Ethics and Information Systems: Making Values Explicit

BY THOMAS F. SCHINDLER, PhD

A t first glance, the information systems department of a healthcare organization might seem an unlikely place to find ethical questions. After all, information systems merely gather and disseminate data. "Data" is a Latin derivative, originally meaning "the given." Questions about data's use and interpretation—ethical questions—would appear to be the business of planners and financial managers—not information systems workers.

VALUES ALWAYS PRESENT

But the matter deserves another look, for two reasons. First, while information systems deal with "the given," they do not in fact collect all possible data. Consider, for example, the types of data that are and are not available about healthcare. One can fairly easily find out the number of admissions and discharges, births and deaths, surgeries and X-rays in a particular geographical area. But it is more difficult to get information on the number of acupunctures performed, on how well patients feel their pain is managed, or on the degree to which attention paid to a patient's spiritual health affects the healing process.

This latter set of categories is no less part of the "given" world than the former, and no less capable of generating bits of information that might be gathered and disseminated.

But if this is the case, why has the latter set of categories been neglected? Probably because data collectors thought the items were not important; the items were not seen as playing a significant role in the achievement of something of value.

There is another reason why we should give data collection a fresh look. While information systems workers do not always pay close attention to which aspects of "the given" they routinely collect and which they overlook, they become immediately attentive is someone suggests there are types of information they should *avoid*. They generally react negatively, basing their protest on what they understand as the ethical neutrality of their work: simply gathering information. There

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may even be a hint of ethical outrage in their protest: The suggestion that one avoid certain data sounds to them like censorship.

But is this the case? Are there types of data that should simply be unavailable? A new Michigan law forbids gathering information about the books a person borrows from a library. In this case, the potential for abuse is judged to outweigh whatever positive use might be made of the information. Such uses of data seem to undermine, rather than promote, the values we want to preserve.

Values are *always* present and operative, even if they are not at first evident. So, as we consider what should and should not be subject to information gathering and dissemination, we should first be clear about what our values are.

WHICH VALUES?

What *are* the values that help us determine which data should, and should not, be collected and disseminated? I offer the following list, though it is certainly not exhaustive.

Financial Stability A healthcare organization rightly seeks to maintain its existence and carry out its mission. Gathering and disseminating information to achieve those goals are appropriate.

Community Health Status Healthcare—like air or water—belongs to the community as a whole. The quality of a healthcare provider is therefore judged not simply by how well individual patients are treated but, more important, by how the community's overall health status is advanced. It follows that the healthcare provider must be well informed about the community's health needs and how best to meet them.

Confidentiality Individuals have a right to control information about their medical conditions, to determine when and with whom that information will be shared.

Wellness and Prevention Promotion There is general agreement that this value needs greater emphasis than it has received in the past in order to better

Calendar

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For information on Catholic Health Association educational events, see pp. 64-65.

SEPTEMBER

American College of Healthcare Executives, San Francisco cluster, 19-23 (312-943-0544)

American Organization of Nurse Executives, "Reengineering Care Delivery," St. Louis, 26-27 (312-280-5995)

American College of Healthcare Executives, Atlanta cluster, 26-30 (312-943-0544)

OCTOBER

Medical Group Management Association, Annual Meeting, Boston, 2-5 (303-799-1111)

National Association for Healthcare Quality, Annual Educational Conference, Reno, NV, 2-5 (708-966-9392, ext. 2231)

American College of Healthcare Executives, Eastern Conference, Miami, FL, 6-7 (312-943-0544)

American Society of Law, Medicine, and Ethics, Annual Meeting, Pittsburgh, 7-8 (617-262-4990)

American College of Healthcare Executives, Squaw Valley, CA, cluster, 10-11 (312-943-0544)

Estes Park Institute, "Can Values Make the Difference?" Squaw Creek Olympic Valley, CA, 16-19 (303-761-7709)

American College of Healthcare Executives, "Partnership Institute," Boca Raton, FL, 17-19 (312-943-0544)

Healthcare Forum, "Transforming Healthcare Delivery," Amelia Island, FL, 23-26 (415-421-8810)

American College of Healthcare Execu-

tives, "Healthcare Executive Leadership Development Institute," Durham, NC, 23-28 (312-943-0544)

National Safety Council, Congress & Exposition, San Diego, 23-28 (708-775-2303)

American Organization of Nurse Executives, "Mastering the New Economics of Health Care Reform," Atlanta, 27-28 (312-280-5213)

National Interfaith Healthcare Leadership Conference, "Religiously Based Healthcare Providers: Do We Have a Future?" Phoenix, 30-November 2 (410-266-3644)

NOVEMBER

American Organization of Nurse Executives, "Reengineering Care Delivery," Baltimore, 3-4; "Mastering the New Economics of Healthcare Reform," Chicago, 10-11 (312-280-5213)

American College of Healthcare Executives, San Antonio cluster, 7 (312-943-0544)

American Society of Law, Medicine & Ethics, "Ethics Committees and the Elderly," New York City, 11-12 (617-262-4990)

American College of Healthcare Executives, "Healthcare Executive Public Policy Institute," Washington, DC, 13-16 (312-943-0544)

DECEMBER

American College of Healthcare Executives, Orlando, FL, cluster, 5-6; 8-9 (312-943-0544)

Medical Group Management Association, "Integrated Care Systems," Dallas, 5-7 (303-799-1111)

Congress on Health Outcomes & Accountability, Washington, DC, 11-14 (415-495-2450)

the community's health in a cost-effective way. Such promotion will obviously require the dissemination of appropriate information.

Accountability Because healthcare is a community resource, those who provide it are accountable to the public. The public therefore needs information about the quality of care provided by its physicians, nurses, hospitals, long-term care facilities, and other providers.

VALUES IN CONFLICT

While we seek ever more information about our community, we must at the same time be mindful of privacy rights. For example, new technologies allow one to identify the names, addresses, and phone numbers of people who call, even if they want to remain anonymous. Using information acquired without the caller's permission strikes me as highly problematic. Since data collectors may be tempted to make use of such information, I question whether it should be collected at all.

And data collectors may face another kind of temptation: As they gather information about the quality of healthcare provided by local physicians and facilities, they may find themselves pressured to keep such data secret, or at least unavailable to the general public. But, given the healthcare providers' accountability to their community, they should resist this temptation as well.

Obviously, the values listed above will sometimes conflict. For example, a concern for improving *community health status* might result in a violation of the *confidentiality* of the community's members. Or the public's right to *accountability* could endanger the *financial stability* of a particular healthcare facility. The pursuit of one value might mean that another must be forgone.

How such conflicts are resolved will depend on the concrete situation. The goal is to act in a way that realizes the most important value in a given situation, while preserving the other values as well. □