

The IMIA Code of Ethics for Health Information Professionals

Preamble

Codes of professional ethics serve several purposes:

1. to provide ethical guidance for the professionals themselves,
2. to furnish a set of principles against which the conduct of the professionals may be measured, and
3. to provide the public with a clear statement of the ethical considerations that should shape the behaviour of the professionals themselves.

A Code of Ethics for Health Informatics Professionals (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 so as to accommodate ongoing changes without sacrificing the applicability of its basic principles. It is therefore inappropriate for a Code of Ethics for HIPs 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 the Health Informatics specialist as a professional, and on the relationships between HIPs and 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 and governmental agencies, etc.

The reason for constructing a code of ethics for HIPs instead of merely adopting one of the codes that have been promulgated by the various general associations of informatics professionals is that HIPs play a unique role in the planning and delivery of health care: a role that is distinct from the role of other informatics professionals who work in different settings.

Part of this uniqueness is centred in the special relationship between the electronic health record (EHR) and the subject of that record. The EHR not only reveals much about the patient that is private and should be kept confidential but, more importantly, it functions as the basis of decisions that have a profound impact on the welfare of the patient. The patient is in a vulnerable position, and any decision regarding the patient and the EHR must acknowledge the fundamental necessity of striking an appropriate balance between ethically justified ends and otherwise appropriate means. Further, the data that are contained in the EHR also provide the raw materials for decision-making by health care institutions, governments and other agencies without which a system of health care delivery simply could not function. The HIP, therefore, by facilitating the construction, maintenance, storage, access, use and manipulation of EHRs, plays a role that is distinct from that of other informatics specialists.

At the same time, precisely because of this facilitating role, HIPs are embedded in a web of relationships that are subject to unique ethical constraints. Thus, over and above the ethical constraints that arise from the relationship between the electronic record and the patient, the ethical conduct of HIPs is also subject to considerations that arise out of the HIPs'

interactions with Health Care Professionals (HCPs), 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 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, juries and judges. However, these standards are formulated on the basis of circumstances as they obtain here and now; they are not anticipatory in nature and therefore can 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.

On the other hand, a Code of Ethics for HIPs is grounded in fundamental ethical principles as these apply to the types of situations that characterize the activities of the Health Informatics specialist. Consequently such a Code, centring in the very essence of what it is to be an HIP, 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 through times of legal or administrative uncertainty and in areas where corresponding laws or administrative provisions do not 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 assists in defining the ethical landscape.

The Code of Ethics that follows was developed on the basis of these considerations. It has two parts:

1. *Introduction*

This part begins with a set of *fundamental ethical principles* that have found general international acceptance. Next is a brief list of *general principles of informatic ethics* that follow from these fundamental ethical principles when these are applied to the electronic gathering, processing, storing, communicating, using, manipulating and accessing of health information in general. These general principles of informatic ethics are high-level principles and provide general guidance.

2. *Rules of Ethical Conduct for HIPs.*

This part lays out a detailed set of ethical rules of behaviour for HIPs. These rules are 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 the *Code of Ethics* and the accompanying set of *Rules of Ethical Conduct* do not include what might be called “technical” provisions. That is to say, they do not make reference to such things as technical standards of secure data communication, or to provisions that are necessary to ensure a high quality in the handling, collecting, storing, transmitting, 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 her or his ability.

B. General Principles of Informatic Ethics

These fundamental ethical principle, when applied to the types of situations that characterize the informatics setting, give rise to general ethical principles of informatic ethics.

1. *Principle of Information-Privacy and Disposition*

All persons have a fundamental right to privacy, and hence to control over the collection, storage, access, use, communication, manipulation and disposition of data about themselves.

2. *Principle of Openness*

The collection, storage, access, use, communication, manipulation and disposition of personal data must be disclosed in an appropriate and timely fashion to the subject of those data.

3. *Principle of Security*

Data that have been legitimately collected about a person should be protected by all reasonable and appropriate measures against loss,

degradation, unauthorized destruction, access, use, manipulation, modification or communication.

4. *Principle of Access*

The subject of an electronic record has the right of access to that record and the right to correct the record with respect to its accurateness, completeness and relevance.

5. *Principle of Legitimate Infringement*

The fundamental right of control over the collection, storage, access, use, manipulation, 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 other persons.

6. *Principle of the Least Intrusive Alternative*

Any infringement of the privacy rights of the individual person, and of the individual's right to control over person-relative data as mandated under *Principle 1*, may only occur in the least intrusive fashion and with a minimum of interference with the rights of the affected person.

7. *Principle of Accountability*

Any infringement of the privacy rights of the individual person, and of the right to control over person-relative data, must be justified to the affected person 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 lives, and to the types of situations that 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 ethical rules of conduct, the *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 for HIPs can be broken down into six general rubrics, each of which has various sub-sections. The general rubrics demarcate the different domains of the ethical relationships that obtain between HIPs and specific stakeholders; the sub-sections detail the specifics of these relationships.

A. Subject-centred duties

These are duties that derive from the relationship in which HIPs stand to the subjects of the electronic records or to the subjects of the electronic communications that are facilitated by the HIPs through their professional actions.

