DATA PROTECTION IN HEALTH INFORMATION SYSTEMS (IMIA WG 4)

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1.   Introduction

WG 4 was set up in the 1970s to examine the issues of Data Protection and Security within the Healthcare environment. Confidentiality has always been a significant issue in healthcare and health professionals always need to be assured about this aspect of any new information system before being prepared to collaborate with, or participate in, any medical computing project.

The aims and objectives of WG 4 are in line with the EC Directive on Data Protection, finalised during 1994, which is to assist Working Group members to institute a national harmonised data protection environment to establish a greater level of protection and security.

In 1995, Barry Barber, UK handed over the chair of WG 4 to Ab Bakker.

2.   Past International Working Conferences

WG 4 ran a successful series of working conference during the late 1970s and early 1980s under the chairmanship of Gerd Griessor and David Kenny. As many countries who had ratified the Council of Europe Convention started to implement data protection legislation, the large scale independent activities of WG 4 diminished for a time in the early 1980s although work continued with many data protection seminars and workshops in the mainstream conferences, e.g. MEDINFO, MIE and EFMI etc.

Workshops were held at the MEDINFO congresses in Singapore, Geneva and Vancouver and encouragement given to present an increasing number of papers on data protection and information systems security. The IMIA Regional Body for Europe (EFMI) was persuaded to establish a corresponding working group (EFMI WG 2 - chaired by the past IMIA WG 4 Chairman, Barry Barber), in order to facilitate collaboration

within Europe and, especially, with the European Commission which was then developing their programme of Advanced Informatics in Medicine (AIM). This resulted in the development of workshops during the EFMI/MIE Congresses in Oslo 1988, collaborating with the Council of Europe and published in a special issue of Medical Informatics, Glasgow 1990, Vienna 1991 and Jerusalem 1993. In addition, EFMI WG 2 supported the AIM secretariat in developing a working conference in Brussels in 1990. Individual participation was possible in various projects of the EC in respect to security of information systems in healthcare.

The working conference at Château Marquette, Heemskerk in The Netherlands, November 1993, entitled Caring for Health Information, was well attended. The authors produced a good range of important papers for an impressive scientific program, covering: the security of electronic patient records; legal issues in data protection; security in connected systems; producing and purchasing safe systems; training, management and development of the security culture, resulting in a productive working conference.

As discussed during our WG 4 meeting at MIE 94 in Lisbon, Portugal, we believe that the Heemskerk working conference will open the way to some very interesting future work in data protection and security. This will ensure that WG 4 is better able to tackle the many security issues that surround the use of information systems in a healthcare environment which is increasingly complex and dependent upon its information systems to treat patients effectively.

A working conference was organised in Helsinki, Finland in October 1995 on the subject: Communicating Health Information in an Insecure World. As preprints of the invited papers were in the hands of the participants 10 days before the conference, the conference was able to devote time to the discussion group sessions, only the highlights of the invited papers were presented in plenary sessions.

The working conference was very successful due to the efforts of both the local organising committee and the scientific programme committee. The results will be published as a special issue of the International Journal of Bio-Medical Computing in the first quarter of 1996. Besides that, a hard cover edition will be published which will also contain the results of each of the discussion group sessions.

3.   Future International Working Conferences/Activities

The next meeting of IMIA WG 4 is to be organised during the MIE 96 conference in Copenhagen.

IMIA WG 4 members from Japan, under the leadership of Koji Yamamoto, have taken the initiative to prepare the next security working conference in Japan. A plan is being prepared and a date will be communicated.

An invitation was received to prepare a three-hour tutorial and a formal presentation of the Helsinki conference results at the conference Toward an Electronic Patient Record 96 in San Diego, USA in May 1996.

Other Activities
An inventory was started for training/education material for security in health information systems. Helsinki working conference participants have received an overview of the initial report and have been asked to complete the inventory.

4.   Proceedings and Publications (WG 4)
Griesser G, Bakker A, Danielsson J, Hirel J.-C, Kenny DJ, Schneider W, Wasserman A, eds. (IMIA WG 4). Data Protection in Health Information Systems: Considerations and Guidelines. Amsterdam: Elsevier Publishing Co, 1980. ISBN 0 444 86052 5.

Griesser G, Jardel JP, Kenny DJ, Sauter K, eds. (IMIA WG 4). Data Protection in Health Information Systems: Where do we Stand? Amsterdam: Elsevier Publishing Co, 1983. ISBN 0 444 86713 9.

Proceedings of a joint workshop on Data Protection with the Council of Europe held during Medical Informatics Europe, MIE-88 in Oslo. Special Issue on Social & Legal Aspects, Med Inform 1989; 14: 207-247.

CEC DG XIII/F AIM. Health Informatics 1991: Handling Health Data in Europe in the Future. (Proceedings of a Working Conference 1990) Amsterdam: IOS Press. ISBN 90 5199 052 9.

Barber B, Bakker A, Bengtsson S, Eds (IMIA WG 4) Caring for Health Information. Amsterdam: Elsevier Publishing Co. 1994 (also special issue of the Intern J Biomed Comput).

Proceedings and reports have been produced for most IMIA WG 4 meetings. *Helsinki report out soon.*

5.   Other involvements and relationships
IMIA Institutional Members continue to be invited to all WG 4 activities.

Various members of WG 4 have had a series of contacts with national and international bodies, such as the Council of Europe Data Protection and Bioethical work, the European Commission work on the EU Directive on Data Projection and the AIM (Advanced Informatics in Medicine). There has also been participation in the activities of INFOSEC, the Fourth Framework and the standards activities of Data Protection and Security in CEN, EWOS and hence in ISO and IEC.

Links with the IFIP Technical Committees continue with interchange of reports.

6.   List of Members
Can be obtained directly from WG 4 Chair.