or someone actively seeking to access company databases. The report outlines many security weaknesses at the individual sites.

5. Health Web sites with privacy policies that disclaim liability for the actions of third parties on the site negate those very policies.

Few health sites maintain a chain of trust with third parties on their site because they do not hold those parties to the same privacy standards they espouse. For example, the overwhelming majority of sites do not extend their privacy policies to business partners and third parties (such as ad networks). This is especially troublesome because users themselves may not be aware of any distinctions among the Web site owner, business parties, and third parties, and they may divulge information without understanding the consequences. Whatever privacy protections exist often do not follow the visitor's data once it leaves the site.

Conclusions and Next Steps

Based on the findings of this report and the most recent survey data of consumer attitudes about the ethical conduct of health Web sites, one thing is clear: There is much work needed to provide consumers with an acceptable level of trust and confidence in the privacy safeguards and practices of health Web sites. At best, the privacy policies of health Web sites are confusing, inconsistent, weak, and often misleading when measured against the sites' actual practices. A site with a privacy policy that disclaims liability for the actions of third parties on the site in effect negates the privacy policy.

For starters, this report recommends that organizations and companies that manage health Web sites take the following steps:

1. Perform a thorough evaluation of your site's privacy policy.

The policy should strive to include all elements of fair information practice principles. It should be conspicuous and user-friendly. And it should disclose all that is taking place. Health Web sites should provide users with better notice of information practices, for instance, by alerting users to information practices before they give information, when they leave sites to link to other sites, and when they give information to a partner. No information should be collected by sites without the user's knowledge, such as through the use of cookies or banner ads.

2. Close the loop between privacy policy and practice.

Measure your site's privacy policy against the information practices at your site. Do the information practices differ as users perform various activities on the site? Know the information practices of third-party advertisers and business partners. If their activities are inconsistent with your privacy policy, either alert users or consider instituting a "chain of trust" so that the privacy protections follow the user's data. Health Web sites should hold business partners, contractors, and others to the site owner's policies.

3. Aim to provide users with anonymity.

Many health sites purport to share only "anonymous" or aggregate data with business partners and third parties. The intent is to protect the confidentiality of user information, for while the use and disclosure of anonymized information may be objectionable to some, it does not in and of itself violate individual privacy. It is not always easy to determine whether information is identifiable or anonymous. Information may be anonymous to the Web site owner, but business partners, third-party ad networks, and others may be able to combine the anonymous information with information collected elsewhere to create an identifiable profile on users. Health Web sites that want to promise confidentiality to users will have to make a determination about whether the information disclosed might be vulnerable to such manipulation.

4. Develop a model privacy policy in cooperation with other Internet health leaders.

Clearly, these efforts will require a commitment by Internet health leaders to the principle that core medical confidentiality ethics should migrate to online activities. The recent formation of the Hi-Ethics group and the

convening of an eHealth Ethics Summit by the Internet Healthcare Coalition are encouraging signs. Each is focused on the adoption of principles and standards and on the establishment of a common set of rules for health Web sites to follow. The e-health community must act quickly in this regard. The time to do the right thing is now.

The public has expressed its desire for the online health world to adopt strong, workable privacy policies and practices, and has also expressed that the lack of fair information practices is a significant barrier to people seeking and sharing information and engaging in online health commerce.

Financial pressures often underlie the increase in the collection and sharing of personal information online, but there is more than ample evidence that the public expects—and indeed deserves—privacy to be a more fundamental principle in the operation of health Web sites. This must be the case if we are to realize the potential and promise the Internet offers to improve the quality of clinical care and the health of millions of Americans.

References

1 For additional information on consumer attitudes about Internet privacy see “Beyond Concern: Understanding Net Users’ Attitudes about Online Privacy,” at <http://www.research.att.com/projects/privacystudy>; and National Consumers League, “Consumers and the 21st Century,” 1999.

2 California HealthCare Foundation and Internet HealthCare Coalition, “Ethics Survey of Consumer Attitudes About Health Web Sites,” January 2000. The full findings are available at <http://ehealth.chcf.org>.

