Chapter 1

Information technologies and twenty-first-century clinical practice

Ethics and the electronic health record

The slow death of maintaining patient records on paper has precipitated a new era. Electronic health records are now required. This is not about fashion, the designs of regulators, or the ambitions of administrators. These electronic records are required because the paper chart was a terrible way to store and (try to) retrieve patient information. It harmed patients. As we will see here, electronic records, in conjunction with personal health records, are transforming the health information ecosystem. This transformation presents us with an ensemble of interesting and important ethical issues, a review of which serves as an introduction to this volume.

Bioethics and health information technology

More than genetics and stem cells, more than left-ventricular-assist devices and extra-corporeal membrane oxygenation, more than organ transplants and gamma knives and nanomedicine and ovarian hyperstimulation – more than any technology of the sort that tends to raise or contribute to interesting and difficult ethical issues – it is the use of computers and communication technologies that will affect the lives of people in the twenty-first century. In the other direction, more human lives will be touched by health information technology than any other technology, ever.

The history of bioethics is in many respects the history of our coming to terms with technology. The machines, tools, and processes that have defined modern health care also press against moral intuitions about the beginning of life, the end of life, and the sometimes rocky journey in the middle. Bioethics 101 is, at least in part, about whether a tool should be used; if so, when and by whom; and, then, by what lights, guidelines, principles, or rules. Most of these tools and technologies help us to see or hear better and to touch or cut with greater sensitivity or precision. They help us to rescue our very cells, clean them, move them, numb them, change them, or kill them; nowadays we even make them.

The tools of information technology are different: These machines can *think* for us. The processes or functions they assist include cognition, reason, and memory.

Medical books and other texts do this too, to some extent, sometimes. But a book (or papyrus scroll or Web page) is, for our purposes here, best thought of as a repository. A book can hold the facts we are looking for, though an e-book can readily be searched; it can help us learn, though the practices of medicine or nursing will never adequately be learned by reading alone; and it can help teach us to reason, but not reason for us. The change from paper-based health records to electronic records is as transformational as the transition from illuminated manuscripts to moveable type was – perhaps greater. The availability of computer decision support systems makes plain the fact that intelligent machines have

inferential and analytic powers that likely exceed those of humans. The ability of computers and associated telecommunications tools to collect, store, and transmit information can turn every clinical encounter into a research event and help fuel a cyclone of science.

The electronic health record, conceived as the successor to the ancient system of keeping records on paper and intended to keep track of health and medical data for patients, emerges as a research tool, embeds decision support systems, enables analyses for quality and resource allocation, and, generally, transforms the way health and medical information are collected and used. Electronic health records cost fortunes and should be able to help coordinate the care of people who are sick and dying. It would be good if we got it right. That has unfortunately turned out to be quite difficult.

What health records are for

The oldest known medical records are contained in the Kahun Papyrus. Dating from Egypt's Middle Kingdom, it is about 3,800 years old and deals mostly with women's health, obstetrics, and gynecology. Mostly, it gives advice. In this respect, this papyrus scroll therefore likely contains the first practice guidelines. It contains 34 prescriptions and instructions for addressing sterility, managing childbirth, and attempting contraception. The prescriptions reveal a diverse pharmacopeia, including the use of herbs, beer, milk, oil, dates, incense, and crocodile dung, which is to be chopped, combined with sour milk, and burned, apparently for a woman to stand over as a contraceptive (Smith 2013). A different translation suggests that the crocodile dung should be placed in a pessary and positioned "at the mouth of her womb" (Stevens 1975, 931).[1] Another recipe calls for honey to be sprinkled on the woman, who should be on a bed of natron, or carbonate salt (Smith 2011); or that the natron should be added to honey and then inserted in the vagina (Stevens 1975). It is not clear precisely when this application should occur or, indeed, how long it would last. Another honey-based, intravaginal contraceptive is said to work for "one, two or three years" (ibid.). While these might be the first practice guidelines, it is clear they are not to be regarded as evidence based.

