Special Section: Bioethics and Information Technology

Guest Editorial

Addressing Ethical Issues in Health Information Technology

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The global bioethics community is, collectively and generally, a quick study. The literature rapidly incorporates, analyzes, and otherwise metabolizes the latest scientific developments as they relate to healthcare and pose new ethical issues. Genetics and genomics shaped a new subspecialty in bioethics; neuroethics arose quickly as brain research evolved and matured; and nanoethics blossomed as nanotechnology and nanoscience posed new challenges ranging from personal tracking to human enhancement.

Strikingly, however, the community of bioethics scholars and educators has been comparatively slow to grasp, let alone analyze, the significant transformations and challenges caused and elicited by the use of health information technology (or biomedical informatics, e-health, or information and communication technology).

The Bioethics and Information Technology section introduces a new *CQ* section that aims to address this shortcoming and fill this lacuna.

Countries around the world are spending billions of dollars, euros, and pounds to promote the use of electronic health records, which are transforming the clinician-patient relationship. Intelligent machines render diagnoses and prognoses more accurately than human experts, challenging traditional notions of professional practice. The analysis of big (and not-so-big) data fosters and identifies conundrums about the limits of privacy and the scope of informed consent. Indeed, every aspect of clinical practice, hospital operations, and biomedical research is touched by the use of computers, by information technology.

This inaugural special section features a suite of articles that begin to identify the breadth and depth of the ethical issues raised by health information technology. The articles range from the theoretical to the conceptual and to the empirical—capturing the intended scope of the section:

- In "Selling Health Data: De-Identification, Privacy, and Speech," Kaplan uses a number of noteworthy cases that address "appropriate use and secondary use of data for data mining, marketing, research, public health, and healthcare; data ownership; and patient and clinician data and privacy protection."
- The bioethics community itself is the focus of "Epistocracy for Online Deliberative Bioethics." Here, Schiavone, Mameli, and Boniolo offer "a set of methodological requirements for online deliberative procedures for bioethics"

and suggest an "epistocratic" approach in which those who are the most knowledgeable should prevail; they also suggest that this approach "can be reconciled with deliberative participatory democracy in the case of policy-making in bioethics."

- Al-Saggaf, in "The Use of Data Mining by Private Health Insurance Companies and Customers' Privacy: An Ethical Analysis," draws on the Australian experience and argues that machine-learning algorithms, if used by insurance companies to cherry-pick customers, cannot be ethically supported.
- "Developing a Research Agenda on Ethical Issues Related to Using Social Media in Healthcare: Lessons from the First Dutch Twitter Heart Operation" analyzes a case in which a patient and clinicians tweeted about a medical procedure—before, during, and afterward. Adams, van Veghel, and Dekker review the ethical and policy issues raised when social media become an intimate part of patient care.
- Social media are also a key part of patient education. In "Ethics Issues in Social Media–Based HIV Prevention in Low- and Middle-Income Countries," Chiu, Menacho, Fisher, and Young provide empirical data bearing on ethical issues raised when the Internet and social media are used in HIV interventions and in research in a vulnerable population.
- An important and underaddressed issue arises concerning the names of websites. "Emerging Ethical Issues in Digital Health Information: ICANN, Health Information, and the Dot-Health Top-Level Domain" sounds a warning about the sale of the ".health" domain name. Solomonides and Mackey review issues in Internet governance and the domain name debate, concluding that the sale of health constitutes a "precautionary case study of the evolution of ethics in health information."

Contemporary biomedical practice and research are inescapably computational. Translational science is information intensive. No less than death and dying, organ transplantation, genetics, or stem cells, the tools of biomedical informatics are a rich source of ethical issues. The six articles in this inaugural collection begin what will be a sustained and robust commitment to address those issues. The following list itemizes some of the topics on which future submissions are solicited:

- Bioinformatics, biorepositories
- The business of health information technology
- Decision support systems and prognostic scoring systems
- Disability and health informatics
- Electronic health records
- Government regulation of health informatics tools
- Information and communications technology (ICT)
- International issues, including harmonization, best practices, and so on
- The Internet and the World Wide Web
- Laboratory information management systems
- Mobile health
- Personal health records
- Privacy and confidentiality
- Professional-patient relationships
- Public health informatics

- Remote presence healthcare, medical homes, and so on
- Replication of research results
- Research and informatics
- Responsible conduct of research (RCR)
- Robots and digital/virtual companions
- Safety, quality, and evaluation
- Social networking
- Software engineering and writing

Although not exhaustive, the list sketches the borders of this important and exciting area of bioethical inquiry.

When the Human Genome Project was launched, it was clear at the outset that it should be accompanied by attention to ethical, legal, and social issues (or implications)—hence the birth of ELSI. It is now equally clear that we need an ELSI initiative to accompany the growth of the use of computers and information technology in patient care and in the health of populations.

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