

Reflections on the Development of Medical Informatics

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Review

ABSTRACT

The recording of numbers appears to pre-date the emergence of writing and excavations of the clay tablets of civilisations in the Middle East have shown that clay tablets were used to keep account of activities undertaken in a systematic fashion. Correspondingly, various forms of abacus have been used types of calculation from the Sumerian abacus dating from about 4 ½ thousand years ago to the Chinese abacus (Suanpan) from around 2 thousand years ago. As time passed various forms of writing were developed using animal hides, which were developed as vellum and papyrus which eventually developed into paper. Wood block printing, also, was a very ancient art and movable type printing had been utilised in the far East but the development of movable type page setting in Europe transformed the process of printing.

Key words: Medical informatics, development, reflections, EFMI, IMIA.

1. IN THE BEGINNING THERE WERE PAPER SYSTEMS

The recording of numbers appears to pre-date the emergence of writing and excavations of the clay tablets of civilisations in the Middle East have shown that clay tablets were used to keep account of activities undertaken in a systematic fashion. Correspondingly, various forms of abacus have been used types of calculation from the Sumerian abacus dating from about 4 ½ thousand years ago to the Chinese abacus (Suanpan) from around 2 thousand years ago. As time passed various forms of writing were developed using animal hides, which were developed as vellum and papyrus which eventually developed into paper. Wood block printing, also, was a very ancient art and movable type printing had been utilised in the far East but the development of movable type page setting in Europe transformed the process of printing. It led to the explosion of printing presses and printed material which transformed the cultural environment by facilitating the transmission of ideas and information. However, paper systems were an essential part of any significant project, accounting or the work performed by individuals.

Caesar Augustus decreed that a census should be taken (1) and there is no doubt that this was part of his system of control. Similarly the Magna Carta (2), commissioned by William the Conqueror of England, was a key component of his system of control and taxation of his conquered land. These activities were expensive and were not undertaken for fun but were active information systems in the modern sense of the term. However, it might be argued that the Jacquard loom (3)] and the use of punched cards in engineering control systems

was the next step from paper systems towards modern, computer-based, information systems. Indeed, the fast, 5-hole, paper tape readers and printers developed during World War II at Bletchley Park might be seen as the next logical step along the road. When The London Hospital, now the Royal London Hospital, took delivery of an Elliott 803 computer in November 1964 (4) nearly 50 years ago, it was the first hospital in the United Kingdom to purchase its own computer.

2. INITIAL LIMITATIONS OF COMPUTERS

The computer that we purchased had 8k of 39-bit words as immediate access memory with a cycle time of 256 μsec and it used three 35mm magnetic film handlers as the backing store. It used 5-hole paper tape as the input and output medium, although we did not know at that time where these facilities had been first developed. The instruction code comprised 6-bit function code operating on an 13-bit address code—which enabled the instruction to thus address the whole store directly. Two machine code instructions could be held in a single word and this allowed for a B-line modifier-bit between them.

The 1000 foot reels of magnetic tape could hold 4096 blocks of 64 39-bit words but all this complicated technology only held just over a megabyte per reel. Data and program input was achieved using a Teletype machine to both print the information on paper as well as on the 5-hole tape. The paper tape reader could input information at 500 char/sec. Correspondingly, the computer printed out paper tape at 100 char/sec which was then run through a printer. Interestingly, we all got quite good at winding up large rolls of paper tape and at deci-

phering—and sometimes adjusting with a Uni-punch—the symbols on the tape!

In purchasing the computer, the Board of Governors of The London Hospital were advised that the financial systems at the heart of the case made out for the computer would only take up half of the computer's time. Accordingly, they decided that the rest of the time should be made available for medical and scientific research as was appropriate for a Teaching Hospital. This directive enabled many projects to be undertaken within both the hospital and the medical college. Thus, computing time was available but the programming, systems development and operating of the non-financial programs was almost exclusively carried out by the users themselves.

The Operational Research Unit, a sister Unit of the Computer Unit, that had developed out of the work carried out in the Medical Physics Department was able to take full advantage of these facilities for the exploration of the use of Operational Research techniques developed during WWII to improve the operation of the hospital. Among the projects it explored were Queueing in Out-Patient clinics, staffing of emergency anaesthetic services, admission and discharge arrangements, planning the haemodialysis programme, running obstetric surveys, examining the nurse training programme, establishing a microfiche nurse record system as well as an assessment of computerised radiotherapy treatment planning systems.

