



The IMIA Code of Ethics for Health Information Professionals

Preamble

The planning, development and delivery of modern health care relies on the collection of data about patients, diseases and conditions which are then processed into health information that is suitable for clinical as well as administrative decision making. Health data are also integral to health related research, and the use of health related data inclusive of consumer data is an essential component of the planning, implementation and maintenance of health care delivery both in the public and the private sector. Finally, these data make possible the development and integration of policies, guidelines and advisories which further the health of the world as a global community

The data in question are sensitive because they are about individuals and populations. They therefore raise questions of privacy, ownership and control; and the use to which such data are put, as well as such things as access, storage, integrity, communication, linkage and manipulation present special ethical concerns.

Health informatics is the discipline that deals with health related data in all of these undertakings, and with how computers, software and telecommunication technologies are used to support the delivery of health care services. Health Information Professionals (HIPs)—individuals who, in their professional capacity, provide health informatics services—therefore occupy a special position in modern health care; and, given the ethically sensitive nature of health data and of health information, it is appropriate that the conduct of HIPs be guided by a Code of Ethics that identifies major lines of responsibility.

Codes of professional ethics serve several purposes: They provide ethical guidance for the professionals themselves, they identify principles against which the conduct of the professionals may be measured, and they present the public with a clear statement of the ethical considerations that should shape the behaviour of the professionals themselves.

A Code of Ethics for HIPs should therefore be clear, unambiguous, and easily applied in practice. Moreover, since the field of informatics is in a state of constant flux, it should be flexible in order to be able to accommodate ongoing changes without sacrificing the applicability of its basic principles. It would therefore be inappropriate for such a Code to deal with the specifics of every possible situation that might arise. That would make the Code too unwieldy, too rigid, and too dependent on the current state of informatics. Instead, such a Code should focus on the ethical position of HIPs as professionals, and on their relationships to the various parties with whom they interact in a professional capacity. These various parties include (but are not limited to) patients, health care professionals, administrative personnel, health care institutions as well as insurance companies, researchers and governmental agencies.



The reason for developing a distinct code of ethics for HIPs instead of merely adopting a code that has been promulgated by some other associations of informatics professionals is that HIPs play a unique role and occupy a unique position that is distinct from that of informatics professionals who do not specialize in health care data and who do not work in the health care setting.

Part of this uniqueness derives from the special relationship between electronic health records and the subjects of those records. Electronic health records not only reveal much that is private and that, all other things being equal, should be kept confidential but, more importantly, function as the basis of decisions that have profound welfare implications for their subjects. Further, the data contained in electronic health records also provide the raw materials for decision-making by health care institutions, governments and other agencies without which modern health care simply could not function. HIPs, therefore, by facilitating the construction, maintenance, storage, access, use, linkage and manipulation of electronic health records, play a role that is distinct from that of other informatics specialists.

Precisely because of this facilitating role, HIPs are embedded in a web of relationships that are subject to important ethical constraints. Thus, over and above the ethical constraints that arise from the relationship between electronic health records and the subjects of those records, the ethical conduct of HIPs is also subject to considerations that arise out of the HIPs' interactions with Health Care Professionals (HCPs), researchers, health care institutions and other agencies. These constraints pull in different directions. It is therefore important that HIPs have some idea of how to resolve these issues in an ethically appropriate fashion. A Code of Ethics for HIPs provides a tool in this regard, and may be of use in effecting a resolution when conflicting roles and constraints collide.

A Code of Ethics for HIPs is also distinct from an account of legally conferred duties and rights. Unquestionably, the law provides the regulatory setting in which HIPs carry out their activities. However, ethical conduct frequently goes beyond what the law requires. The reason is that legal regulations have purely juridical significance and represent, as it were, a minimum standard as envisioned by legislators, judges and juries. Moreover, legal standards are formulated on the basis of current circumstances and tend not to be anticipatory in nature. They therefore provide little guidance for a rapidly evolving discipline in which new types of situations constantly arise. HIPs who only followed the law, and who only adjusted their conduct to legal precedent, would be ill equipped to deal with situations that were not envisioned by the lawmakers and would be subject to the vagaries of the next judicial process.