Now visit the Web site http://archive.nlm.nih.gov/proj/ttp/books.htm and click around. The "Turning the Pages Information System" was originally created by the British Library, and it has been adopted and adapted by the US National Library of Medicine "for visitors to touch and turn the pages of virtual books." The first "book" on display has come to be known as "The Edwin Smith Surgical Papyrus" (Al-Awqati 2006; Gillum 2013). Here is Case 22, about fractures of the temporal bone:

> If you treat a man for a fracture in his temple, you have to put your finger on his chin and your finger on the end of his ramus [of the mandible]. Blood will fall from his nostrils and the interior of his ears from that fracture. Wipe for him with a plug of cloth until you see its [bone] chips inside his ears. If you have called to him and he is dazed and does not speak, then you say about him, "One who has a fracture in his temple, who bleeds from his nostrils and his ears, is dazed and suffers stiffness in his neck: an ailment for which nothing is done."
>
> (Al-Awqati 2006, 2114)

This is perhaps the first documented case of clinical futility. Al-Awqati writes, "the conclusions remain correct to this day" (ibid.).

This is a case study, a guideline, and a teaching tool. These early attempts to record what healers encountered and to share with others are the first-known intellectual and conceptual

antecedents of today's electronic health records. By the time of Hippocrates more than a millennium later, case studies had become common, and were still used to teach. While the historical Hippocrates is actually elusive and vague, the case histories attributed to him are early masterpieces of observation and documentation, and they fueled the inchoate sciences of diagnosis and prognosis. When Hippocrates and his students got it right, it was in part because they learned from previous patients. As we will see in Chapter 8, the ancient use of one patient's information to try to help another patient is near the foundation of obligations to make de-identified health care information available for research and other legitimate analysis, sometimes without the consent of those who are the sources of the information.

The Hippocratic case report is chronological, sometimes blunt: "Thirty-fourth day. Death" (Reiser 1991, 902). The chronological structure supported the Greeks' interest in what Reiser calls "therapeutic timing" and on symptoms "most predictive of outcome. The Hippocratic physician used this prognostic power to decide which cases to accept or decline. This action had its origin in a fundamental tenet of Greek medicine of this period, namely, that futile therapy should not be used" (ibid.).[2]

The seventeenth-century physician Thomas Sydenham (1624–1689), called by some the "English Hippocrates," likewise saw patterns in the symptoms reported by his patients and elicited from these patterns distinctive profiles of diseases. Reiser attributes this in part to Sydenham's work at the dawn of the age of classification of plants and animals (Linnaeus published his *Philosophia Botanica* in 1751 and the *Species Plantarum* in 1753), and it inspired in him the ability to "synthesize from clinical records the case histories of individual patients into a disease history" (ibid., 903). These disease histories were of the greatest ontological significance: Diseases emerged as entities with specific etiologies and distinctive properties. This insight is the conceptual antecedent of contemporary work in biomedical ontology[3] and undergirds work in computational genomics and work on the Semantic Web. It is the great-grandparent of The International Classification of Diseases (e.g., ICD-9 and ICD-10) maintained by the World Health Organization; ICD codes undergird some computerized decision support systems and medical billing protocols.

Where Sydenham's case histories emphasized patients' self-reports, the French physician René Laennec (1781–1826) flipped the medical record to highlight physicians' observations and measurements. He was inspired in part by modesty: Where physicians since antiquity had listened to hearts by placing their ears on patients' chests, Laennec regarded the practice with female patients as "conduct unbecoming to the gentleman doctor" (ibid., 904). He placed a rolled tube of paper on a patient's chest and found that heart sounds traveled clearly through the tube. This invention, the stethoscope, enabled more precise auscultation and hence fostered a flow of increasingly reliable data into the case report. Listen:

> A man, aged 65, came into hospital on the 29th of November [apparently 1819], affected with slight pulmonary symptoms, chiefly marked by dyspnea, to which he had been long subject, and which he considered as Asthma. Percussion afforded no result, owing to the excessive fatness of the individual; only the chest appeared to sound somewhat less below the right clavicle. Respiration was inaudible over the whole of the right side, but was very sonorous on the left. From these results I considered this person as affected with a latent peripneumony [pneumonia] of the right lung.
>
> Five days after this, there was observed slight oedema of the right side of the chest; and on applying the stethoscope to the back, respiration was somewhat perceptible along the edge of the spine on the right side, though less so than on the left. There was very little

> cough, and scarcely any expectoration. These symptoms indicating pleurisy rather than peripneumony, necessarily modified our diagnostics. After a few days the oppression became less, and we began to hear the sound of respiration, in a slight degree, below the right clavicle … On the eleventh [day] the chest sounded still better in this point, and respiration became distinct as in the opposite side, but was not perceptible lower than the third rib. It was, also, sufficiently distinct between the spine and scapula. At this time the patient expectorated some opaque, yellow, puriform [purulent] sputa. The symptoms continued much the same until the middle of February, when he died, apparently from an attack of peritonitis. (Laennec 1821, 398–9; cf. Reiser 1991)

The information contained in the medical record forms the basis for diagnosis. It is a story, but a story made useful by efforts at precision and rigor, efforts embodied in the medical record. Alas, available treatments lagged, and at the time the best response to tuberculosis, for instance, involved the application of leeches.

At about the same time in North America, David Hosack (the physician who unsuccessfully attended to former US secretary of the treasury Alexander Hamilton in his duel with Vice President Aaron Burr in 1804) suggested that some cases were especially good for teaching medical students, and so should be carefully recorded. The Board of Governors of the Society of the New York Hospital had already approved the first hospital rules, in 1793, such that the "apothecary prepared and delivered a monthly report of the 'Names and Diseases of the Persons, received, deceased or discharged in the same, with the date of each event, and the Place from whence the Patients last came'" (Siegler 2010, 672). In 1805, the board agreed with Dr. Hosack: "The house-physician, with the aid of his assistant, under the direction of the attending physician, shall keep a register of all medical cases which occur in the hospital, and which the latter shall think worthy of preservation, which book shall be neatly bound, and kept in the library for the inspection of the friends of the patients, the governors, physicians and surgeons, and the students attending the hospital" (ibid.). By 1830, it was required that all cases be recorded and that no one could be appointed a House Physician or Surgeon until he had entered at least 12 cases in the register.

The history and evolving utility of the medical record intersect at interesting points with the history of evidence-based practice. Good case records can help evaluate the effectiveness of therapies. Perhaps the first instance of this was the discovery that the long-standing practice of bloodletting did not work. Bloodletting, a consequence of the humoral theory of disease, had been practiced since antiquity in several cultures. It was responsible for countless deaths (including perhaps that of George Washington, who died after some five pints of blood were removed by his doctors [Morens 1999]). The French physician Pierre Charles Alexandre Louis (1787–1872) undertook a detailed review of hospital cases and determined by a simple analysis, which he called the "numerical method," that bloodletting was by no means curative and, on the contrary, generally harmful (Louis 1836; cf. Louis 1835). Earlier he had written:

> As to different methods of treatment, it is possible for us to assure ourselves of the superiority of one or other … by enquiring if the greater number of individuals have been cured by one means than another. Here it is necessary to count. And it is, in great part at least, because hitherto this method has not at all, or rarely been employed, that the science of therapeutics is so uncertain. (Louis 1834, 26–28)[4]

This numerical method has been cited as a significant milestone in the history of evidence-based practice (Sackett et al. 2000; cf. Goodman 2003), despite flaws in some analyses.[5]

The nineteenth and twentieth centuries saw sustained use of the hospital record in medical education. In 1910, Massachusetts General Hospital began weekly conferences to review cases and analyze "clinical logic" of patient management (comparing clinical and pathologic analyses); in 1915 the hospital began publishing the cases and analyses for subscribers, prompting one physician to write, "To a great many of us, these cases are the only postgraduate work we have at the present time" (Reiser 1991, 907). By 1923, case studies and analyses had become a regular feature of the *Boston Medical and Surgical Journal.* Even after the journal was renamed in 1928, and to the present day, "Case Records of the Massachusetts General Hospital" remains a weekly feature of *The New England Journal of Medicine*.