As with much university computing on large batch machines, this work was helped by the availability of “High Level Programming Languages”. In the case of the Elliott 803 we had 803 Autocode and, at a later stage, we had 803 Algol although this was really designed for the Elliott 503, which was about 60 times faster although only twice as expensive!

Although these facilities were an amazing improvement on the use of a mechanical calculator or the punched card equipment of the finance department, a quick comparison with the personal computers now readily available in many homes shows how limited they were in comparison with the tasks that began to be tackled. However, the work undertaken did enable staff to begin to explore the data that was routinely handled in the hospital and in the research work of the Medical College and this expertise formed the basis for subsequent developments in the use of “Real Time” hospital systems.

The three Annual Reports from the Computer and Operational Research Units covering the first three years of use of the Elliott 803 showed how the computer had been used and what the next steps in computerisation of the hospital might be. The average weekly running time grew from 50.7 hours in the first full year to 74.4 and 104.6 hours in the following two years.

The third report outlined the next step in which a “batch processing system” could be used to handle the basic “Patient Administration” of the hospital (5). It should be noted that at this same time Elliott Medical Automation Ltd was established under the direction of Dr L C Payne and he made an arrangement with

University College Hospital to install an Elliott 803 on their premises as a means of exploring a wide variety of health computing problems, which included laboratory computing with auto-analysers and radiotherapy treatment planning but his ideas went much further into the areas of medical informatics (6).

3. CULTURAL LIMITATIONS

Unlike the present day, computers were housed in large airconditioned rooms which could only be accessed by authorised people. Frequently, there was a viewing window for visitors but these were soon discontinued for security reasons. There was little or no public or professional understanding of:

- The uses and limitations of computers;
- How information could be entered into computers;
- How information systems could provide information;
- No teaching about computers in schools.

Culturally, it was thought that typing was a “secretarial skill” beneath the dignity of professional people like doctors and nurses and collating information was a job for clerical staff.

These ideas have only slowly changed as more and more people have had access to more and more powerful computers. Like journalists before them who found that typing was an important skill for their profession, many professional staff, especially at Universities, where there was access to large computer systems, found that they could draft their research papers and reports by typing into computer systems and that errors could be easily corrected as their ideas were developed.

This drift in work patterns was accelerated as many organisations moved away from providing personal secretaries towards typing pools and then to providing computing facilities instead.

Although the culture was changing solutions had to be found to achieve data input to computer systems that did not involve memorising complex systems of codes. As ideas developed different approaches were explored and tested it was found that:

- A tree-branching approach in which the users selected options from short lists enabled them to locate appropriate parts of a record for data entry or inspection.
- More powerful computer systems could assist the data entry process with basic validation checks and spell checking.
- Staff were no longer “afraid” of using computers.
- Some early systems envisaged data entry being handled by a core of individuals like telephone operators but it quickly became apparent that the only way to capture reliable information was for it to be entered directly by those involved in creating it.

For this to happen, the process had to be made easy and fast. One of the major reasons for the termination of Prof John Anderson's Kings College Hospital Medical Records System was the appearance of a paper by his colleagues claiming that it took longer to enter the medical record into the computer system than when the recording was done by hand (7).

4. OPPORTUNITIES OFFERED

On the other side of the equation computers offered amazing opportunities for the communication and analysis of information and for improvements in the functioning of organisations. At one go they could overcome the limitations of a single medical record located in one place. In an increasingly distributed health care system up-to-date medical records can be available wherever they are needed crossing whatever organisational boundaries are necessary, subject only to the issues of patient confidentiality. By collecting information about the passage of patients through their care the medical information systems can automatically provide information about the functioning of a hospital or other care system in order to facilitate improvements in the delivery of care both from the patients' perspective of avoiding non-clinical delays and worry as well as from the organisation's perspective in terms of the efficiency of the delivery of care. It should be noted too, that almost every aspect of clinical care has been transformed over the last 50 years with dedicated information systems and devices which assist clinicians in the processes of diagnosis, therapy and recording of clinical findings—quite apart from the larger systems for hospitals as a whole. However, these advances have only been possible as a result of the improvements in the speed and size of computer systems, the ease of computer usage and data input, the the clinical and organisational research that has been incorporated into modern information systems.

