Call for Papers
IMIA WG4 (SiHIS) Workshop
2009

Trustworthiness of Health Information
< Issues on security, privacy protection and system for the management of patient safety >
- Will the OECD principles still be valid in future? -

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IMIA Working Group Security in Health Information Systems (SiHIS/WG4) will work towards a practical direction for the next generation management of health care information and its supporting systems. It is expected that health care professionals, managers, academic researchers, and representatives from industry will join us with practical and theoretical issues. A prize will be awarded for the best paper authored by a young researcher under the age of thirty five.

Scope
1. Trustworthiness of health information
   As the essence of good health care relies on the trustful patient-physician relationship, a physician usually explains in some detail the medical treatment to be applied to the patient by using the patient’s chart. Though it may be sometimes very difficult for the patient to fully understand the issues, the doctor and/or persons assisting him have opportunities to explain further whenever it is necessary. But, with the spread of electronic health records and the advent of a society in which the patient carries his/her medical records, the medical records
should explain their true meaning by themselves. Moreover, misunderstanding or confusion of the patient at the initial stage of communication between the patient and the doctor must be avoided. If the medical records tell us incorrect information due to the deficiencies or inaccuracies of data or misunderstanding, it is very dangerous to make any decisions relying on such untrustworthy information. The trustworthiness of health information, which is based on information validity, is thus the basis for the ability to share patient information among health care communities. The health information, however, contains various kinds of data. In some cases, it is easy to understand their meanings. Clinical test results, for example, may belong in this category. On the other hand, there is a concern of misunderstanding of diagnoses or doctors’ opinions without detailed explanation or reasoning. Though the patient has a right to access their own medical records, it may be necessary to classify the medical records and the access methods so as to avoid misunderstanding.

2. **Is it necessary to regulate the information flow?**

   The patient has a right to access his/her medical records. However, in some cases, he/she may have a desire not to have some information disclosed to him/her because they are not prepared for serious. The physicians, on the other hand, are responsible for the results of their decisions to disclose or not to disclose the information. There are many reasons in the team care or community care process to restrict sharing some health information of the patient to the care team only. The decision to hide information from the patient in the patients’ own interest should be the responsibility of the care team. They can provide a clear explanation if asked. Here there are key issues concerning management policies and solutions: how to take the responsibility, how to regulate information flow, and how to identify the information – if any – that should be hidden from the patient.

3. **Trustworthiness of health information management**

   As medical data is gathered during the course of patient care, it should be used for the treatment of the patient. But, the improvement in medical care also depends on how to use the accumulated data. Therefore it is crucial to gather “correct data”, which will lead to the trustworthiness of health information.

   In 1980, the OECD decreed that use of personal information in a variety of circumstances, including patient care, be allowed only when the subject (patient) has accepted the specific use, or when there are rules authorized by law. In the age of networked computer systems, vast amounts of data can be manipulated outside the patient-physicians relationship. Hence the vague statement in the OECD guideline causes an embarrassment. It will be necessary to issue a guideline that supports both the good patient-physicians relationship in the course of care (primary information use), and the development of social welfare and scientific advancement (secondary use). If the participants ask for opportunities to discuss commercial issues, we will endeavor to accommodate such discussion as well. Please contact the SPC.

   The discussions are intended to result in a new management guideline for effective use of health information, intended to be issued as the "Hiroshima Statement", which will be expected to contribute to the innovative ICT-based healthcare.
Program

Session 1: Trustful sharing of information in clinical use (Issues of primary use)

Issues relating to the trustful sharing of information among the patient and the care teams are treated.

Focuses:
1) Can personal health and welfare related information collected outside the care or treatment context be included to the EHR?
2) Should the objectives of the collection and the purposes the use of collected information be informed in advance to the patient and/or an authorized legal guardian?
3) Should all members of the care team sharing the information be identified and get permission beforehand from the patient and/or an authorized legal guardian?
4) Is there any method to assure the trustworthiness of information, i.e., that it is truly understood among the patient and/or the care team, and is it safe to take action based on that information?
5) How to collect data for the research use and improve the patient-care team relationship.

Session 2: Trusted use of of personal information for academic, social and other purposes (Issues of secondary use)

Issues relating we can use personal information for the development of social welfare, healthcare technology, and scientific advancement in trusted way.

Focuses:
1) Is it effective to define and restrict the objectives of research before data collection? If not, how can one obtain permission?
2) What is the patients' right to control the accumulated data?
3) What is the practical method of encryption? Is it possible to encrypt in any case?
4) Problems relating to the use of data distributed among various data sources such as different hospitals.
5) Some miscellaneous problems such as the illegal use of information.

Session 3: The system solution

Issues relating to ICT system solutions to fulfill the requirements derived from the discussions of the above two sessions are treated.

Focuses:
1) The computer systems that can quickly reflect patients' preferences regarding the use of their personal information.
2) The technical solutions that allow the care team to regulate the sharing of information in accordance with the consensus and/or preferences of the patient.
3) The technical solutions that allow the care team to manage the access control dynamically to cope with abrupt changes of the patient's status or accidents.
4) The technical solutions that can assure the trustworthiness of information.
5) The desirable system style and/or the technical solutions that can meet the requirements of both primary and secondary uses.
Our plan was made out with the help of Jochen Moehr (the Former President of IMIA WG4 (SiHIS) and Professor Emeritus of Univ. Victoria, Canada)

**Important Dates**

- **Online Paper Submission System Open**: Feb 12, 2009
- **Submission Deadline**: May 4, 2009
- **Notification of Acceptance**: Jun 22, 2009
- **Submission of Final Version**: Aug 21, 2009
- **Early bird registration deadline**: Sep 30, 2009
- **Conference**: Nov 21-24, 2009

**SUBMISSION OF PAPERS**

1) Authors should submit an original paper in English using the on-line submission system (http://home.hiroshima-u.ac.jp/~humind1/comhi2009/submission.html#).

2) The provided MS Word templates should be used for paper format. Authors are requested to upload their MS Word files (with a maximum of six double-column single-spaced pages) through the on-line submission system.

3) All Submitted papers will be reviewed by the SPC (Science Program Committee).

4) Papers that are out of the conference scope will be rejected or recommended to other internal sessions in **COMHI in Hiroshima 2009**.

5) An award is available for the best paper submitted by a student or researcher under the age of 35.

6) All accepted papers will be published in "Yearbook of Medical Informatics" and special edition of "International Journal of Medical Informatics".