The medical record increased in formality with a commensurate loss in narrative. "House physicians," writes Siegler, "no longer summarized the course of a patient's hospitalization; they recorded their observations but not their thinking" (Siegler 2010, 675).

The need for careful documentation was magnified by social factors and movements. The United Kingdom's National Insurance Act of 1911 required health insurance for workers and that participating general practitioners keep medical records in a specific format, in part to ensure that useful health information about workers could be analyzed. This initiative was put on hold as a wartime measure in 1917; a postwar commission tried to stipulate what information should be contained in the records. This is what it came up with, in part as an inducement to improve the quality of care: "We consider, therefore, that on the whole the most advantageous system will be to require such notes to be kept for every case treated as are likely to be of value to the practitioner himself, or to any other practitioner treating the same patient in subsequent illnesses; and we recommend that the obligations be thus defined" (Tait 1981, 703). This could be said to be patient-centered, though in the ensuing decades difficulties arose in the size of the envelope used to hold the forms – largely because the size of the envelope was stipulated to fit the metal file cabinets already in use (ibid.). Difficulties continued through the creation of the National Health Service in 1946; one reformer in the 1970s noted the absence of a place to record important background information.

The inevitable move from a paper record to an electronic one – some hospitals still have not completed it – exemplifies the way change often occurs in applied sciences such as medicine: There was no experiment, no vote, no edict. Some partisans, activists, and forward-lookers simply began the process of development and adoption. It is a primitive approach, but it has worked well enough often enough to invite tolerance, if not command enthusiasm. It is an embodiment of the anonymous quip, "Modern man is just ancient man – with way better electronics."

What is right – and wrong – with electronic health records

In an early and important attempt to identify and address ethical issues raised by electronic health records (EHR), the philosopher Eike-Henner Kluge suggests that the primary difference between paper and electronics "lies in their logical natures as records and the functional manipulations to which they can be subjected. For instance, electronic patient records can be manipulated in a holistic fashion to yield an integrated picture (representation) of the patient which can be directly involved in, and integrated into, the decision-making process that surrounds patients and health care consumers in a way that is not possible for paper-based records" (2001, 20). It has developed that Professor Kluge was

optimistic and so limned a state of affairs that is more aspirational than descriptive. Electronic records *should* have a structure that permits such integration – but, as it develops, they do not. Worse, and as we will see in Chapter 5, the uncontroversially worthy goal of interoperability remains outside our grasp.

That electronic records must replace paper ones is not seriously in dispute. Paper records are "woefully inadequate for meeting the needs of modern medicine" (Shortliffe and Blois 2014, 5). They are inefficient, difficult to read, counterintuitive, cumbersome, difficult to correct meaningfully, and give up their information reluctantly if at all – sifting through large sheaves of paper to acquire important information about a patient is a fool's errand, a frustrating, dispiriting, and sometimes quixotic exercise. Indeed, we have known this for a very long time, at least in some respects (Whiting-O'Keefe et al. 1985). The history of paper (and papyrus) records notwithstanding, they have lost their capacity to save and help recover facts, as well as their ability to deliver patient narratives.