5. SOME KEYS TO SUCCESSFUL INFORMATION SYSTEMS

The early computing systems tended to use a “batch processing” approach in which information was recorded and analysed for later use but the advent of much faster and more powerful computer systems began to enable computers to accept information that has been input and provide an almost instant response. This “Real Time” approach provided opportunities for the direct interaction of doctors and nurses with the computer systems for the first time. However, it was very demanding of the computing facilities because, if the computer's responses were too long in coming, the users would simply walk away and get on with other work—and the system as designed would be an evident failure. The total system of hardware, software and user activity must be fast enough in providing results for the users to complete their tasks without any perceptible delay.

The Management of Change in any organisation requires serious attention and all the key disciplines must be brought into the process at the right organisational level and with experienced individuals. In setting up the Real Time System at The London Hospital, an Executive was established chaired by a senior administrator and which included a senior doctor and nurse as well as the Directors of the Computer and Operational Research Units—which provided the technical input. Although the technical staff were engaged full time, they were often involved in many other activities than the process of building the Hospital's Real Time Computer System.

The other staff simply had the routine oversight of the process of building the system added to their other professional activities. At the start, the five initial members of this Executive had, between them, over 100 person years of experience at the hospital. This Executive was responsible for all the decision-making in the project. Once the outline of the project was clear, it established “Training and Consultation” sessions, initially with the senior medical, scientific and nursing staff but then focussing later on user training with more junior staff as various parts of the system were moving towards implementation. The Executive, decided to address the areas of activity that we described as Patient Administration in order to gain experience of these systems before tackling the more life threatening issues of the full medical record.

Although, even then once a part of the system had been introduced and was running routinely, any interruption or failure to deliver results could cause considerable organisational problems—and would have the senior doctor and nurse out on the wards trouble shooting the clinical issues. The whole process was that of exploring an area of systems activity with surveys or Operational Research techniques, developing a feasible computer-based system, testing the users reactions and making changes as needed, establishing an appropriate training programme and then proceeding to full implementation – and reviewing problems and progress some weeks after implementation. During the development of the project, the hospital Chairman, Sir Harry Moore, provided us with a copy of an early paper outlining why computer systems fail (8) and he advised us that he did not expect us to fail for any of the reasons outlined in that early paper! That paper listed many of the reasons why so many computer systems have failed and still continue to fail! An early review of the project was given in (9); the basic software developed “in-house” for the system was ported from the initial Univac 418/III fast message-switching hardware to two other platforms before finally being decommissioned after some 36 years a few years ago. The reason for the original choice of computer system was that it was a very fast message switching system with a 750ns cycle time, 80k of 18-bit words of RAM and two fast drums holding 3m 6-bit characters with 4 ¼ms access time backed up with a Fast-rand II holding 132m characters with a 90ms access time. The whole scheme was designed to facilitate the fast menu selection process (10). Although the system came with a basic RTOS operating system, it was necessary for the staff to write all the “middleware” to enable the system to function as needed by the designers and the hospital staff.

6. THE EMERGENCE OF NURSING INFORMATICS

Although the term medical informatics was frequently used, it was inevitable that nurses should become heavily involved in the use and design of health care information systems. Indeed at the foundation of EFMI there was considerable discussion about the name but it was finally decided that the term “medical” should