1. HIPs have a duty to ensure that the potential subjects of electronic records are aware of the existence of systems, programmes or devices whose purpose it 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 records are established or communicated only with the voluntary, competent and informed consent of the subjects of those records, and
 - b. if an electronic record is established or communicated in contravention of **A.2.a**, the need to establish or communicate such a record has been demonstrated on independent ethical grounds to the subject of the record, in good time and in an appropriate fashion.
3. HIPs have a duty to ensure that the subject of an electronic record is made aware that
 - a. an electronic record has been established about her/him,
 - b. who has established the record and who continues to maintain it,
 - c. what is contained in the electronic record,
 - d. the purpose for which it is established,
 - e. the individuals, institutions or agencies who have access to it or to whom it (or an identifiable part of it) may be communicated,
 - f. where the electronic record is maintained,
 - g. the length of time it will be maintained, and
 - h. the ultimate nature of its disposition.
4. HIPs have a duty to ensure that the subject of an electronic record is aware of the origin of the data contained in the record.
5. HIPs have a duty to ensure that the subject of an electronic record is aware of any rights that he or she may have with respect to
 - a. access, use and storage,

- b. communication and manipulation,
- c. quality and correction, and
- d. disposition

of her or his electronic record and of the data contained in it.

6. HIPs have a duty to ensure that

- a. electronic records are stored, accessed, used, manipulated or communicated only for legitimate purposes;
- b. there are appropriate protocols and mechanisms in place to monitor the storage, accessing, use, manipulation or communication of electronic records, or of the data contained in them, in accordance with section **A.6.a**;
- c. there are appropriate 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 electronic records, and
- e. there are appropriate means for subjects of electronic 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 records as though they had the same rights concerning the electronic records as the subjects of the record 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 records are treated in a just, fair and equitable fashion.

9. HIPs have a duty to ensure that appropriate measures are in place that may reasonably be expected to safeguard the

- a. security,
- b. integrity,
- c. material quality,
- d. usability, and
- e. accessibility

of electronic records.

10. HIPs have a duty to ensure, insofar as this lies within their power, that an electronic record or the data contained in it 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 have a duty to ensure that the subjects of electronic records or communications are aware of possible breaches of the preceding duties and the reason for them.

B. Duties towards HCPs

HCPs who care for patients depend on the technological skills of HIPs in the fulfilment of their patient-centred obligations. Consequently, HIPs have an obligation to assist these HCPs insofar as this is compatible with the HIPs' primary duty towards the subjects of the electronic records. Specifically, this means that

1. HIPs have a duty

- a. to assist duly empowered HCPs who are engaged in patient care in having appropriate, timely and secure access to relevant electronic 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 that might be necessary for the HCPs 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 or that could reasonably be expected to arise in connection with these informatic services.
- 3.** 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.
- 4.** 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.
- 5.** HCPs who are directly involved in the construction of electronic 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 record, or
 - b.** those formal features of the data collection, retrieval, storage or usage system in which the electronic record is embedded
 in which the HCP has, or may reasonably be expected to have, an intellectual property interest.

C. Duties towards institutions/employers

- 1.** HIPs owe their employers and the institutions in which they work a duty of
 - a.** competence,
 - b.** diligence,
 - c.** integrity, and
 - d.** loyalty.
- 2.** HIPs have a duty to
 - a.** foster an ethically sensitive security culture in the institutional 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 institutional setting in which they work,
 - c.** implement and maintain the highest possible qualitative standards of data collection, storage, retrieval, processing, accessing, communication and utilization in all areas of their professional endeavour.
- 3.** HIPs have a duty to ensure, to the best of their ability, that appropriate structures are in place to evaluate the technical, legal and ethical acceptability of the data-collection, storage, retrieval, processing, accessing, communication, and utilization of data in the settings in which they carry out their work or with which they are affiliated.
- 4.** 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 and communication systems, programmes, devices or procedures of the institution with which they are affiliated or of the employers for whom they provide professional services.
- 5.** HIPs should immediately inform the institutions with which they are affiliated or the employers for whom they provide a professional service of any problems or difficulties that could reasonably be expected to arise in connection with the performance of their contractually stipulated services.

6. HIPs should immediately inform the institutions with which they are affiliated or the employers for whom they provide a professional service of circumstances that might prejudice the objectivity of the advice they give.

7. Except in emergencies, HIPs should only provide services in their areas of competence; however, they should always be honest and forthright about their education, experience or training.

8. HIPs should only use suitable and ethically acquired or developed tools, techniques or devices in the execution of their duties.

9. HIPs have a duty to assist in the development and provision of appropriate informatics-oriented educational services in the institution which they are affiliated or for the employer 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, and
- e. manipulation

of health care data that are necessary for the planning and providing of health care services on a social scale.

2. HIPs have a duty to ensure that

- a. only data that are relevant to legitimate 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 and use of electronic health-data and to make society aware of any problems, dangers, implications or limitations that might reasonably be associated with the collection, storage, usage and manipulation of socially relevant health 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,
- 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 always to 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 technologies, and to advance and further the discipline of Health Informatics.