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# The Ethics of Health Privacy — A Matter of Environmental Ethics

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*Health information privacy is frequently neglected in health care reform plans; however, the integrity of health information and health care overall will quickly erode if individuals feel compelled to engage in privacy-protective behaviors. People who fear that an intrusive use of their information could occur as a result of their consent to disclosure, or that breaches of confidentiality are likely to interfere with their future plans and opportunities, may be reluctant to make disclosures and some may delay seeking medical treatment. This article explores health information disclosure duties and utilities and frustrated plans and expectations as a special problem in environmental ethics. It argues — not on the basis of law and the ethics of privacy, but on social, community-oriented, and utilitarian grounds — that our need for a climate of sustainable privacy is analogous to, and as vital to individuals and society, as our need for clean air, water, and land.*

**M**uch attention has been focused in recent years on how to improve health care, but a factor that has frequently been neglected is the role that health information privacy plays in the health care setting. Protecting privacy is typically regarded as an obstacle to achieving health care-related goals. Some believe that protecting privacy will impede the flow of health information and jeopardize research, public health, emergency care services, and other health-related objectives.

In fact, the opposite is true: lacking the necessary confidence that their health information will be safeguarded, consumers will be more and more reluctant to accurately disclose health information, or they may systematically delay or avoid seeking care for fear of experiencing adverse consequences, such as discrimination (Goldman 1998). People realize that the consent forms for disclosure they now sign as a condition of receiving health care and reimbursement leave them susceptible to various reuses of their medical records, and they are increasingly likely to engage in privacy-protective behaviors to guard against what they believe to

be harmful and intrusive uses of their health information (Baron 1998). If doctors and other health care providers receive incomplete or

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*We do not call anything wrong, unless we mean that a person ought to be penalized in some way or another for doing it; if not by law, by the opinion of his fellow creatures; if not by opinion, by the reproaches of his own conscience.*

*John Stuart Mill*

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inaccurate information from patients, the data they disclose for payment, research, public health reporting, outcomes analysis, and other purposes would ill serve individuals and society as a whole. The integrity of health information and health care overall would be eroded.

Breaches of confidentiality primarily bring about harm to individuals by interfering with a person's future plans and opportunities. Some causes of frustrated plans are, of course, internal to the individual. Here we focus on frustrations that are due to external factors involving interaction among individuals or between an individual and the society at large.

Fear of individual future harm, to themselves or to members of their families, is, of course, a common reason why many people prefer that their personal medical information not be disclosed or reused. Not all harms related to health information privacy are individual harms, however. In situations like those envisioned in bills currently before the U.S. Congress (carryovers of last session's S. 1368 and S. 1921), where the individual is empowered to grant or withhold access to her medical records — that is, to disclose or not to disclose selected portions of them, to selected parties and for selected purposes — widespread decisions to not disclose personal information may result in harm (or diminished benefit or happiness) for other individuals and for society.

In this essay, I propose that health information disclosure duties and utilities and frustrated plans and expectations are a special problem in environmental ethics (Bazerman 1997, DesJardins 1996, Elliot 1995, Johnson 1993, Palmer 1997).

### **Our Duty to a Sustainable Privacy "Environment"**

The law and ethics of privacy have usually proceeded from an individualistic perspective, conducted in terms of rights and contracts, property ownership, torts and justice. The analysis need not be a justice-based one, though; there are social, community-oriented, and utilitarian arguments worthy of our attention as well. If you will, the integrity of health information can be likened to the integrity of clean air, water, or land.

Consider a hypothetical situation of land distribution and soil erosion in the Brazilian countryside. For each individual farmer, removal of

the trees is a rational strategy for maximizing value, tied to the individual's plans and uses for agricultural land that the individual controls. This stance on control and displacement of trees for individual gain or preference is analogous to an individual's misleading disclosures or withholding selected health information, or to a categorical and selfish refusal to permit one's health records to be used in confidence, say, for a particular IRB-approved research study, from which the individual does not stand to benefit directly.

When all farmers behave in this way, erosion ensues, and everyone ends up with less productive, less valuable agricultural land (Berry 1996). For each individual farmer, deforestation seems optimal, regardless of what others do. If other farmers keep their trees (disclose their health information), he will get the additional land he hoped for. If they don't, he will at least get wood for fuel or lumber for export, since the character of the land will change in any case. (Per our analogy, he will at least get some health services, even if they are inequitably allocated and even if they are based on faulty information.)

The causal mechanism underlying this hypothetical scenario is one of externalities. By unilaterally and destructively controlling the trees on his plot, each farmer raises the probability of erosion on all plots by a small amount. His utility calculus tells him that the risk is worth it.

However, widespread or universalized deforestation raises the probability of erosion to a certainty. In the utility calculus pertinent to the society or community in the long run, it is not worth it. The same is true with regard to health information disclosure decisions. Without privacy protection, the integrity of the information and the community health care environment will erode.