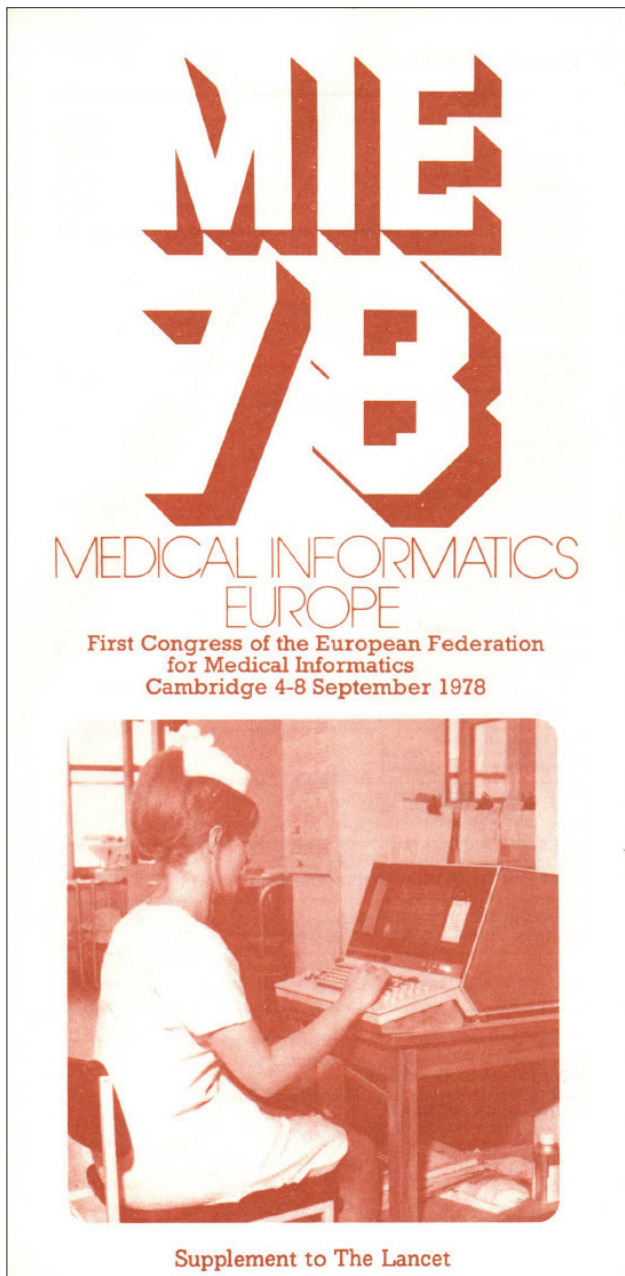


Figure 1. Poster of MIE 1978 Conference .

be interpreted as including all aspects of health care—instead of specifically including the words “health” or “health care” in the title.

The issues of nurse allocation were an early interest of mathematicians and some computer solutions followed but a more important issue surfaced in the handling of the records of nurses in training and the development of training programmes. If the allocation programs were somewhat too complex for the early computers, it became clear that as “nurses looked after patients who were visited from time to time by doctors”, they would be closely involved in the acceptance or rejection of medical information systems both on the hospital ward and in the community. Successful projects invariably involved nurses who could focus on the systems aspects with their colleagues and ensure that they were designed to help their colleagues carry out their activities. The recording of these activities became integral

with the activities themselves rather than an additional task added at the expense of providing care for their patients. As with doctors, the important issue was to find some acceptable means of data capture “in real time” instead of creating additional time-consuming work. It appears to be true today that some systems still absorb far too much nursing time and take nurses away from the basics of patient care.

The first conference of the pre-cursor of the International Medical Informatics Association was MEDINFO 74 (11) and already there were a number of papers on nursing issues and systems in the first conference raising issues relating to the processes of caring for patients (12), drug administration (13), intensive care (14) and education (15). However, following increasing interest in nursing systems at MEDINFO 80 (16) in Tokyo with the Japanese nurses the British Computer Society’s medical computing groups agreed to host a special conference on nursing systems that aimed to bring together the first international meeting concerned with Nursing Informatics to pull together what was known and going on in the field. Maureen Scholes co-ordinated and chaired this activity and the resultant conference in London and Harrogate is recorded in reference (17). The success of this effort led to the formation of IMIA WG8 on Nursing Informatics, with Maureen Scholes as the first chairman who was then followed by Prof Kathy Hannah.

7. BUILDING AN INTERNATIONAL COMMUNITY

Prof François Grémy’s initiative from led to the formation of Technical Committee 4 of the International Federation for Information Processing [IFIP]. When we received his invitation to participate in this activity we were surprised that anyone would contemplate “going overseas” for a committee meeting but his insight and forward thinking led to the amazing world-wide series of activities of the International Medical Informatics Association [IMIA]. In the process of participating in and contributing to these IMIA and EFMI events, we have all developed a network of friends and colleagues across the world who have helped us sharpen our ideas and helped us find solutions to problems as a result of their different perspectives and types of expertise. This globalisation began long before e-mail and the internet but the Group 4 fax machine did mean that, for the first time, it was possible to contact colleagues where one’s poor language skills made it impossible to get past our colleague’s telephone operator! This international community who manage happily to turn up at very unlikely locations across the world to attend committee meetings and to participate in conferences is the most precious asset that we have in medical informatics.

The British Computer Society [BCS] had established a Medical Specialist Group in 1967 to explore the growing ways in which computer systems were beginning to be used in a variety of hospitals and health care organisations but we were able to find limited funding that enabled us to participate in the activities of IFIP/TC4—an obscure designation that lasted for the first 10

years until we were able to gain independence as IMIA. The first major activity was the development of the MEDINFO conference in Stockholm on August 5–10, 1974 (11) which started the three-year series of world-wide conferences. In addition, various working groups were established to explore particular issues in detail—Education was a major issue but so was Data Protection and Security which was initiated as WG4 under Prof Gerd Griesser. The second MEDINFO (18) was held in Toronto on August 8–12, 1977 against a backdrop of strikes which made attendance problematic and the third was, as already noted in Tokyo in 1980 (16) from 29 September to 4 October thus circling the globe. Prof John Anderson and Dr Hans Peterson were closely involved in these early developments with Prof Grémy but MEDINFO 74 brought together a remarkable collection of people who went on to change the world and develop Medical Informatics as a subject and introduce that subject to the world as a whole.