Obligations to improve electronic records

Electronic records are rich in facts, often redundantly, and they, too, do no honor to patient stories. The literature of complaints about, shortcomings in, and failures of electronic records has become a growth industry (just for instance: Bernat 2013; DeAngelis 2014; Hill et al. 2013; Koppel et al. 2005). Wears (2015) despairs for the future of electronic health records, and notes the development of the "shadow chart" to fill gaps in existing systems (Wears 2008). There remain serious questions about the history and course of England's national program for health information technology (Greenhalgh and Keen 2013), alleged to be a source of "patient harm or death" (Magrabi et al. 2015). Many, if not most, of these criticisms are smart, concerned, and constructive. There is much room for improvement, both in the behavior of electronic record users (Chapter 4) and in system manufacture and oversight (Chapters 5 and 6). Between dark nihilism and slavish boosterism lies a sober middle ground, a position that simultaneously recognizes electronic health records as both irreplaceable and improvable; we want to be able to move toward a kind of "electronic standard of care" to which all would aspire and, indeed, would meet. This points to the first of several ethical challenges and, especially, simple-to-state and interlocking ethical obligations (EO):

Improve electronic health records. (EO 1)

In many respects, other chapters in this volume address ways in which such improvement might occur: electronic records must foster reliable decision support, be secure and protect privacy, be used appropriately by well-trained professionals, be safe and interoperable, be patient-centered and manufactured and sold as such, and support research and public health. There is a great deal of work to be done. Such work has, indeed, begun in the form of measured and thoughtful analyses of EHR functions, use, and utility (Kuhn et al. 2015; Mamykina et al. 2012).

Consider the Ebola scare of 2014 and, especially, the allegation that a hospital's electronic health record either did not have the information that a patient (i) presented with fever, dizziness, nausea, abdominal pain, a sharp headache, and decreased urination, and (ii) was from Liberia; or did have the information but was unable to link or synthesize it for clinicians (Upadhyay et al. 2014). We need to collect and study case studies of systems working well, and of systems behaving badly; of humans using tools correctly, or dimly; and

so on. Such cases, reviews, analyses, and assays are essential to establish an evidence-base to guide and inform improvement. This entails a second duty:

Expand research on electronic health records. (EO 2)

Such research ought not only to find out what is wrong, but identify best practices. For instance, a common complaint about electronic records, namely their intrusiveness in the clinical encounter (Lown and Rodriguez 2012), should inspire us to explore and document ways to reduce and manage that intrusiveness. In response to the apparent need to type and click during patient encounters, some clinicians have come to share documentation duties with patients, even turning the screen so patients can see what is being entered and so have the opportunity to add, correct, or question.[6] Such a practice can even help improve patients' digital health literacy, itself a worthy topic of research. Some of these issues are taken up in Chapter 4.

There has been a sea change over the past quarter-century in the relationship between patients and their information (we will expand on this shortly, in a review of personal health records). Because patients want and ought to have access to their information (Patel et al. 2014), we must do a better job of respecting that desire and facilitating that access. Generally speaking, and all other things being equal, there is no good reason not to allow patients to see their records, to share them, to make them available for research and analysis, and, indeed, to exercise control over access to their records. (Privacy law in the United States, for instance, requires that patients be able to review their records but makes an exception for psychotherapy notes; this is not unreasonable.) The "Blue Button" utility for online patient portals, developed by the US Department of Veterans Affairs as part of its personal health record system, is a splendid example of efforts to reduce or eliminate barriers to patient access to their information (Turvey et al. 2014), and to share it for health service research (Nazi et al. 2010). Furthermore, it has been widely and compellingly suggested that patients should also enjoy "granular control" over those who view their information, and, moreover, such a feature of EHR design can be driven by adherence to various principles of bioethics (Meslin et al. 2013; Meslin and Schwartz 2014). This celebration of applied autonomy or functional self-determination suggests a third obligation to be met in the ongoing improvement of electronic health records:

Foster and support patient access to and control of their information. (EO 3)

In the next chapter, on computerized decision support, we will emphasize the importance of system evaluation, especially in the contexts in which systems will be used. The long-standing advice to conduct such evaluation seems rarely to be taken. This is also true of research, findings in human factors science, and studies related to organizational and social issues. This points to a divide, a disconnect, between the development and manufacture of electronic health records, on the one hand, and human factors science (e.g., Lowry et al. 2015), and organizational issues, on the other (e.g., Kaplan and Shaw 2004). It might even be safe to infer that if such considerations were given greater weight, electronic health record systems would function better. This suggests a fourth duty:

Improve usability by addressing and accommodating human factors, social and organizational issues, and system research. (EO 4)

Indeed, and as a result of many causes, systems suffer from poor usability, and this has itself assumed a central role in debates over the status and future of electronic health records. Usability issues may be regarded as central to many of the challenges we address in this book, perhaps especially including safety (see Chapter 5). Concerns about unintended consequences of EHR design and implementation have led to a variety of attempts to recommend system improvements.

The Institute of Medicine's 2012 report, *Health IT and Patient Safety: Building Safer Systems for Better Care*, made nine applicable recommendations; Middleton and others (2013) recommend 14 "usability principles"; and the American Medical Association identifies a suite of eight "priorities to improve electronic health record usability" (American Medical Association 2014). Note the similarities between some of these principles and priorities and several of the ethical obligations being identified here.[7]

Personal health records

If you are old enough, you might have had the experience of being informed that you may not look at or have a copy of your medical record. "It's a *medical* record," I was once told, impatiently and incredulously. Her brow was knitted and her mouth opened, literally slack-jawed. This is what she meant:

1. They are notes made by a licensed physician who intended they be used to jog his memory and to share with other physicians as needed.
2. These pages were simply and utterly not to be shared with me, the patient, who had done something outré and improper by asking to take a look.
3. If I was moving to another city, I could not be entrusted to deliver a copy of my medical record to my new physician – that new physician would have to send a letter requesting my chart, which would then be sent directly, doctor to doctor.

The medical record was special, and so, special anointment was required for access. Moreover, it was not exactly clear what use or interest a patient might have in this special collection of Latin abbreviations, hard-to-read observations, and authoritative diagnostic scrawls. This was the age, recall, of hard-to-read prescriptions (sometimes joked about) and occult runes: privileged, secret, and not for you. Moreover, a patient might draw the wrong conclusion, and sharing the record might even be atherapeutic.

As we saw just earlier, however, there is no good reason to prohibit patient access to the records kept of their clinical and hospital history and treatments. Moreover, patients do not want merely to access and to some extent control use of their health information – they also want a role in tracking and generating or producing it. Patients know more than reckoned, and this can likely be put to good use – for them. Consider:

- According to University of Wisconsin Professor Patricia Flatley Brennan, National Program Director for the Robert Wood Johnson Foundation's Project HealthDesign: "Doctors and nurses are experts in clinical care; patients are experts in their daily experiences. Both need to share more with each other and health data from everyday life can help bridge that gap."[8]
- "'This patient knows more about her disease than I do.' This passing remark was made more than 30 years ago to a group of new medical students as we stood around the bedside of a woman with long-standing diabetes mellitus. It is a sentiment that has probably been expressed or felt by doctors many thousands of times since … Yet until

recently the wisdom and experience of the patient has been only a tacit form of knowledge whose potential to improve the outcome of care and quality of life has been largely untapped. In England alone, there are now nearly 10 million people with a chronic disease. It has been estimated that non-communicable diseases account for almost 40% of deaths in developing countries and 75% in industrialised countries" (Donaldson 2003, commenting on a chronic disease self-management program).

- "The best thing you can do for your patients with chronic diseases is to let them run with the ball … effective chronic illness care requires two things. First, it requires a team with the patient at the center. Second, it requires active, involved participants – especially an active, involved patient. This model of care can be described using various terms – empowerment, informed choice, patient centered – but they all have the same underlying concept: The patient is at the center and is actively involved in his or her own health care" (Funnell 2000, 47).