3 Twenty-one Web sites were included in the study. General consumer health sites: www.drkoop.com, www.webmd.com, www.mediconsult.com, www.mayohealth.com, www.healthcentral.com, and www.intelihealth.com; disease-specific sites where consumer desire for anonymity might be more crucial: www.oncolink.com (cancer), www.cansearch.org (cancer), www.thebody.com (HIV/AIDS), hivinsite.ucsf.edu (HIV/AIDS), and www.mhnet.org (mental health); Health retail sites where pharmaceuticals and health products may be researched and purchased: www.planetrx.com, www.drugstore.com, www.cvs.com, and www.mothernature.com; general search engines or portals that get a high degree of Internet traffic per media matrix statistics: www.yahoo.com, www.altavista.com, and www.excite.com; and sites that target a specific demographic or type of user: www.onhealth.com (women), www.ivillage.com (women), and www.medscape.com (physicians).

IN THE NEWS

PUBLIC CONSULTATION ON OVERSIGHT OF GENETIC TESTS

On December 1, 1999, the Secretary’s Advisory Committee on Genetic Testing (SACGT) released a document entitled “A Public Consultation on Oversight of Genetic Tests” in response to a request by the US Assistant Secretary of Health and Surgeon General, David Satcher, to use public input to assess the current oversight of genetic tests in the US.

SACGT was chartered in 1998 by Donna Shalala, Secretary of Human and Health Services, to advise the Department of Health and Human Services on the issues raised by the development and use of genetic tests. The document provides background information on the current limitations, benefits, and risks of genetic tests, and the provisions for oversight now in place.

In addition, there are several specific issues and related questions for public comment. These include topics such as criteria for assessing benefits and risks of genetic tests; the use of these criteria in differentiating categories of tests; processes for collection, evaluation, and dissemination of data on tests in each of the categories; and options and levels of oversight in these categories. Another set of questions provides the public with an opportunity to comment on other issues relevant to genetic testing, such as release of test results for research purposes, written informed consent issues, and examination of the role of health care providers in obtaining these tests. Following the public comment period (which closed on January 31, 2000), SACGT will analyze the response and provide advice to the Surgeon General and Secretary of Human and Health Services.

NIH AND DUPONT REACH AGREEMENT ON ONCOMOUSE

The National Institutes of Health and the pharmaceutical company DuPont have signed an agreement that will allow NIH funded researchers to freely use the “OncoMouse” technology licensed by DuPont. Prior to the agreement all non-DuPont researchers, whether in government, academia, or industry, were legally required to pay DuPont for the use of the technology, and the company retained “reach-through” rights on any discoveries deriving from research using the transgenic mice.

The “OncoMouse” technology allows researchers to insert activated cancer-causing genes into an animal’s DNA, creating a mouse that will develop tumors at a much higher rate than a normal animal. The technology was developed with funding by DuPont, and was subsequently patented by the company. DuPont did not begin to enforce the patent until the mid 1990s, by which time the mice were being widely used to study cancer and to test potential treatments. Researchers who had been sharing these mice and publishing research based on their use suddenly were warned that they might be guilty of patent infringement.

Under the *Memorandum of Understanding* signed in January, NIH funded researchers may now use the “OncoMouse” technique without alerting DuPont, and may freely share the resulting transgenic mice with other NIH grantees and non-profit researchers. The existing patent laws will still bind all commercial researchers. Full text of the agreement is available at WWW <http://www.nih.gov/od/ott>. NIH’s principles for sharing biomedical research resources can be found at WWW http://www.nih.gov/od/ott/RTguide_final.htm.

MEDICAL JOURNAL VIOLATES ITS OWN CONFLICT OF INTEREST POLICY

The *New England Journal of Medicine*, well known for having one of the most restrictive conflict-of-interest policies of all medical journals, announced on February 24 that the Journal had broken its own guidelines 19 times over the last three years. The *Journal* apologized to its readers for those violations and vowed to uphold its own policies more consistently in the future.