I have cast the farmer's dilemma as a Prisoner's Dilemma, but this is something of an oversimplification. In more sharply drawn Prisoner's Dilemma situations such as pollution or crowded streets, all participants are aware of the causes and effects, and they know that others

are also aware. Nobody is surprised when they find the water poisoned or the streets gridlocked, for this is only the predictable outcome of others' selfish, mostly-overt behavior. But when farmers lose their land, they are surprised. Likewise, when patients find that the integrity of medical knowledge and health care services has been eroded, they will be surprised. Initially at least, the farmers may ascribe the trend to El Niño — to something out of their control. Only after a while, after irreversible damage has been done, will they grasp that the erosion is the result of their own tactical, my-vote-doesn't-matter, self-exculpating decisions. And even then they may not understand the cause-effect relationships involved. Perhaps each farmer comes to believe that the erosion on his plot is fully explained by the deforestation on his plot. He may then try to

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remedy the situation by planting new trees (consenting to selected disclosures), and be frustrated again when he finds that it doesn't help. A noxious pattern of behavior has been fostered that will be exceedingly difficult to reverse.

Much as with our failures to understand the consequences of our health information disclosure decisions, the frustrated expectations in the Brazilian countryside example are due to the failure of the farmers to understand the strategic and collective nature of their situation. Once each comes to understand that it would be irrational to believe that others are less rational, he can form rational expectations that will have the self-fulfilling property that, when everyone

acts on them, they will be exactly fulfilled. This is in fact the definition of what is called the "Nash equilibrium" in economics: a set of strategies, one for each participant, with the property that each strategy is the optimal response to the others. Under conditions of equilibrium, nobody has an incentive to deviate.

However, the existence of an equilibrium is not enough to ensure the nonfrustration of individuals' expectations and plans. In the first place, the participants may not know enough about each other to converge to an equilibrium. This is certainly so in regard to private decisions about what information to keep private. Only if the participants jointly share a dominant, universalizable strategy, as in a classic Prisoner's Dilemma, will they be able to figure out what they ought do and act on it, without figuring out first what others are going to do. In the absence of a dominant strategy, they cannot identify an equilibrium-producing choice without knowledge of the preferences of the other participants. Even if they possessed this knowledge, they may hesitate to use their equilibrium strategy if they are unsure whether others have enough knowledge or commitment to do the same.

An even more serious problem besets dilemmas of this kind. Sometimes, there is more than one equilibrium. This need not entail any interindividual coordination difficulties or intergenerational inequities, but it often does. In an idealized situation, if one equilibrium is better for everybody than all the others, it will tend to be the one chosen (if the awareness condition is satisfied). But often one equilibrium is better for some, and another is better for others.

For example, individuals whose risk factors or diseases may benefit from intensified research or individuals who are likely to be helped by public health measures may consider broad disclosure and extensive reuse of health information better; so, too, will "windfall" groups whose favorable genetics and epidemiological and actuarial merits entitle them to lower insurance premiums or other fortuitous preferential treatment. By

contrast, healthy individuals who, for whatever reasons, are likely to remain healthy may prefer nondisclosure as a matter of preserving personal freedom; so, too, may some groups like Ashkenazi Jews, Mormons, Amish, and First Peoples, whose hereditary patterns cause them to be intensively studied, resulting in adverse "publication bias" (Baron 1998, Hiskes 1998). If only two persons are involved, then considerations of bargaining power may help to predict the outcome. But in large market-oriented situations with many equilibria evolving over many decades, the outcome is inherently indeterminate. We depend, therefore, on social policies to foster the collective as well as the individual good, to encourage the exercise of conscience and principled public opinion, and to promote ethical (as well as rational) choices.

### **Toward a National Health Information Privacy Policy**

Much of the current debate on health privacy dwells on the harms of disclosure and emphasizes an individualistic framework of rights and duties and civil and criminal penalties. In the health care setting, when people decide to withhold or falsify health information, or go to four providers instead of to one and so by fragmentation deliberately prevent collocation of information, or, to protect their privacy, entirely avoid seeking health care services for which they are eligible and from which they might benefit, they calculate with the flawed calculus of our hypothetical community-disregarding farmers. But if people are assured that their health information will be safeguarded, and if they are empowered to make informed choices about the secondary uses of their health information, then they are likely to seek and receive appropriate, high-quality, effective care and make ethically sound decisions about the disclosure and use of their personal health information.

Some health care organizations are concerned that health privacy regulation will go too far in the direction of confidentiality and hinder research and public health programs. Such a risk

is surely real. A greater risk exists, however: that of consumers who act on their fears (fears that, once they disclose information to a health care provider, they will lose control over who else might access the information) and unreasonably withhold selective access to their medical records. The flow and integrity of health information — an "environment" in which we and future generations all have a stake — is more likely to be strengthened if a comprehensive national health information privacy policy is enacted.

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