Author's Commentary on "Paper or Plastic? From Paper Records to Electronic Database"

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Scientists are always searching for better ways to test their hypotheses, to ask smarter questions and to get the most out of their data. Today, not only does the science drive the technology, but the technology drives the science, as well. That is especially true in the case of computers, with their increasing speed and sophistication, which allow us to ask bigger, more complex questions about the data we generate and collect. In this case, Edwards tries to take advantage of the technology for the benefit of his patients and colleagues.

Since the advent of computers, questions and fears have been raised about their role in our lives and their potential for harm. The line between benefit and harm can be blurry, and a balance must be struck. Edwards, with his development of Medusa, must make a host of decisions in which the "right" answer is not necessarily clear.

Is there a substantive difference between paper records and Medusa?

Concerns have long been voiced about the ill uses to which computers might be adapted. Concerns about privacy and security continue. The main issue in this case, I think, is not so much the security of medical information in isolation - in my experience, paper records are often no more secure than electronic ones - but rather the power of medical information when used in the context of a broader scheme of information collection or database mining (DG Johnson 2001). Presumably, Edwards will ensure that his patients' data are adequately protected from unauthorized access over the network, as well as unauthorized direct terminal access.

Is Edwards justified in his use of patient information for database development and promotion? Why or why not?

Two major issues must be addressed here: informed consent and conflict of interest. The issue of informed consent is a tricky one because it is understood that one's physician will keep a thorough and accurate medical history for each patient. While historically such records have been kept in manila folders in file cabinets, it does not follow that technological advances ought to be ignored. The question then, is whether database development constitutes "research." It may seem clear that if Edwards were to begin to mine the database in an attempt to ask questions about his patient population as a whole, it would be appropriate and required that he formally enroll his patients as participants in a study - with appropriate consent. However, what if he wants to ask whether patients with different income levels have significantly different health outcomes? Is it clear that this question goes outside the bounds of his duty as a physician to provide the best possible care to his patients? Where does one draw the line? Does the mere development of the capacity for such queries constitute a need for consent?

In regard to the potential conflict of interest, it cannot be assumed that Edwards's obvious *perceived* conflict of interest is, in fact, a real conflict of interest about which his patients ought to be concerned. It may be reasonable to give him the benefit of the doubt, to assume that he is driven by a genuine desire to help present and future patients through the development of his database. Medusa certainly has the potential to allow elaborate and unwieldy data analyses and lead to valuable findings that significantly impact science and medicine. That is not to say that Edwards ought to be absolved of responsibility, only that we cannot assume that he is acting out of pure self-interest - the situation is likely far more complex than that.

Given this additional information, do you feel differently about Edwards's use of patient information in the development and promotion of Medusa? Why or why not?

Edwards has clearly failed to think through the implications of his actions in regard to the distribution of the encryption key. As their physician, it is his responsibility to protect the confidentiality of his patients' information. He might have preempted this sort of behavior by having all persons receiving the encryption key read and sign a statement of confidentiality and/or participate in some sort of training related to working with sensitive information.

Some people may suggest that despite the difficulties, Edwards ought to have created a mirror database, with fake names and information; however, it is important to keep in mind that Edwards's primary interest is in getting Medusa out

there, in use and serving patients, physicians and scientists. Again, that is not to absolve Edwards of responsibility, but only to show that this case is much messier than one might think at first blush.

References

- Johnson, D. G. *Computer Ethics*. Englewood Cliffs, N.J.: Prentice Hall, 2001.