NEJM’s stated policy is that it will not publish a drug review or editorial by a researcher with “any financial interest in a company (or competing company) that makes a product discussed in the article.” At many other journals, researchers with industry ties may publish their findings as long as their funding sources are clearly stated alongside the article.

The February 24th announcement came after a Los Angeles Times article reported in 1999 that a *NEJM* drug review of hair replacement drugs was written by a researcher who received significant funding from a manufacturer of one of the drugs. A series of articles in the Times revealed several other examples of drug reviews in which the journal violated its own conflict-of-interest policy. The subsequent internal review by *NEJM* found nineteen instances since January 1, 1997, where authors of drug therapy reviews received funding from relevant pharmaceutical companies. Some of these authors did not receive funding directly from pharmaceutical companies, but the companies had supported their research projects through funds given to the universities at which the researchers worked. *NEJM* stated that this type of indirect funding did in fact violate their conflict-of-interest policy and should not have been allowed.

ONCOLOGIST FIRED FOR SCIENTIFIC MISCONDUCT

A breast cancer researcher at a South African university was fired on March 10, 2000, for committing scientific misconduct after an audit of his research by an international team of doctors found that he had falsified data and misrepresented his research at a scientific conference. Werner Bezwoda, who chaired the University of Witwatersrand’s Department of Oncology and Hematology, was also found to have ignored university regulations by failing to submit his research protocol to the University’s Committee for Research on Human Subjects prior to instigating the study.

The independent audit was prompted by Bezwoda’s presentation at the American Society of Clinical Oncology’s May 1999 meeting in Atlanta, where he showed data indicating an increased life expectancy for women with advanced breast cancer who were treated with high-dose chemotherapy and bone marrow transplants compared to those given a more traditional treatment. Four other studies also presented at the meeting found no prognostic improvement for women given this controversial procedure, which has been demanded by many patients despite a lack of supporting clinical evidence. Bezwoda’s data, which offered hope to many doctors and patients, were met with both excitement and skepticism from the audience. A larger randomized trial was planned to test his findings, but suspicious

researchers called first for an independent review of his research.

The auditors performed an on-site audit in February and reported their findings in the March 18 Lancet. The team of doctors and nurses were not allowed to see the medical records for over half of the purported 154 study participants, and those they did examine revealed many deviations in treatment design and patient profiles from the protocol presented at the May meeting. Bezwonda admitted that the control group had actually received an experimental drug treatment instead of the standard therapy, invalidating the experiment's results. No evidence was found that any of the study subjects had signed informed consent agreements, and the study had not been registered with the University's institutional review board (IRB). After a disciplinary hearing on March 10, Bezwonda was fired by the University. He is appealing his dismissal.

In a statement issued by the University of Witwatersrand on March 10, Vice Chancellor Colin Bundy pledged that a complete review of all Bezwonda's recent research would be conducted, and stated that "the University regrets this deplorable breach of ethics....We will do everything possible to prevent this shocking breach of individual rights of our people from ever occurring again."

SPECIAL NEWS BRIEF

GENETIC DISCRIMINATION BANNED

by Rachel Gray

On February 8, at the American Association for the Advancement of Science (AAAS), President Clinton signed the first executive order (EO) of 2000. The signing of the EO at AAAS was significant considering that a group convened under the auspices of AAAS issued a statement last fall on genetic discrimination in health insurance.⁽¹⁾ Additionally, the same day the President issued his EO, AAAS released a statement emphasizing its opposition to the use of genetic knowledge as a tool for discrimination.⁽²⁾ This historic action by the President prohibits genetic discrimination in the workplace and is part of the Administration's longstanding effort to ensure that new discoveries "do not pry open the protective doors of privacy." The President was joined by Francis Collins, director of the Human Genome Research Institute at the National Institutes of Health and Shirley Malcolm, directorate head for education and human resources at the AAAS. Collins hailed Clinton's action to protect federal workers as an example of "preventive policy making" that offers a model for dealing with the issue before genetic privacy becomes a "crisis situation."

