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Hospitals, patients clash on privacy rights: Bioethics & hospital economics

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“Patients are grateful - it is reasonable for hospitals to ask them to help out... but it is impolite and erodes trust for hospitals not to ask specifically if patient information can be shared for fundraising.” said Professor Robert Baker of Union Graduate College and panelist for NYC-based Bioethics International’s United Nations-affiliate conference when interviewed about Hospitals and other health care organizations using patient information, without explicit consent, for fundraising. SfGate article below on institutions mining patient lists to find wealthy potential donors.

Joan Broner, like many people, never reads the fine print at her medical appointments. As a consequence, the 58-year-old San Francisco resident, who has arthritis, regularly receives solicitation letters at home from several local hospitals. The letters infuriate her. “It feels like an invasion of privacy,” she said. “If I’m sick and I go to a doctor, I don’t want them telling anybody about it. My disease is not for sale.”

When patients check into hospitals or doctor offices, they presume their information will be kept in strictest confidence, but often, amid the pile of papers, they overlook fine print describing how their personal information can be farmed out for fundraising.

Hospitals and other health care organizations widely use patient information, without patients’ explicit permission, to raise funds. To the dismay of privacy-rights advocates and some in the medical field, fundraising to benefit medical institutions is allowed under federal law. Patients can opt out - after the fact.

Critics say the practice of soliciting donations from current and former patients - no matter how worthy the beneficiary - symbolizes the erosion of personal privacy in contemporary life. To privacy advocate Dennis Melamed, the federal law has an egregious loophole. “It’s a big surprise to patients just how far and wide their data is going,” said Melamed, editor of the Health Information Privacy/Security Alert, a trade newsletter.

Fundraising efforts by UCSF led to a recent privacy breach involving more than 6,300 patients whose names and other information were inadvertently posted on the Internet - the institution had shared patient information with a vendor that searches databases to find wealthy potential donors.

Mark Laret, chief executive of the UCSF Medical Center, in an interview with The Chronicle, called the breach a “serious problem.” In its wake, fundraising practices are being re-examined, he said.

“I’m sorry that it happened,” he said. “This whole circumstance has caused us to take another look at the information we give patients and how we ask for their permission for nonmedical issues. Protecting privacy and confidentiality is among the most important things we do for everyone who comes to this medical center.”

UCSF received \$252 million in private support during fiscal year 2006-07, a 25 percent increase over the prior year.

For Laret, the breach triggered an important question: Are patients given too much information to sort through at the time of admission?

Typically in medical settings, patients are handed booklets called “notice of privacy practices.” The documents explain the numerous ways patient information can be used, including fundraising to benefit the health care operation. When patients sign the statement, it’s an acknowledgement that they’ve received the information.

In the UCSF breach, the names of the patients and the medical departments where they were treated were shared with the vendor and exposed on the Internet along with the patients’ medical record numbers.

The information provided to the vendor exceeded what is permitted by federal law, which allows only patient “demographic information,” including name, address and dates of medical care, to be used for fundraising purposes without specific patient consent.

#### Fundraising: A critical need

With a third of the nation’s hospitals operating in the red and another third struggling to break even, fundraising has become an increasingly critical, fruitful endeavor. In 2006, \$8 billion was raised through philanthropy by U.S. hospitals, medical centers, hospices and long-term-care facilities, an 11 percent increase over the previous year, says the Association for Healthcare Philanthropy, a not-for-profit organization that works with health care fundraisers.

Many hospitals rely on fundraising - what some development experts call “high touch direct mail” - to finance costly new equipment, a new wing, a chapel.

“It really helps hospitals in terms of getting equipment they couldn’t afford or it helps offset the amount of money they have to borrow,” said Jan Emerson, speaking for the California Hospital Association.

A Chronicle survey of a dozen Bay Area hospitals and medical centers found that the majority directly solicit current or former patients. “It is part of our culture in America,” said Bill McGinly, president and chief executive of the philanthropy association. “Universities and colleges have access to student records. Grateful patients are our alumni.”

Implemented in 2003, federal patient privacy provisions have made fundraising more restrictive, McGinly said. "Before, our members had access to patient records," he said. The law set limitations. If a medical center wants to do targeted mailings to cardiac patients, for example, to help fund a new heart center, the patients' direct authorization would be needed.

Research Professor Joy Pritts of the Center for Medical Record Rights and Privacy at Georgetown University's Health Policy Institute believes the limitations are not enough. A more "respectful" approach, she said, would be to require a patient's explicit consent before the patient's data can be used for fundraising.

Patient privacy, said Pritts, "is about more than improper disclosures; it is also about patient control over how their information is to be used."

"Some hospitals have started the practice of asking patients up front," she said. "The benefit is when the patient receives the fundraising information, it is not a surprise. The argument against asking up front is that people might say no."

McGinly said many hospitals are reluctant to seek written approval because "it becomes a tracking nightmare." Typically, he said, hospitals do general appeals to all patients.

#### California's privacy act

California has a medical privacy act "designed to prevent patients from being used as a marketing database," said San Francisco attorney Khaldoun Baghdadi, who has handled claims from patients who believe their privacy has been violated. "If that medical information was disclosed negligently, each patient can be awarded \$1,000 per violation."

Patient privacy consciousness has heightened in recent years, say experts, in part because of the electronic explosion of information sharing.

Joanne McNabb, chief of the California Office of Privacy Protection, said that, as a basic principle, "information collected for one purpose shouldn't be used for another without specific consent. If you are going to use it for a secondary purpose, you should disclose it."

Some doctors believe that revealing any patient information, even for benevolent purposes, violates a relationship of trust.

"Patients are grateful - it is reasonable for hospitals to ask them to help out," said Professor Robert Baker, head of the bioethics program at Union Graduate College in New York. "But it is impolite and erodes trust for hospitals not to ask specifically if patient information can be shared for fundraising."

To Dr. Steven Fugaro, an internist and president of the San Francisco Medical Society, the matter raises ethical concerns.

“When you go to Macy’s or Wal-Mart or buy a car, it has come to be expected that your name will be used for commercial purposes,” he said. “But it seems to me that physicians and hospitals have higher standards. People come to us ... because they are sick. They have an expectation that their names will be kept private, even the fact that they were treated by the doctor or hospital.

“I’m sure that the vast majority of patients are not aware that this is done.”

That was the case for Warren Lambert, a San Francisco resident whose name was part of the UCSF breach.

“I assumed my privacy was protected, but it wasn’t,” he said. “Their vendor pried into my personal financial matters for the direct benefit of UCSF. It is outrageous - and to me it is unethical.”