A Code of Ethics that is grounded in fundamental ethical principles as these apply to the types of situations that characterize the activities of HIPs does not suffer from these shortcomings. It is independent of the vagaries of the judicial process and, rather than following it, may well guide it; and rather than becoming invalidated by changes in technology or administrative fashion, may well indicate the direction in which these developments should proceed. Therefore, while in many cases the clauses of such a Code will be reflected in corresponding juridical injunctions or administrative provisions, they provide guidance in times of legal or administrative uncertainty and in areas where corresponding laws or administrative provisions do not as yet exist. At a more general level, such a



Code may even assist in the resolution of the problems posed by the technological imperative. Not everything that can be done should be done. A Code of Ethics can assist in defining the ethical landscape.

The Code of Ethics that follows was developed on the basis of these considerations. It has two parts: an *Introduction* and *Rules of Ethical Conduct*. The *Introduction* begins with a set of fundamental ethical principles that have found general international acceptance. Next is a list of general principles of informatic ethics that follow from these fundamental ethical principles when the latter are applied to the gathering, processing, storing, communicating, using, linking, manipulating and accessing health data in general. These general principles of informatic ethics are high-level principles and provide general guidance.

The *Rules of Ethical Conduct* lay out a more particular set of ethical rules that should guide the behaviour for HIPs. These rules were developed by applying the general principles of informatic ethics to the types of relationships that characterize the professional lives of HIPs. They are more specific than the general principles of informatic ethics, and offer more particular guidance.

The precise reasoning that shows how the *Principles of Informatic Ethics* follow from the *Fundamental Ethical Principles* and that indicates how the *Principles of Informatic Ethics* give rise to the more specific *Rules of Ethical Conduct for HIPs* is contained in a separate Handbook and may be consulted there for greater clarity.

It should also be noted that this *Code of Ethics* does not include what might be called “technical” provisions. That is to say, it does not make reference to such things as technical standards of secure data communication or to provisions that are necessary to ensure high quality in the handling, collecting, storing, transmitting, linking, manipulating, etc. of health care data. This is deliberate. While the development and implementation of technical standards has ethical dimensions, and while these dimensions are reflected in the *Code and the Rules* as ethical duties, the details of such technical standards are not themselves a matter of ethics.



Part I.

Introduction

A. Fundamental Ethical Principles

All social interactions are subject to fundamental ethical principles. HIPs function in a social setting. Consequently, their actions are also subject to these principles. The most important of these principles are:

- 1. Principle of Autonomy*
All persons have a fundamental right to self-determination.
- 2. Principle of Equality and Justice*
All persons are equal as persons and have a right to be treated accordingly.
- 3. Principle of Beneficence*
All persons have a duty to advance the good of others where the nature of this good is in keeping with the fundamental and ethically defensible values of the affected party.
- 4. Principle of Non-Maleficance*
All persons have a duty to prevent harm to other persons insofar as it lies within their power to do so without undue harm to themselves.
- 5. Principle of Impossibility*
All rights and duties hold subject to the condition that it is possible to meet them under the circumstances that obtain.
- 6. Principle of Integrity*
Whoever has an obligation has a duty to fulfil that obligation to the best of their ability.

B. General Principles of Informatic Ethics

These fundamental ethical principles, when applied to the informatic setting, give rise to general ethical principles of informatic ethics.

- 1. Principle of Information-Privacy and Disposition*
All persons and group of persons have a fundamental right to privacy, and hence to control over the collection, storage, access, use, communication, manipulation, linkage and disposition of data about themselves.
- 2. Principle of Openness*
The collection, storage, access, use, communication, manipulation, linkage and disposition of personal data must be disclosed in an appropriate and timely fashion to the subject or subjects of those data.
- 3. Principle of Security*
Data that have been legitimately collected about persons or groups of persons should be protected by all reasonable and appropriate measures against loss degradation, unauthorized destruction, access, use, manipulation, linkage, modification or communication.
- 4. Principle of Access*
The subjects of electronic health records have the right of access to those records and the right to correct them with respect to its accurateness, completeness and relevance.



5. *Principle of Legitimate Infringement*

The fundamental right of privacy and of control over the collection, storage, access, use, manipulation, linkage, communication and disposition of personal data is conditioned only by the legitimate, appropriate and relevant data-needs of a free, responsible and democratic society, and by the equal and competing rights of others.

6. *Principle of the Least Intrusive Alternative*

Any infringement of the privacy rights of a person or group of persons, and of their right of control over data about them, may only occur in the least intrusive fashion and with a minimum of interference with the rights of the affected parties.

7. *Principle of Accountability*

Any infringement of the privacy rights of a person or group of persons, and of the right to control over data about them, must be justified to the latter in good time and in an appropriate fashion.