The President expressed his amazement at the rapid progress science has made in understanding human genetics, noting that the Human Genome Research Project is expected to finish a draft of the human genome by April of 2000. In light of this and numerous other advances, he said that this action will ensure that health information from genetic tests will be kept private. Clinton stressed the importance of preventing "the misuse of genetic tests to discriminate against any American."

The EO prohibits federal employers from requiring or requesting genetic tests as a condition of being hired or receiving benefits. Employers would not be able to require employees to undergo genetic tests in order to evaluate an employee's ability to perform his or her job. The EO also prohibits federal employees from using protected information to classify employees in a manner that deprives them of advancement opportunities. For example, employers would not be able to deny promotion or overseas posts due to a genetic predisposition for certain diseases. Additionally, the EO provides strong privacy protections to any genetic information used for medical treatment and research. Under the EO, obtaining or disclosing genetic information about employees or potential employees is prohibited, except when it is necessary to provide medical treatment to employees, ensure workplace health and safety, or provide occupational health and health researchers access to data. The President stated that he wants this action to "set an example for every employer" and that he believes "no employer should ever review your genetic records along with your resume."

In addition to the EO, the President will endorse the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999. This Act (HR 2457), sponsored by Rep. Louise Slaughter (D-NY) and Senate Minority Leader Tom

Daschle (D-SD) will extend the privacy protection of genetic information to the private sector, and to individuals purchasing health insurance. In 1996, the President signed the Health Insurance Portability Act (HIPPA) which prevents group health insurers from using genetic information to deny individuals health insurance benefits. The Daschle-Slaughter legislation finishes the job begun by HIPPA, by ensuring that genetic information used to help predict, prevent, and treat disease will not also be used to discriminate against those seeking employment, promotion, or health insurance.

On a related topic, the President spoke about the present controversy surrounding gene therapy clinical trials. Specifically, he mentioned researchers failing to comply with federal regulations that require the reporting of any serious injury or death, and allegations that patients may have been misinformed about the risks associated with the gene therapy trials. In response to these events, the President requested that the Secretary for Health and Human Resources expedite the Federal Drug Administration and National Institutes of Health's review of gene therapy guidelines and regulations.

The President cautioned that "we cannot allow our remarkable progress in genomic research to be undermined by concerns over the privacy of genetic data or the safety of gene therapies." We must "do whatever it takes to address these legitimate concerns." The EO can be found on the WWW at <http://www.pub.whitehouse.gov/urires/>

[12R?urn:pdi://oma.eop.gov.us/2000/2/8/8.text.1](http://www.eop.gov.us/2000/2/8/8.text.1)

1 The AAAS statement can be found on the [WWW at http://www.aaas.org/spp/dbsr/news/gdiscrim.htm](http://www.aaas.org/spp/dbsr/news/gdiscrim.htm)

2 For a copy or more information on the *AAAS Statement on Genetic Discrimination* contact Ginger Pinholster, AAAS New and Information at (202) 326-6421 or by email gpinhols@aaas.org

ETHICS, LAW AND PUBLIC POLICY

PROTECTING HUMAN SUBJECTS IN CLINICAL RESEARCH: MOVING BEYOND A COMPLIANCE ORIENTATION

by Mark R. Yessian, Ph.D.

Mark R. Yessian, Ph.D., is Regional Inspector General for Evaluation and Inspections (Boston Office) of the US Department of Health and Human Services. His office played the leading role in preparing the Office of Inspector General's (OIG) June 1998 study entitled, Institutional Review Boards: A Time for Reform. (This report and subsequent ones are available on the WWW at <http://www.dhhs.gov/progorg/oei>.) For the most part this commentary parallels recommendations made in the OIG reports. It is offered here with the caveat that the views expressed do not necessarily represent those of the OIG or the U.S. Department of Health and Human Services.