Bud Abbott and John Flint worked hard to stabilise the finances after the Toronto MEDINFO. Profs Francis Roger-France, Peter Reichertz, Jan van Bommel, Jean-Raoul Scherrer and Otto Rienhoff together with Stellan Bengtsson, Jan Roukens and Dr Jana Zvárová provided substantial European input, while Shigekoto Kaihara brought Japan into the IMIA orbit and, of course, there were many distinguished Americans who brought the USA into the world-wide activities - Morris Collen, Donald Lindberg, Marion Ball - to name but a few! The MEDINFO congresses continued as the main showcase of medical informatics with the sequence etched in the mind much more clearly than the dates of the kings of England that we learned at school! Each MEDINFO was memorable for different things but many of us remember Jean-Raoul Scherrer riding an elephant into the circus one evening in Geneva at MEDINFO 92. MEDINFO 89 was intended to be held in Beijing and the programme committee were meeting colleagues who had not spoken english for thirty years. It was sad that events outside our control led to a split conference where the main part was moved to Singapore while the mainly Chinese participants met as originally planned in Beijing. However, I succeeded Peter Reichertz as editor and, with Gustav Wagner's help, we produced the proceedings of MEDINFO 89 (19) exactly as the programme committee had planned the meeting rather than as it eventually turned out—it was the meeting as it never was and our Chinese colleagues were very pleased with that result! In addition to the large conferences, IFIP/TC4 established a series of working groups. There was an early interest in the issues of education with the establishment of WG1 and the issues of confidentiality were developed in WG4. Prof Gerd Griesser and then David Kenny, chaired the first activities of WG4 leading to monographs on the issues (20, 21). These early working conferences were successfully re-initiated in conjunction with Prof Ab Bakker with follow-up conferences in 1992 every two years with working conferences in Heemskerk (22), Helsinki (23), Osaka/Kobe (24), Victoria (25) and Varenna (26). Ab Bakker, Tervo Pellikka,

François-Andre Allaert, Kiyomo Ishikawa, Joechen Mother and Francesco Pincroli all played their part in making these working conferences happen. Another working conference on Hospital Information Systems held in Cape Town (27) led to another working group but everyone's experience is clouded by their specific interests as the field is so wide and so expanding that no-one can embrace the totality of these developments.

The Journées d'Informatique Médicale were held in Toulouse for some 10 years providing an international meeting place for many interested in Medical Informatics but eventually it became clear to many in Europe that IFIP TC4 and its Working Groups would not be able to address all the needs of the developing European Medical Informatics community and the Toulouse meetings needed to be built upon by an organisation that embraced all European countries. Thought was given to the development of a European Medical Informatics body that would complement the world-wide body—although many of the participants in IFIP TC4 were worried that this might detract from the world-wide activities. A meeting was convened at WHO Headquarters in Copenhagen on 10–11 September 1976 that led to the establishment of the European Federation for Medical Informatics [EFMI]. The need for this European dimension was underlined by a very successful Medical Informatics conference, MEDCOMP 77 (28), organised in Berlin by Online Conferences Ltd based at Uxbridge University. Further conferences were considered but when the BCS offered to host the first EFMI conference it firmly put in place a professional organisation providing these events instead of a private commercial but friendly and interested commercial concern. The first EFMI conference took place in Cambridge on 4–8 September 1978 (29). (figure 1). These, MIE, conferences followed thereafter in the years between MEDINFO conferences. The second conference followed in Berlin and the third in Toulouse. MIE 79 (30) successfully confirmed EFMI as the key European professional conference organisation in Medical Informatics. Correspondingly, MIE-81 (31) in Toulouse provided a flourish to a very successful sequence of Journées d'Informatique Médicale that provided the initial European platform for medical informatics—the world community taking on the French concept of Informatics!!! The Medical Informatics Europe conferences continued to flourish and Special Interest Conferences were added to the repertoire as the needs of particular subject areas developed. EFMI developed some working groups particularly so that it could interface directly with the developing activities of the European Commission and European Standardisation Bodies.

