Charter for an Ethic of Medical Informatics

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The French User's Club of the International Classification of Primary Care, an association affiliated with the WICC (Wonca International Classification Committee), and better known under the name CISP Club, has met annually since 1998. As an ongoing result of these reunions, the present document has been written by Bruno Seys (GP in Brussels), Madeleine Favre (GP in Paris) and Michel De Jonghe (GP in Tournai) and edited by Marc Jamoulle (GP in Charleroi).

We, members of the CISP Club, a group of healthcare professionals and informaticians, experts in the treatment and processing of medical information, herein express

- our desire to preserve a meaningful therapeutic relationship with our patients
- our desire to promote the intelligent and ethical use of information technology when working with and managing electronic health records
- our desire to call to the attention of our colleagues the potential problems posed by the future of electronic health records
- a persistent worry about the effects of political or corporate intrusions into the principles of medical secrecy and the private lives of citizens
- our dismay about the increasing interest in the use of personal medical information as a financial object and potential profit center
- our awareness that many healthcare professionals are unsure of the procedures for following disparate or unreliable technical specifications or recommendations concerning personal medical information
- our anxiety about the potential consequences of a careless usage of information technology by healthcare providers when working with patients' medical records
- our uneasiness in the face of mounting pressure on medical practitioners to disrespect their patient's rights to information and privacy.
- Our worry about the prevailing lax attitude being shown for the ongoing integrity of personal medical data

We further believe it vital that we affirm our commitment to three basic ethical principles that we believe must guide and govern the processing of all personal medical information:

- Respect of individual privacy
- Confidentiality of the doctor/patient relationship
- Patient consent

These three principles are developed and defended by several universally respected sources:

- **1. Fundamental References**
  - 1. The Helsinki Declaration, 1964
  - 2. AMM: Lisbon Declaration, 1981
  - 3. GEE: Ethical Aspects of the Use of Personal Medical Data in the Information Society, 1999
2. International Treaties:
   - 3. The European Charter of Fundamental Rights, art 3 & 8.

3. Belgian national texts:
   - "Recommendations on the establishment and maintenance of medical databases containing nominative data" Council of the National Order of Doctors (Belgium), Bulletin of the National Council, #97 p.6 (Ref: A097008)

4. Academic works:
     (Other resources are noted in the bibliography at the end of this document.)

After much reflection, we draw the following conclusions:

1: Concerning the Patient
   - 1. He is owner of his medical records and confers stewardship of these records to healthcare professionals. He can at any time, consult, modify, or suppress information contained therein.
   - 2. He has the right of confidentiality over his medical information.
   - 3. He can demand that certain personal medical information be neither noted nor divulged.
   - 4. He acknowledges the existence and consents to the use of his personal medical information.
   - 5. He is a full partner in his personal healthcare.
   - 6. He has the right to understanding the meaning of information pertinent to his health.

2: Concerning the Healthcare Professional
   - 1. He is responsible for the integrity of all patient information received.
   - 2. He is the guarantor of the confidentiality of this information.
   - 3. He respects the reluctance a patient may express toward recording or divulging personal medical data.
   - 4. He informs the patient of the possible uses of personal medical information.
   - 5. He respects the patient's active role in his/her own healthcare and accordingly, will release any personal medical information when requested to do so by the patient.
   - 6. He will respect the patient's request to not include sensitive information.

3: Concerning the electronic health record administrator
   - 1. He is responsible to both the healthcare provider and the patient concerning the use made of personal medical data.
   - 2. He is sworn to professional secrecy.
   - 3. He is able to guarantee that confidentiality always takes precedence over technical performance or ease-of-use.
   - 4. He can demonstrate to the healthcare provider that the confidentiality principle is respected, both in everyday interactions and in backend technical operations.
   - 5. He is obliged to respect patient desires about the non-recording or nondivulgation of personal medical data.
   - 6. He is the conceptor of the consent form that the healthcare provider submits to the patient.
   - 7. He is obliged to provide the healthcare provider with means of informing the patient of the results when new personal medical information has been generated or processed.
   - 8. The processes by which original personal medical information is destroyed shall be explicitly respected and recorded.

Chapter 4: Other Intermediaries
   - 1. He respects the roles and obligations of the actors described in the preceding paragraphs.
   - 2. He respects the venerable principles of reciprocal doctor/patient confidence and confidentiality.
embodied in healthcare philosophy over the centuries since Hippocrates.

In Conclusion We recognize that the health information process is complex. We fully acknowledge the need for continuing medical research, are convinced of its role in improving the quality of healthcare. We also believe that medical informatics will play a crucial role in delivering improved healthcare in the years to come, and that the sharing of personal information and medical data can be an important tool in improving efficacy and equity of healthcare.

We believe strongly that each practitioner must work in the environment of his choice. Accordingly, we ask all our colleagues in the healthcare community to exercise the highest levels of critical judgement when confronted with new situations arising from the digitalisation and sharing of patient healthcare information.

We call on all healthcare professionals to act conscientiously whenever confronted with the non-respect of the issues concerning patient medical data integrity and confidentiality described in the preceeding paragraphs of this charter.

Signed in Sables d'Olonne, 9 October 2005 Philippe Ameline, IT specialist, Paris (F)
Manu Berquin, general practitioner, Brussels (B)
Alain Brohée, family doctor, healthcare information manager, Ghlin (B)
Jean-François, Brulet, general practitioner, Saint Martin IT, Lestra (F)
Michel De Jonghe, general practitioner, researcher at the University Libre of Brussels, Département of general medicine, Rongy (B)
Bernard Dendeau, IT, Waterloo (B)
Madeleine Favre, general practitioner, Vincennes (F)
Jacques Hidier, Challans (F)
Joseph Hubert, family doctor, Ciney (B)
Jacques Humbert, family doctor, Beauvoir Sur Mer (F)
Onesphore Kubwimana, medical oo-ordinator, MdM Monrovia, Liberia (LIB)
Marc Jamoulle, family doctor, healthcare information manager, Gilly (B)
Olivier Latignies, IT specialist, Fosses-la-ville (B)
Laurent Letrilliart, general practitioner, primary care researcher, Villeurbanne (F)
Luc Ribetou, general practitioner, Centre 15, Bordeaux Saint-Loubes, (F)
Michel Roland, general practitioner, healthcare information manager, University Libre of Brussels, département de Médecine Générale, Bruxelles (B)
Marc Vanmeerebeek, general practitioner, Public health information manager, Departement of General Medicine, Liège (B)
Marc Verbeke, Assistant at the University of Gand, Department of primary health care, Zele (B)
Désiré Verbraeck, general practitioner, healthcare information manager, Flawinne (B)
Christian Simon, médical IT specialist, Angers (F)
Bruno Seys, family doctor, healthcare information manager, Bruxelles (B)

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Adopted by the 34th World Medical Assembly Lisbon, Portugal, September/October 1981 and amended by the 47th General Assembly Bali, Indonesia, September 1995.
11/01/2001 (rectificatif).
7. Recommandations relatives à la tenue de bases de données médicales contenant des données nominatives ou identifiables, Conseil national de l'Ordre de médecins (Belgique), Bulletin du Conseil National, n°97 p. 6 (doc : A097008).
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