In June 1998, the Office of Inspector General in the U.S. Department of Health and Human Services issued a report warning that the effectiveness of Institutional Review Boards (IRBs) was in jeopardy. Subsequent to that, the Office for Protection from Research Risks (OPRR), located within the National Institutes of Health, substantially stepped up its enforcement of Federal human-subject protections. In a number of cases, this has led to the temporary suspension of all federally funded research at medical centers.

In the face of these enhanced enforcement efforts, medical centers have become increasingly focused on compliance with federal requirements. They are keenly aware that noncompliance can cost their institutions significant amounts of money, affect their reputations, and slow down vital research. Such concern has been highlighted further by the recent fallout concerning the lack of oversight given to gene transfer trials.

This heightened attention to compliance is a positive development. But it runs the danger of approaching human-subject protections in a narrow mode aimed at staying out of trouble with the regulators rather than in a systemic manner intended to incorporate protections as an integral element of the clinical research process. In this commentary,

based on a January 2000 presentation before a meeting of the American Health Lawyers Association, I offer six suggestions on how medical centers can move in the latter direction.

1. Approach human-subject protections as an institutional, not just an IRB responsibility.

Too often and too easily in the research community the “default” position is that it is the IRB’s job to protect human subjects. If the IRB has approved a research plan, then ipso facto the protections have been provided. Thus, by extension, if a consent form has been approved, then informed consent has been adequately taken care of, regardless of the dynamics of the actual process of obtaining consent. All too easily, sponsors, investigators, and others involved with that process can lose a sense of responsibility for what takes place.

This is a dangerous position, one that expects too much of already overburdened IRBs. Moreover, it leads almost inevitably to reinforcing the perception of IRBs as bureaucratic gateways and as policing functions that unnecessarily slow down and interfere with the research process. It loses sight of the reality that, while investigators are the ones that can do the most harm to subjects, they are also the ones that can do the most good.

The challenge to medical centers is for executive leadership to make it clear to the research community that providing proper protections is everyone’s job and that all parties will be held accountable for performing that job well. This message is particularly important at the current time when medical centers are highly dependent on operating revenue generated by industry-sponsored trials, when IRBs face pressures to conduct rapid reviews, and when investigators face similar pressures to achieve rapid enrollment of human subjects. In subtle and sometimes not so subtle ways, these developments can compromise the protections afforded to subjects.

2. Grant IRBs the organizational status and resources befitting their importance.

It is beginning to change, but IRBs are typically located somewhere in the organizational hinterland of a medical center. More troubling, they often are housed in offices of grants and contracts—the offices geared to bringing in research funds. While this does not necessarily lead to a conflict, it certainly creates the appearance of one. If executive leadership seeks to convey a strong message that IRBs have a vital role to play, then it can provide valuable support to that message by insulating the IRBs from the business, revenue-producing interests of the institution.

Of course, there are also other more tangible ways that the message can be reinforced. These include commitments of staff, equipment, office-space, and the like. And they include commitments from the institution as a whole and the academic departments to encourage faculty and investigators to serve on IRBs and to give them recognition for doing so.

3. Educate! Educate! Educate!

In the research community, this is the common refrain when we and others bring to light shortcomings in human-subject protections. If investigators, sponsors, and others associated with the research process become more sensitized to and informed about ethical standards for research involving human subjects, many of these shortcomings, it is felt, will be solved. This proposition is a sound one, but too often we have found that it is followed by insufficient action. For instance, I have been to medical centers that have established exemplary education programs that have fallen well short of reaching their potential because investigators seldom attended.

A key reality here is one that Dr. H. K. Beecher underscored many years ago: the most basic protection afforded to research subjects is that which comes from well-trained, well-meaning investigators. If we ensure that is in place, we may not be so dependent on the IRBs.

4. Develop guidelines for human-subject recruitment practices.

Clinical research is taking place in increasingly commercialized and competitive environments where sponsors and investigators face growing difficulty finding human subjects and finding them quickly. In this environment, sponsors and investigators are relying on a variety of techniques, some rather aggressive in nature, to recruit human subjects. IRBs are hardpressed to stay on top of these developments and have little guidance they can draw upon to determine

the appropriateness of recruitment practices.

