



Health Information Professionals in a Global eHealth World: Ethical and legal arguments for the international certification and accreditation of health information professionals



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ABSTRACT

Background: Issues such as privacy, security, quality, etc. have received considerable attention in discussions of eHealth, mHealth and pHealth. However, comparatively little attention has been paid to the fact that these methods of delivering health care situate Health Information Professionals (HIPs) in an ethical context that is importantly different from that of traditional health care because they assign a fiduciary role to HIPs that they did not have before, their previous technical involvement notwithstanding. Even less attention has been paid to the fact that when these methods of health care delivery are interjurisdictional, they situate HIPs in an ethical fabric that does not exist in the intra-jurisdictional setting.

Method: Privacy and other informatic patient rights in the context of traditional health care are identified and the role that HIPs play in this connection is analysed and distinguished from the role HIPs play in eHealth in order to determine whether the 2002 IMIA Code of Ethics provides sufficient guidance for HIPs in eHealth and associated settings. The position of inter-jurisdictional corporate eHealth providers is also touched upon.

Results: It is found that in eHealth, mHealth and pHealth the ethical and legal position of HIPs differs importantly from that in traditional technologically-assisted health care because HIPs have fiduciary obligations they did not have before. It is also found that the 2002 IMIA Code of Ethics, which provides the framework for the codes of ethics that are promulgated by its various member organizations, provides insufficient guidance for dealing with issues that arise in this connection because they do not acknowledge this important change. It is also found that interjurisdictional eHealth etc. raises new ethical and legal issues for the corporate sector that transcend contractual arrangements.

Conclusion: The 2002 IMIA Code of Ethics should be revised and updated to provide guidance for HIPs who are engaged in eHealth and related methods of health care delivery, and to provide a model for a corresponding up-to-date revision of the ethical guidelines that are promulgated by IMIA's member organizations. Similar steps should be taken in the corporate sector so that the ethical rules that govern the working environment of HIPs in the eHealth setting will not pose ethical and professional problems. A possible solution in terms of accreditation and certification is outlined.

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The transfer of technology from one domain to another often raises ethical issues that ideally should be identified, explored and addressed before the transfer is initiated. The reason is simple. Different domains of application are situated differently in the social matrix. Therefore even when technically the same issues are at stake, how they should be handled may be quite different because of this difference in social embedding. Simply to transfer the technology and trust to the ingenuity of technical experts to solve these

problems is to go forward in the belief that ethical solutions are one-size-fits-all and, more importantly, that technical solutions are answers to ethical problems. As past experience has shown—the transfer of genetic technology from plant and animal husbandry to human medicine provides a glaring example—this belief is not entirely warranted.

eHealth, mHealth and pHealth are quintessential paradigms of technology transfer. In their case, the electronic data collection, transmission, analysis, storage and manipulation technology that had originally been developed for scientific, commercial and internet-related purposes is used to deliver health care-at-distance

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without direct interpersonal contact between health care providers and patients. At first glance, this transfer does not require a fundamental reassessment of the ethical status of individuals who are professionally active in the design, development, adoption or application of IT-based health information systems and in the collection, handling, analysis, storage, linkage, use, manipulation or communication of health information either in an administrative or technical capacity—in short, of health information professionals (HIPs). Privacy, security and confidentiality—issues that are integral to these new methods of health care delivery—had already arisen with the introduction of electronic health records (EHRs). [1–6] Likewise, the issues that are associated with electronic communication and transmission technologies have been extensively canvassed and discussed [7–26]; and even the problem of legacy systems had already been identified as far back as the 1990s [27–30]. Further, the competence and knowledgeability of HIPs regarding technical and ethical standards had been a matter of concern from the beginning [31–33]. Even ethical concerns over the use of the internet in providing health information had surfaced early on [34], and IMIA took the lead in dealing with these and related ethical matters as they concern HIPs by promulgating its Code of Ethics in 2002.[35] However, treatments of these new methods of health care delivery have essentially been silent about the fact that the introduction of eHealth, mHealth and pHealth has resulted in fundamental change in the HIP's professional ethical standing.