These general principles of informatic ethics, when applied to the types of relationships into which HIPs enter in their professional capacity and to the types of situations they encounter when thus engaged, give rise to more specific ethical duties. The Rules of Conduct for HIPs that follow outline the more important of these ethical duties. It should be noted that as with any rules of ethical conduct, these Rules cannot do more than provide guidance. The precise way in which the Rules apply in a given context, and the precise nature of a particular ethical right or obligation, depends on the specific nature of the relevant situation.

Part II.

Rules of Ethical Conduct for HIPs

The rules of ethical conduct that follow fall into six general rubrics, each with several sub-sections. The general rubrics demarcate the different domains of the ethical relationships between HIPs and specific stakeholders; the sub-sections list specific rules within these domains. For the sake of clarity, and in keeping with the varieties of functions that HIPs perform, the phrase 'subject of health care records' is used rather than the term 'patient' because not all subjects of health care records or of communications that are facilitated by HIPs are patients. Further, it is understood that even when not explicitly stated, the terms 'record' and 'health care record' respectively refer to electronic health care records.

A. Subject-centred duties

These are duties that derive from the relationship between electronic health records, the data contained in them and the subjects of those records. The duties arise from the fact that HIPs are instrumental in their construction, maintenance, storage, linkage, use, manipulation and communication.

1. HIPs have a duty to ensure that the potential subjects of electronic health records are aware of the existence of systems, programmes, protocols or devices whose purpose is to collect and/or communicate data about them.



2. HIPs have a duty to ensure that appropriate procedures are in place so that:
 - a. electronic health records are established, maintained, stored, used, linked, manipulated or communicated only with the voluntary, competent and informed consent of the subjects of such records, and
 - b. the subjects of electronic health records are informed of any contravention of A.2.a in good time and in an appropriate fashion.
3. HIPs have a duty to ensure that the subjects of electronic health records are made aware
 - a. who has established them and who maintains them,
 - b. what is contained in them,
 - c. the purpose for which they are established,
 - d. the individuals, institutions or agencies who have access to them or to whom they (or an identifiable part of them) may be communicated,
 - e. where the records are maintained,
 - f. the length of time they will be maintained, and
 - g. the ultimate nature of their disposition.
4. HIPs have a duty to ensure that the subjects of electronic health records are aware of the origin of the data contained in their records.
5. HIPs have a duty to ensure that the subjects of electronic health records are aware of any rights they may have with respect to
 - a. access, use and storage,
 - b. communication, linkage and manipulation,
 - c. quality and correction, and
 - d. dispositionof their electronic health records and of the data contained in them.
6. HIPs have a duty to ensure that
 - a. electronic health records are stored, accessed, used, linked, manipulated or communicated only for legitimate purposes;
 - b. there are appropriate protocols and mechanisms in place to monitor the storage, access, use, linkage, manipulation or communication of electronic health records, or of the data contained in them, in accordance with section A.6.a;
 - c. there are appropriating protocols and mechanisms in place to act on the basis of the information under section A.6.b as and when the occasion demands;
 - d. the existence of these protocols and mechanisms is known to the subjects of the records, and
 - e. there are appropriate means for subjects of the records to enquire into and to engage the relevant review protocols and mechanisms.



7. HIPs have a duty to treat the duly empowered representatives of the subjects of electronic health records as though they had the same rights concerning the records as the subjects of the records themselves, and that the duly empowered representatives (and, if appropriate, the subjects of the records themselves) are aware of this fact.
8. HIPs have a duty to ensure that all electronic health records are treated in a just, fair and equitable fashion.
9. HIPs have a duty to ensure that all reasonable and appropriate measures are in place to safeguard the
 - a. security,
 - b. integrity,
 - c. material quality,
 - d. usability, and
 - e. accessibilityof electronic health records.
10. HIPs have a duty to ensure, insofar as this lies within their power, that electronic health records and the data contained in them are used only
 - a. for the stated purposes for which the data were collected, or
 - b. for purposes that are otherwise ethically defensible.
11. HIPs who are professionally involved in the establishment, maintenance or conduct of eHealth have an obligation
 - a. to take all reasonable steps to ensure that the rules, regulations and procedural guidelines that govern the informatic practices and services of the eHealth providers with whom they are professionally associated are consistent with the informatic rights of the subjects of electronic health records in
 - i. the eHealth providers' jurisdiction of incorporation,
 - ii. the jurisdiction where the records are stored, accessed, used, linked, manipulated or communicated by the eHealth providers, and
 - iii. the jurisdiction in which the subjects of the records receive the services that are delivered by the eHealth providers;
 - b. to take all reasonable steps to ensure that the eHealth providers with whom they are professionally associated have effective measures in place to ensure that the individuals who are served by the eHealth providers are aware of their informatic rights, and have effective means in place for addressing any disputes or matters that may arise in this regard;
 - c. to take all reasonable steps to ensure that the eHealth providers with whom they are professionally associated have effective measures in place to review and, if necessary, to appropriately amend the measures indicated under 11(a)-11(b) on a regular basis in order to ensure that they are consistent with evolving informatic standards and laws in the eHealth providers' domains of operation; and
 - d. to engage in a professional capacity only with those eHealth providers whose operative frameworks meet the standard enunciated in 11(a)-11(c).
12. HIPs have a duty to ensure that the subjects of electronic health records are made aware in good time and in an appropriate fashion of possible breaches of the preceding duties and the reason for such breaches.