Medical centers can help here by developing guidelines that address questions such as the following: Is it acceptable for sponsors to offer bonuses to investigators for successfully recruiting patients? Should physicians and others be allowed to receive fees for referring patients as potential subjects for a clinical trial? Should the financial arrangements between sponsors and investigators be disclosed to potential subjects, and, if so, how? Does searching medical records for potential subjects constitute a breach of confidentiality?

5. Expand outside representation on IRBs.

Federal regulations now require that IRBs have one noninstitutional and one nonscientific member. Thus, if an IRB has one member who fills both roles, it is in compliance with federal law, even if the IRB board includes 15 to 20 members. Here, then, is a good example of how a medical center can stay out of trouble with the regulators but still fail to take sufficient action to shore up its human-subject protections. Noninstitutional representatives on an IRB can play valuable roles in providing balance and greater public credibility to IRB deliberations, particularly in the current highly commercialized environment. Yes, it can be difficult to find, train, and retain such outside members, but the effort is well worth it.

The national commission that developed the framework for federal human-subject protections in the 1970s was well ahead of the curve here. At that time, it concluded that at least one-third but no more than two-thirds of IRB members should be scientists as a way “to assure the IRB’s access to scientific expertise, yet guard against self-interest influencing or appearing to influence IRB determinations.”

6. Evaluate! Evaluate! Evaluate!

When meeting with the leadership of medical centers, I often ask: “How do you know if the IRB at your institution is doing an effective job in protecting human subjects?” Too often, I get an answer something like this: “If I don’t read anything about it in the newspaper.”

In the real world of multiple pressures and strains, that response is understandable. But surely even the respondents recognize that it is insufficient. This issue is too important to be left just to the regulators. The centers and the IRBs themselves must find ways of determining not just if the IRBs are in compliance with regulations, but how well they are protecting subjects. In this context, it is important to determine not only that informed consent forms include the necessary information and are properly signed, but also that the consent process takes place in ways that foster understanding and voluntary, informed participation. Similarly, it is important to confirm that proper trade-offs are being made between the risks and benefits of research, not just at the beginning point of the research but throughout the course of the research.

Closing

To the extent medical centers move in the directions I outline above, they should enhance their prospects of staying out of trouble with the regulators and of avoiding costly slip-ups that stall research efforts. But at the same time they should be able to accomplish much more. They should find that they are placing their human-subject protections on a solid foundation, one that will not only uphold the interests of potential and existing subjects, but also advance the clinical research process through which such subjects and all of society can gain so much. To the extent medical centers move in the directions I outline above, they should enhance their prospects of staying out of trouble with the regulators and of avoiding costly slip-ups that stall research efforts. But at the same time they should be able to accomplish much more. They should find that they are placing their human-subject protections on a solid foundation, one that will not only uphold the interests of potential and existing subjects, but also advance the clinical research process through which such subjects and all of society can gain so much.

IN THE SOCIETIES

SCIENTIFIC SOCIETIES PROTEST LEE'S INCARCERATION

Within the last month, three major American scientific organizations wrote to US Attorney General Janet Reno, voicing their distress with the conditions of pre-trial incarceration for Wen Ho Lee. The organizations are the Committee on Scientific Freedom and Responsibility (CSFR) of the American Association for the Advancement of Science (AAAS), the Committee on Human Rights of Scientists (CHRS) of the New York Academy of Sciences (NYAS) and the American Physical Society (APS).

In 1999, Wen Ho Lee, a physicist at Los Alamos National Laboratory, was accused of improperly downloading secret information onto unsecure computers at the Laboratory and onto portable computer tapes. Since being charged, Lee has been incarcerated and denied bail. The computer tapes have not yet been found.

The three letters protested the harshness of Lee's treatment in prison, and raised the possibility that his treatment may stem from his ethnic background. The February 29th letter from Irving Lerch, Chair of CSFR, listed the reported conditions of Lee's detention, which include cell confinement for 23 hours a day, shackling of arms and legs when moving within the confines of prison, no access to TV, and monitored meetings with family members.