In a sense, there have been exceptions. For example, in 2013 the World Health Assembly (WHA)—the decision-making body of World Health Organization—suggested that there was a need for overall standardization of eHealth systems and for the development of an integrated and ethically sound eHealth infrastructure, that it was important to develop and institute some means of proper ethical governance, and that this extended even to such things as the operation of health-related global top-level internet domain names including “health”. [36] The WHA further highlighted the need for “devising assessment methodologies” for the technical parameters and devices that are used in eHealth, and suggested that it would be appropriate to “further” ethical standards “through diffusion of guidelines.” However, it made no mention of the fact that eHealth and associated delivery modalities situate HIPs in a fundamentally new way in health care delivery, and it was silent on the need for ethical certification of eHealth providers and health information professionals in order to ensure uniformity; nor did it mention the issue of ethical standards for outsourcing eHealth services or when eHealth corporations act across national boundaries. It also did not touch on the issues of liability, of venues for bringing and settling relevant actions, etc. Not surprisingly, therefore, the question of who should function as an authority for deciding these issues and of methods of enforcement was also not addressed. Therefore while the WHA resolution went some way towards outlining issues that emerge when eHealth functions as global method of delivering health care, it did not provide a conceptually and ethically integrated answer to where HIPs stand ethically in this connection.

What follows is an attempt to outline why and how eHealth, mHealth and pHealth have resulted in a fundamental change in the ethical standing of HIPs, and to make some suggestions about how this should be reflected in a revision of the 2002 IMIA Code of Ethics. It also sketches how all of this may appropriately be acknowledged by introducing or adjusting international certification requirements for HIPs. The focus of the discussion will be eHealth but, with due alteration of detail, similar considerations apply to mHealth and pHealth.

To set the stage, it may be appropriate to briefly highlight how eHealth differs from traditional health care and what this means for the status of HIPs. The fundamental difference between the two approaches for delivering health care lies in the fact that

traditional health care involves the direct and personal interaction between health care professionals (HCPs) and patients, which in turn establishes a fiduciary relationship between the former and the latter. Of course, in one way or another, patient records have always played an important role in fulfilling this fiduciary duty [37,38], and the introduction of EHRs did not change this [39]. However the records, whether paper or electronic, were never integral to the inception of the fiduciary relationship itself. That was grounded in the direct physician-patient interaction. The records were merely tools—important tools, to be sure, but tools nevertheless. And while the quality of health care has been tremendously improved by the advent of electronic diagnosing, data gathering and manipulation technology, etc. and while the professional-patient interaction has been facilitated by the advent of electronic communication technologies, none of this affected the primacy of direct and interpersonal professional-patient interaction as grounding the relationship itself. Moreover, the role of health information professionals in all of this was that of technical assistants who played a facilitating role, but they were never integral to the establishment of the relationship itself.

In eHealth all of this underwent a fundamental restructuring. The fiduciary physician-patient relationship can no longer be grounded in the direct professional-patient interaction because the very nature of physician-patient interaction has changed. Direct and interpersonal contact has been replaced by electronically mediated contact, and EHRs—which hitherto had been pragmatic tools that could in principle be dispensed with—became an integral feature not merely of the encounter itself but of the very conduct of health care, effectively assuming the role of patient analogues in the health care interaction. [39]

With this, the role of HIPs changed from that of supportive technical players in a framework that was rooted in the physician-patient encounter to that of operant facilitators and interfaces between health care institutions, physicians and patients. As a result, the whole obligation structure that had previously attached primarily to HCPs and institutions and had only incidentally extended to HIPs came to include HIPs in a direct manner. They now acquired a fiduciary role they had not had before except, if at all, in an accidental sense.

To highlight what this means for HIPs it may be useful to focus on privacy and confidentiality as a particular example. Privacy and confidentiality concerns are as old as Hippocrates. They have been addressed in codes of ethics ever since such codes have existed, and have received special attention with the advent of electronic data gathering, communication, storage and manipulation technology and with the development of EHRs themselves. Thus, in 1995 the European Union issued its Data Directive 95/46 EC. [40] It subsequently updated this in 2012 with a new Regulation for the protection of data rights, and the latter replaced the previous Directive in 2016 as Regulation (EU) 2016/679. [41] Likewise, in 2015 the OECD released its Health Policy Studies Health Data Governance Privacy, Monitoring and Research [42] which considered these issues on a global scale. Some of the ethical and legal issues that are here involved were spelled out explicitly in the European Court Ruling C-131/12 of 13 May 2014[43] which stipulated that controllers, operators, users, holders etc. of personal information are not owners but custodians of that information. In fact, it was recognized that informatic rights in health care are a subspecies of human rights, [43,31] and that whoever is involved in their development, communication, maintenance and manipulation has a fiduciary obligation towards the subjects of the relevant records. [44]

From an ethical perspective, how this affects HIPs who are engaged in eHealth is not merely a matter of juridical decisions and considerations but is grounded in the role of HIPs in eHealth and in the relationship between moral responsibility and complicity.

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