B. Duties towards HCPs

HCPs who care for patients depend on the services of HIPs for the fulfillment of their patient-centered obligations. Consequently, HIPs have an obligation to assist the HCPs with whom they are associated in a professional capacity insofar as this is compatible with the HIPs' primary duty towards the subjects of the electronic health records. Specifically, this means that

1. HIPs have a duty
 - a. to assist duly empowered HCPs who are engaged in patient care or planning in having appropriate, timely and secure access to relevant electronic health records (or parts of thereof), and to ensure the usability, integrity, and highest possible technical quality of these records; and
 - b. to provide those informatic services on which the HCPs rely to carry out their mandate.
2. HIPs should keep HCPs informed of the status of the informatic services on which the HCPs rely, and immediately advise them of any problems or difficulties that might be associated with or that could reasonably be expected to arise in connection with these informatic services.
3. HIPs have an obligation to take all reasonable steps to ensure that
 - a. HCPs who are engaged in eHealth and who depend on the HIPs' informatic services are aware of any differences in informatic rights or standards that might affect the HCPs' ability to carry out their mandate in the relevant interjurisdictional settings;
 - b. HCPs who are engaged in eHealth and who depend on the HIPs' informatic services are aware of any differences in the availability of informatic devices, protocols, tools etc. that exist between the HCPs' location and the location of the patients with whom they interact and that are relevant to the HCPs' ability to carry out their health care mandate insofar as this can reasonably be ascertained by the HIP; and
 - c. are aware of any difference in qualitative standards of the informatic devices, protocols, tools etc. that exist between the HCPs' location and the location of the patients with whom they interact and that are relevant to the HCPs' ability to carry out their health care mandate insofar as this can reasonably be ascertained by the HIP.
4. HIPs should advise the HCPs with whom they interact on a professional basis, or for whom they provide professional services, of any circumstances that might prejudice the objectivity of the advice they give or that might impair the nature or quality of the services that they perform for the HCPs.
5. HIPs have a general duty to foster an environment that is conducive to the maintenance of the highest possible ethical and material standards of data collection, storage, management, communication and use by HCPs within the health care setting.
6. HCPs who are directly involved in the construction of electronic health records may have an intellectual property right in certain formal features of these records. Consequently, HIPs have a duty to safeguard
 - a. those formal features of the electronic health record, or
 - b. those formal features of the data collection, retrieval, storage or usage system in which the electronic health record is embedded

in which the HCPs have, or may reasonably be expected to have, an intellectual property interest.



C. Duties towards institutions, employers and agencies

1. HIPs owe the institutions, employers or agencies with whom they are professionally associated a duty of
 - a. competence,
 - b. diligence,
 - c. integrity, and
 - d. loyalty.
2. HIPs have a duty
 - a. to take all reasonable steps to ensure that the informatic products, services, tools or devices they recommend to the institutions, employers or agencies with whom they are associated in a professional capacity are
 - (i) suitable,
 - (ii) reliable,
 - (iii) effective, and
 - (iv) qualitatively appropriate

so as to allow the latter to meet their respective obligations;

- b. to take all reasonable steps to ensure that the informatic protocols or procedures they recommend or institute are
 - (i) suitable,
 - (ii) reliable,
 - (iii) effective, and
 - (iv) qualitatively appropriate

to allow the institutions, employers or agencies with whom they are associated in a professional capacity to meet their relevant obligations;

- c. to take all reasonable steps to ensure that the institutions, employers or agencies with whom they are associated in a professional capacity are made aware in good time and in an appropriate fashion of any differences in the informatic obligations that may reasonably be expected to affect the latter's operation in an eHealth context or in an interjurisdictional domain of operation;
- d. to take all reasonable steps to ensure that the institutions, employers or agencies with whom they are associated in a professional capacity are made aware in good time and in an appropriate fashion of any differences in the material and technical resources that may reasonably be expected to affect the latter's operation in an eHealth context or in an interjurisdictional domain of operation;
- e. to be professionally qualified and certified, and to continue to be qualified and certified, in keeping with the highest current professional standards in the institutions', employers' or agencies' domains of operation.