"The extraordinarily harsh conditions under which he (Lee) is detained suggest to the outside world that he is presumed guilty, and is being punished, before his trial has even begun," wrote James S. Langer in the February 28th letter on behalf of APS. Furthermore, all three organizations raised concerns regarding the adverse impact of the situation upon the scientific community. This sentiment was reflected in a March 14th letter from Joseph L. Birman, chairman of the CHRS, in which he states, "We earnestly call to your attention that Dr Lee's treatment during his detention has had a seriously chilling effect on the scientific community, especially because of the suspicions that his ethnic background has played some role in this treatment and in the unproven public allegations made about his possible motives for the acts of which he is accused.

Federal officials justify the extreme conditions of Lee's incarceration by arguing that it is a way to ensure that the accused does not communicate the location of any of the missing tapes to others. If released, they contend, Lee could pose a threat to US national security, a presumption challenged by AAAS in its letter.

None of the three letters made a judgment about Lee's guilt or innocence.

ANNOUNCEMENTS

Computer Ethics: Philosophical Enquiry (CEPE2000) will be held July 14-16, 2000, at Dartmouth College. The conference aims to foster and promote philosophical work which makes a constructive contribution to the ethical questions associated with the adoption, use, and development of information and communications technology (ICT). Information technology and human values, the ethics of artificial intelligence, privacy and surveillance, and the rights and obligations of cyberspace are among the topics to be explored. The conference is being sponsored by the Dartmouth College Philosophy Department and the American Computing Machinery Special Interest Group on Computers and Society. Contact Deborah G. Johnson, Program In Philosophy, Science, and Technology, School of Public Policy, Georgia Institute of Technology, Atlanta, Georgia 30332-0345, Email deborah.johnson@pubpolicy.gatech.edu; James H. Moor, Dartmouth College, james.h.moor@dartmouth.edu or Herman T. Tavani, Rivier College, htavani@rivier.edu; WWW <http://www.dartmouth.edu/~phil/events/CEPE2000.html>

Ethics & Behavior will publish a special issue in early 2001 on the topic of "Employee Relations Ethics." Andrew Sikula, Sr., a member of the Editorial Board, will be guest editor. Articles addressing the ethical implications of the changing social contract between employers and employees in both the public and the private work sectors, with a focus on the American experience, are welcome. Articles on other topics such as the changing nature of work; the altered composition of the work force; the effects of re-engineering and down-sizing; the declining impact of unions; and other ethics in employment issues are also of interest. The deadline for manuscript submission is July 1, 2000. Contact Andrew Sikula, Sr., Elizabeth McDowell Lewis College of Business, Graduate School of Management, Marshall University Graduate College, 100 Angus E. Peyton Drive, South Charleston, WV 25303-1600; (304) 746-

1956; Fax(304) 746-2063; Email sikula@marshall.edu

The **University of Montana** will offer three short courses in Ethics during the summer of 2000. "Ethics Across the Curriculum" will be held July 24-28, 2000. It is a five-day workshop designed to help instructors integrate the teaching of ethics into the curriculum throughout the university. Course topics include goals for teaching ethics, the use of classical theory, moral development theory, activities to teach systematic moral analysis, and evaluating outcomes. Ethical issues to be explored include justice, blameworthiness and praiseworthiness, loyalty, honesty, and special role-related responsibilities and privileges. "Foundations of Moral Philosophy" will be held on August 14-25, 2000, and the two-week intensive workshop will provide an introduction to three major Western approaches to ethics: virtue theory, deontology, and utilitarianism. Contact the Practical Ethics Center, Department of Philosophy, University of Montana, Missoula, MT 59812. (406) 243-5744; Email ethics@selway.umt.edu; WWW <http://www.umt.edu/ethics>