This is exciting, provocative, and encouraging. In the form of personal health records, there is a rare opportunity to test a broad variety of hypotheses about the use of electronic health tools controlled in part by patients. Personal health records:

> encompass a wide variety of applications that enable people to collect, view, manage, or share copies of their health information or transactions electronically. Although there are many variants, PHRs are based on the fundamental concept of facilitating an individual's access to and creation of personal health information in a usable computer application that the individual (or a designee) controls. We do not envision PHRs as a substitute for the professional and legal obligation for recordkeeping by health care professionals and entities. However, they do portend a beneficial trend toward greater engagement of consumers in their own health and health care. (Markle Foundation 2006, 2)

With personal health records, patients can view their "official" records (or copies or versions of them) and provide information that might be appropriate for a physician or nurse to include in an electronic health record; and patients and clinicians can communicate swiftly and directly. Most electronic health record manufacturers include a personal health record as a feature or adjunct to the electronic record. As with the electronic records themselves, this means that many personal health records in use are provided on an as-is basis and cannot be customized. Moreover, like the larger electronic record system, personal health records are not usually interoperable; that is, a personal health record tethered to a particular hospital's electronic patient record is not likely to be accessible by anyone who lacks privileges at that hospital.

At any rate, these new tools are seen to hold great promise for providing patients, especially those with chronic maladies, with a larger role in their own care, and for supporting health care research and the education of clinicians and patients (Phelps et al. 2014; Mandl and Kohane 2008; Tang et al. 2006; for a more cautionary note, see de Lusignan et al. 2014; and regarding the intersection of social networking and personal genetic testing, see Esposito and Goodman 2009); patients themselves believe these tools could improve their health (Markle Foundation 2008). This is adequate to commend another ethical obligation, a modification to EO 3:

> *Enable easy use of personal health records and conduct more research on their usability, design features, efficacy, and effectiveness.* (EO 3.1)

The point about research cannot be overstated. We have a lot to learn. Preliminary research is fertile (Brennan et al. 2010; Johnson 2010), and early efforts to identify ethical issues are suggestive. They also provide a good introduction to the idea that applied ethics is rarely useful in isolation. In bioethics, or the study of ethical issues arising in health practice, policy, and research, they are often closely related to legal and social issues. This recognition was formalized in 1990 when the US Human Genome Project included an Ethical, Legal and Social Implications (ELSI) Research Program as a core component of its mission (cf. McEwen et al. 2014). (That there is yet no ELSI program in biomedical informatics is an unhappy mystery.) Ethical, legal, and social issues can be particularly difficult to disentangle in studies of health information technology and, relatedly, information and communication technology. ("ICT" studies are better known in Europe than in the United States, and apply to several fields of practice and inquiry beyond the health sciences.) Here is one way to map the personal health record's ELSI space:

- Privacy and confidentiality
  - granular control over PHR disclosure
  - ubiquitous monitoring to generate PHR data
  - cohort effects and vulnerable populations using PHRs
  - social networking reliance of PHRs
  - legal uncertainty regarding nontraditional actors
- Data security
  - challenges of PHR data protection in distributed environments
- Decision support
  - when provided to patients without clinical intermediaries and in extraclinical settings
- Legal-regulatory environment
  - multiple federal requirements and state requirements for PHR-based data and new environments, all of which are evolving, leaving us with few if any standards (adapted with modifications from Cushman et al. 2010, S52).

It was also determined that there are many ethical duties to go around, and it is reasonable to require that patients take some responsibility for the management of their information – at least once they become partners in controlling it. To be sure, these issues are specific, some perhaps unique, to personal health records. Writ larger, many other issues related to privacy, decision support, governance and regulation, and so on will also apply; these and other issues are taken up in subsequent chapters. One of the interesting yet not surprising findings of this initial ELSI survey was that the willingness to share information using a personal health record seemed to correlate with age; that is, younger people were more willing to make their health information available via the Web and perhaps using a mobile device, apparently without clear security measures (cf. Carrión et al. 2012). Although there are several possible explanations for this, it does augur a dynamic future course – which itself is a kind of tacit index of the need for more and ongoing research.