3. HIPs have a duty to
 - a. foster an ethically sensitive security culture in the setting in which they practice their profession,
 - b. facilitate the planning and implementation of the best and most appropriate data security measures possible for the setting in which they work,
 - c. implement and maintain the highest possible qualitative and ethical standards of data collection, storage, retrieval, processing, accessing, communication, linkage and utilization in all areas of their professional endeavour.
4. HIPs have a duty to ensure, to the best of their ability, that appropriate measures are in place to evaluate the technical, legal and ethical acceptability of the data-collection, storage, retrieval, processing, accessing, communication, linkage and utilization of data in the settings in which they carry out their work or with which they are affiliated.
5. HIPs have a duty to alert, in good time and in a suitable manner, appropriately placed decision-makers of the security- and quality-status of the data-generating, storing, accessing, handling, linking and communication systems, programmes, devices or procedures of the institutions with whom they are affiliated or of the employers for whom they provide professional services.
6. HIPs should immediately inform the institutions, employers or agencies with whom they are affiliated or for whom they provide professional services of any problems or difficulties that could reasonably be expected to arise in connection with the performance of their contractually stipulated services.
7. HIPs should immediately inform the institutions, employers or agencies with whom they are affiliated or for whom they provide professional services of circumstances that might prejudice the objectivity of the advice they give.
8. Except in emergencies, HIPs should only provide services in their areas of competence, and should always be honest and forthright about their education, experience, qualification and training.
9. HIPs should only use suitable and ethically acquired or developed tools, protocols, techniques or devices in the execution of their duties.
10. HIPs have a duty to assist in the development and provision of appropriate informatics-oriented educational services in the institutions or agencies with whom they are professionally affiliated or for the employers for whom they work.

D. Duties towards society

1. HIPs have a duty to facilitate the appropriate
 - a. collection,
 - b. storage,
 - c. communication,
 - d. use,
 - e. linkage and
 - f. manipulation

of health care data that are legitimately used in research or that are necessary for the planning and providing of health care services on a social scale.



2. HIPs have a duty to ensure, insofar as this falls within their area of competence, that
 - a. only data that are relevant to legitimate research or planning needs are collected;
 - b. the data that are collected are de-identified or rendered anonymous as much as possible, in keeping with the legitimate aims of the collection;
 - c. the linkage of data bases can occur only for otherwise legitimate and defensible reasons that do not violate the fundamental rights of the subjects of the records; and
 - d. only duly authorised persons have access to the relevant data.
3. HIPs have a duty to educate the public about the various issues associated with the nature, collection, storage, use, linkage and manipulation of health related data and to make society aware of any problems, dangers, implications or limitations that might reasonably be associated with the collection, storage, use, linkage and manipulation of such data.
4. HIPs will refuse to participate in or support practices that violate human rights.
5. HIPs will be responsible in setting the fee for their services and in their demands for working conditions, benefits, etc.

E. Self-regarding duties

HIPs have a duty to

1. recognize the limits of their competence,
2. consult when necessary or appropriate,
3. maintain competence,
4. take responsibility for all actions performed by them or under their control or authority,
5. avoid conflict of interest,
6. give appropriate credit for work done, and
7. act with honesty, integrity and diligence.

F. Duties towards the profession

1. HIPs have a duty to always act in such a fashion as not to bring the profession into disrepute.
2. HIPs have a duty to assist in the development of the highest possible standards of professional competence, to ensure that these standards are publicly known, and to see that they are applied in an impartial and transparent manner.
3. HIPs will refrain from impugning the reputation of colleagues but will report to the appropriate authority any unprofessional conduct by a colleague.
4. HIPs have a duty to assist their colleagues in living up to the highest technical and ethical standards of the profession.
5. HIPs have a duty to promote the understanding, appropriate utilization, and ethical use of health information protocols and technologies, and to advance and further the discipline of Health Informatics.