Integrating Ethics into Technical Education II will be held on June 1-2, 2000, at Raritan Valley Community College. The goal of the conference is to provide a stimulating forum for the exchange of ideas between technical educators and ethicists regarding best practices and the development of new approaches to the integration of ethics into the technical curriculum. Discussion will focus on some of the following topics: defining new ethical issues in technical education; sharing experiences in integrating ethics and technical education in the classroom; establishing criteria for ethical decision-making and norms for ethical conduct; and assessing the importance of ethical conduct to the corporation. Contact Joyce Tigner, Humanities Department, Raritan Valley Community College, P.O. Box 3300, Somerville, NJ 08876-1265; (908) 526-1200, ext. 8305; Fax (908) 526-0253; Email jtigner@rvcc.raritanval.edu.

A conference on **Philosophical Issues in Ethics Across the Curriculum** will be held on October 19-22, 2000, in Salt Lake City. The intent of the conference is to lay bare the variety of philosophical and pedagogical issues raised by teaching ethics. Papers and presentations due June 1, 2000. Contact Wade Robison, Department of Philosophy, Rochester Institute of Technology, Rochester, NY 14623; (716) 475 6643; Email wlrgh@rit.edu.

Indiana University's seventh annual **Teaching Research Ethics Workshop** will be held on May 17-20, 2000. Faculty participating in the workshop will be able to design syllabi or course units integrating substantive issues in research ethics. Students of participating faculty will develop better moral reasoning skills and will be better able to recognize and act on ethical issues. Contact Kenneth D. Pimple, Poynter Center, Indiana University, 618 East Third Street, Bloomington IN 47405-3602; (812) 855-0261; Fax (812) 855-3315; Email pimple@indiana.edu; WWW <http://www.indiana.edu/~poynter/>

Organizational Ethics for Clinical Ethicists will be held in Chicago on June 15-17, 2000. The conference is being co-sponsored by the Loyola University of Chicago Center for Ethics and the Joint Commission for the Accreditation of Healthcare Organizations. Clinical ethicists, ethics committee members in hospitals, health systems, and health care organizations, ethics faculty in medical schools, nursing schools, and other health disciplines professional schools; and HMO compliance and business conduct officers are invited to registrar. Contact the Center for Ethics, Loyola University of Chicago, 6525 North Sheridan Rd., Chicago IL 60626; (773) 508-8349, (773) 508-8879; Email bjanis@luc.edu; WWW <http://www.luc.edu/depts/ethics>

Research on Research Integrity will convene a conference on in the Washington, DC, on November 18-20, 2000 to discuss emerging challenges for the responsible conduct of research. The conference is being sponsored by The Office of Research Integrity (ORI), along with the American Association for the Advancement of Science (AAAS), the Association of American Medical Colleges (AAMC), the National Institutes of Health (NIH) and the National Science Foundation (NSF). It will provide a forum for sharing information and ideas to aid decision making about promoting research integrity and monitoring research misconduct. Scholars from various disciplines are encouraged to submit abstracts and participate in the dialogue for understanding issues related to research integrity. Abstracts for papers and poster sessions are due by April 30, 2000 Contact Nicholas Steneck, Office of Research Integrity, 5515 Security Lane, Suite 700, Rockville, MD 20814; (301) 443-2080; Email nsteneck@osophs.dhhs.gov

As part of the Hawaii International Conference on Systems Sciences, to be held January 3-6, 2001 on the island of Maui, the **Professional Ethics in Information Systems** minitrack invites paper submissions from a wide spectrum of disciplines where professional ethics in information systems are relevant. Appropriate topics include: data protection

and privacy, academic dishonesty, adherence to confidentiality agreements, intellectual property rights, cross-cultural analysis, and the teaching of ethics in IS.. The journal *Ethics and Information Technology* has indicated that it is interested in fast-track publication of selected best papers from this minitrack. Deadline for submission of full articles is June 1, 2000. Contact Eileen Dennis; (706) 613-7807, (706) 613-5348. Email edennis@uga.edu; WWW http://www.hicss.hawaii.edu/HICSS_34/h34cfp.htm