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Collaborative Patient Centred eHealth

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Preface

Medical Informatics in Evolution

Evolution in Hardware

Twenty-five years ago, in 1983, the first MIC congress was organized, in collaboration between the Dutch VMBI, founded in 1971, and the Belgian MIM, founded in 1974. This collaboration proved to be a golden choice. But who of the participants of the current MIC ever used 5- or 7-hole paper tapes or punched cards, 5¼ or 3½ inch diskettes, DEC-tapes or digital magnetic tapes? Who still remembers the time that the speed of computers was measured in thousands of instructions per second, that computers had magnetic core memory, and that removable magnetic disks had a storage capacity of a mere hundred thousand bytes? Besides, who can still read his old digital files, produced by a mainframe or minicomputer of those early years? Perhaps, the most impressive observation is that Moore's Law (that the number of transistors on integrated circuits doubles every two years) has proven to be valid for half a century, until today.

Evolution in Software

Indeed, incredibly many changes took place regarding computer hardware. But this is not less the case with respect to the software. Are there still any MIC-participants who ever programmed in Assembler, Fortran, Cobol, ALGOL? Are there still systems operational in MUMPS or Basic? Anyway, the writers of this foreword, who stood at the cradle of both associations, VMBI and MIM, have experienced all this – although they can hardly remember these developments, because of the extremely high speed by which they occurred.

Evolution in Manware

The expectations in the 'ancient times' of VMBI, MIM and MIC were tremendous but nobody was able to predict the advent of the PC (cf. MITS' Altair 8080 in 1974), of the world-wide web in 1991, and the public start of the Internet in 1992; and who at that time had ever heard of computer viruses and computer crime? Who was concerned about computer security, data confidentiality and privacy protection? Nobody expected the incredibly fast proliferation and processing speed of computers and their application for actually all aspects of society, including health care. Who could have predicted, that not the hardware or the software, but that manware, the human factor, would be the crucial factor for successful applications in the medical domain? Anyway, this remark pertains to all applications in society. If there is anything special that we have discovered during the last 25 years, it is that computers can only be successfully applied when

processing systems can be formalized and when to be automated processes are repeatable and procedures can be standardized.

Evolution in Disciplines

All this applies in particular to health care, where the human factor is perhaps the most prominent of all computer applications in whole society. Our processing methods have become more and more abstract, and are less and less dependent on concrete hardware and software. In the beginning, Medical Informatics was foremost an art, an applied technology.

In the early eighties, books written by Marsden S. Blois, François Grémy and others introduced the term of Medical Information Science (instead of Medical Informatics), hereby emphasizing the differences in information processing in medicine.

Gradually, R&D departments were founded in universities to develop advanced training and education programs. Medical Informatics evolved from a domain of computer applications to a multidisciplinary field, where medical students, MSc and PhD students were trained and progressively adopted the methods used in this field. As it became clear that specific methods were lacking for medical informatics applications we decided to borrow and adapt some from adjacent scientific disciplines such as physics, statistics and informatics. Therefore, it also became evident that Medical Informatics is not a fundamental scientific area on its own, but an applied field. It is at most an ancillary science, only existing for the benefit of health care. It is not an independent, 'stand-alone' domain, such as astronomy, geology or biology. As medicine itself is a combination of many different disciplines, medical informatics bears the same characteristics. For every different application in medicine and health care, multidisciplinary teams are composed to solve specific problems. Likewise, different people, disciplines and skills are required for computer interpretation of medical signals or images than for the construction of electronic health records or for the development of modern hospital networks providing seamless access to patient data, or again for R&D pertaining to the development of systems for intensive care units. Home care and remote patient monitoring even involve participation of patients in the management of their condition, hence their influence and input in the design of such systems cannot be underestimated.

Evolution in Types of Processes

In Medical Informatics three types of processes play a central role: (1) organizational (2) patient-related and (3) decision making-related. The first type deals with settings, such as a hospital care setting or a primary care setting; the second is related to health and disease (i.e. to patients); the third type of process aims at assisting in decision making and therapy and evolves in the brains of healthcare professionals. Hence, in all domains data, information, and knowledge play a key role. As these three processes evolve, dealing with individuals – patients, doctors, and nurses – because of that human factor there are obviously limitations imposed by formalization and standardization.