The Council of Europe and European Union

One of the successes of the immediate post-WWII era was the development of the Council of Europe and the Convention for the Protection of Human Rights and Fundamental Freedoms in 1950 (32). As computer systems for holding Personal Data were developed the issues of data protection and privacy became important. The Convention "For the Protection of Individuals with

regard to Automatic Processing of Personal Data was developed in 1981 (33) together with a Recommendation on “Automated Medical Data Banks (34) which was developed further in 1997 as a Recommendation “On the Protection of Medical Data” (35). These issues were taken much more seriously in Europe than elsewhere and the European Union based its Directive “On the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of such Data” (36) in 1995 on the previous work of the Council of Europe and the needs of the Single Market. Unfortunately, many of the freedoms established in these documents have been eroded by the significant but often over-exaggerated fear of “terrorism” in a fashion reminiscent of the religious wars of the middle ages.

At the start of the European Union’s programme of Advanced Informatics in Medicine [AIM] a conference was organised in Brussels to explore the current issues of data protection within the health care arena (37) which set the scene for how these issues should be handled by the various projects within the programme. Even while these initial projects were running the secretariat established an AIM Requirements Board to explore generic issues for AIM and future programmes in the wider medical area (38) and published this more widely (39). Amongst this work there was developed a series of “Six Safety First Principles” for medical information systems (40, 41) which required that systems should be:

- * Safe for Patients and Users;
- * Secure for Patients, Users and Others;
- * Convenient for Users;
- * Legally Satisfactory for Users and Suppliers;
- * With Legal Protection of Software Products;
- * Multi-Lingual.

Perhaps for the first time thought was being given to systems safety in the light of emerging problems of safety (42) as opposed to simply data protection and of external systems control (43). The AIM programme and subsequent programmes included a number of medical data protection and security projects such as SEISMED [overview 44 & final Guidelines 45], ISHTAR (46) and MEDSEC (47) among many others. Some of these issues were presented to the annual British Computer Society Healthcare Computing conference in 1992 exploring the “Worst Case Scenarios” or “What happens when it all goes wrong?” (48). These issues were raised again under the heading of “Info Vigilance” at MEDINFO 2001 (49). The issue of safe information systems is a subset of the wider issue of the delivery of safe health care and it needs to be tackled in that context. The AIM programme was looking towards new standards for health information systems as well as new systems. The MEDSEC project was exploring these issues and the European Standards Organisation [CEN] had established a Technical Committee 251 to develop appropriate standards for medical information systems [CEN/TC251] and working group 6 had been addressing information safety and security and a number of draft standards were developed including prENV 12924 which attempted to categorise Healthcare Information Systems and prescribe the pro-

tection that each category needed (50). The fundamental conclusion that we reached was that we needed a safety standard developed in the context of IEC 61508 for medical systems and devices (51). Meanwhile, the clinicians were becoming concerned about safety issues in medicine more generally. The British Medical Journal ran an issue specifically on this topic in March 2000 “Reducing Errors; Improving Safety” (52) with 5 editorials on various aspects of these issues, 4 major papers and a clinical review. Sir Brian Jarman raised these issues in his Harveian Oration at the Royal College of Physicians in London in 1999 (53) and this had extensive coverage in the British press at the time. In America Kohn et al raised these safety issues in their book with the eye-catching title of “Too Err is Human: Building a Safer Health System” (54).

The Department of Health in London published its approach to these issues in “Building a Safer NHS for Patients” (55) and then established the National Patient Safety Agency to provide a continuing focus for advice and guidance (56). This work developed to the point where the BMA and the Royal College of Physicians set up a major two day conference to address various aspects of the matter on 21-22 October 2004 with the proceedings released later on a CD-ROM (57). The conference included a positively glittering array of medical and legal speakers including experts from other countries and industries. There was even a “mock legal negligence trial” presided over by a retired Lord Justice of Appeal in which the claimant succeeded in her appeal whereas the audience, comprising mostly of medical practitioners, thought that the appeal would fail! The issue of patient safety – and the safety of health information systems – is a cultural one of continual learning and improvement and, if some of the news from our hospitals today is correct, there is still a great deal to rectify and to learn. The adoption by IMIA of the Code of Ethics for Health Informatics Professionals developed by Eike-Henner Kluge in conjunction with IMIA WG4 could be a major step along the way to clarifying some of the issues involved (58).

CONFLICT OF INTEREST: NONE DECLARED.

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