This is why medical informatics R&D most often bears a multidisciplinary character. This is caused by the fact that (1) medical informatics deals in essence with the entire and very complex domains of medicine and health care (2) R&D is conducted by individuals originating from multiple and distinct scientific disciplines (3) R&D should

not only incorporate knowledge from the natural sciences but should also be based on 'soft' knowledge stemming from the behavioral sciences and medical experience, and should also take into account ethical aspects.

Evolution in Patient Involvement

Nobody could have predicted the enormous impact of the PC and the Internet on modern society, including health care. The patients are also increasingly using the computer and are browsing the Internet to find answers related to their health condition. Since the moment that PubMed was made accessible to patients, the number of consultations by patients has grown by a factor of 10. Patients and their relatives or friends are increasingly interested to obtain information from MEDLINE or other resources on specific diseases and health related matters. This is also why the reliability of such information is crucial. For this reason, about 15 years ago HON (Health on the Net), founded by Jean-Raoul Scherrer in cooperation with the EC, developed the HON Code of Conduct for medical websites. Websites which comply with the HON Code of Conduct are allowed to use the HON logo as a sign of the higher reliability of the information they present.

Evolution of Biomedical Informatics

In parallel to medical research medical informatics is evolving constantly. It is only about fifteen years ago that basic medical research was primarily concerned with problems in physiology, anatomy, embryology, or immunology; fundamental research in biomedicine was generally done on the level of organs and organisms. Nowadays, the challenges are of a different nature where many research projects are primarily conducted at the level of biomolecules and cells. This is partly the effect of the unravelling of the genome and the proteome. Genomics (the study of the genome and the genes) and proteomics (the study of the proteins produced by the cell on the basis of information encoded in the genes) have also a profound effect on modern clinical research and population-based research. Therefore, a new branch of informatics in medicine emerged under the name of bioinformatics (or biomedical informatics). Despite these rapid and important changes it will still take a considerable amount of time before the newly gained insights in biomolecular and bioinformatics research can be translated into clinical and medical practice, i.e., into new diagnostic and therapeutic techniques.

Evolution in eHealth R&D

In the last 15 years, the European Commission has supported major research, development and deployment programs which also facilitated international cooperation. Over the years the nomenclature used to designate our field also evolved from medical informatics, to medical telematics, to ICT in health and now to eHealth. Today's research priorities focus on personalized systems, on modeling and simulation (VPH), on accelerating the convergence of biomaterial development (nanotechnology and microsystems) and on blurring the boundaries between the fields of research and care. De-

ployment initiatives address cross-border communication (e.g. of health record summaries and e-prescriptions) and on interoperability between eHealth systems in general. In this rapidly evolving (and rather technical) environment one significant challenge remains: more consistency and continuity to support in a substantial way the longer term views such as semantics research (following Basic Formal Ontology principles), international standardization, and eHealth systems' quality labeling and certification. Without these, interoperability will continue to be an illusion.

Evolution in Expectations and Future Needs

In the past, there have been some unrealistic expectations regarding the possible contributions of medical informatics to health care such as the predictions in the 1970s on the expected impact of medical decision-support systems and expert systems on health care. However such contributions appeared to be very modest, to say the least. The same applies to the overly optimistic expectations regarding the introduction of electronic health records. Although the technology is widely available all these developments appear to be far more complex than expected. Many effects related to (1) the human factor and (2) obstacles which we regard as informational in nature, were underestimated and still continue to slow down our efforts.

The need for an improved understanding of the nature of medical knowledge to better serve health remains to be emphasized.

Medicine and health care offer us wonderful opportunities (but assign us also a heavy and unique responsibility) to better understand and describe the human nature in all the interrelated levels influencing health. Let us therefore join forces (biomedical, ICT staff and clinicians) to address this challenge!

Rotterdam, Jan H. van Bemmel
Gent, Georges J.E. De Moor

August 2008

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Dear congress participants,

It is a privilege for the VMBI to co-organize this year's MIC in collaboration with our Belgian colleagues from the MIM, Sixi and NVKVV, the Belgian Ministry of Public Health and the Dutch Nursing Informatics association V&VN. The 25th anniversary of this event is proof for the need to keep increasing our strains in the field of Medical and Nursing informatics. Technique is no longer the major item as the programme shows you, but human and organizational processes are becoming more and more important. From within our Dutch association the urge to continue and extend the international collaboration is high. So, it is an honour for us to present and to sponsor this exceptional edition of the 25th MIC Proceedings. Special thanks to the BIGN foundation which made the sponsoring happen. We hope that you'll enjoy the lectures and use the material in further education, research or profession.

Johan van der Lei, Chairman VMBI

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