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Preface

Access to Knowledge

Thanks and congratulations are due to Jan van Bemmel and Alexa McCray for doing such a fine job in continuing the IMIA Yearbook! As in previous years, it is a pleasure to read and to own. The work reported here reflects well on progress in medical informatics.

Yet — it does make one pause to wonder if "reading and owning" paper journals may already be quaint. One has more than once heard the end of the print journal announced. Was NLM's making MEDLINE free worldwide "the beginning of the end," or did it rather signal "the end of the beginning?" Certainly, from the point of view of sharing scientific truth with patients, families, and the public, it was distinctly a real beginning [1]. In less than a year NLM's volume of MEDLINE searching has increased by ten-fold. Patients, families, and the public now constitute 30% of our users - and growing in number. Of course this is a general trend, seen in many automated information systems. Professionals in medical informatics will probably become increasingly aware of others in the laity who are rapidly developing skills in computing. There is a bit of "heat" and even of competition from the "non experts". The Internet and World Wide Web (celebrated by this very publication) do bring a world of information to just about every doorstep (potentially). They do not, however, bring understanding, discernment, or sophistication of choice. These most important traits

will always be the reward of scholarship and learning.

There is a reciprocal of this relationship: *noblesse oblige.* An old-fashioned term, to be sure, but not an old-fashioned idea. Those with education and learning — in computing and medicine in our case — bear a responsibility to share with the public the knowledge that is important for health. Even beyond this, we have a responsibility to share, so far as we can, the skills important for finding and using that knowledge. This is really the importance of IMIA's meetings and open publications such as this fine review.

Still — where are we now in this quest? In his Preface to the Yearbook in 1994 [2], François Grémy acknowledged that "informatics gives rise to both fantasies and disappointments". He pointed out painfully that ". . . the routine use of computerized medical records, of computer-aided medical training, of decision-support systems, remains more of a hope than a reality." Grémy carefully pointed to the lack of understanding of ". . . the psychology of man-machine interaction . . . especially when the user is no more than a layman." Going even further, Grémy recommended a strong dose of medicine: ". . . Informatics in general and, more particularly, medical informatics, is in great need of a philosophy . . ."

We seem never to be satisfied with our progress in medical informatics. In 1996, Otto Rienhoff in his Preface [3]

brought forward a contrasting interpretation of events, but one that also has a strong appeal to logic and common sense. "Although this matter [very powerful integrated workstations for health care professionals] has been discussed for about ten years, only now has the computer power, the resolution of display screens, and the communication speed reached a sufficient cost-efficiency level that integrated workstations, including image processing, are available at reasonable cost. Thus it becomes feasible to bring a multiplicity of computer-supported functions onto the desk of the health-care professional, which will eventually change the way these professionals handle information about a patient."

Two years later, in 1998, we reflect in this publication upon the surprisingly strong (and seemingly favorable) effect of worldwide network connectivity upon our ability to compute. This is very different from either super-strong workstations or supercomputers. Internet and WWW-based systems free us from platform-dependent systems and encourage distributed knowledge sources. These are precisely the attributes many medical system builders sought for years! Regrettably it must be confessed that no medical philosophy has guided us onto the Internet, unless muddling through is a philosophy. We have been incredibly lucky beneficiaries of nuclear physics at CERN and of NCSA's clever packaging and distribution of Mosaic and subsequent rapid commercial improvements in the browsers. Thus it appears we are presently not much better able to explain our successes than our failures.

Since even Preface writers devoid of either philosophy or technique are expected to present the reader with a prediction or two, here are my offerings.

Technically, the further development of what has been called "multimedia" will enhance and radically change the way scientists and the public use information technology. Control by speech, touch, and gesture will supplant our over-dependence upon the keyboard. Likewise, retrieved output will combine images, text, speech, and control of motion in new and useful ways.

Socially and politically, there will be solutions — probably by successive approximations — to the current crying need for legislative protection of medical data privacy. There are similar urgent needs for protection of individual rights in the face of widespread genetic testing. Computational issues of substantial theoretical importance remain. For example, one wants encryption schemes that are practical but strong and that can coexist on some level with national and international military and police protection. Convincing means are needed to "blind" the identity of individuals' medical data when they are combined into public-health databases and patient observations within research clinical trials. Yet for the most part, these major dilemmas are questions of public policy much more than of science and technology. Their solution is, however, absolutely essential lest progress in informatics and genetics be halted.

Lastly, *The Sphere of Biology.* Medicine and biology have changed greatly since my own studies began 40 years ago. The most dramatic progress so far has been in molecular genetics. This work has redefined our expectations of what can be diagnosed, what can be treated, and how drugs can be designed and produced. And all this has simultaneously re-shaped medical informatics accordingly. Such work is quite likely to lead to much improved understanding of the scenarios of gene expression that permit neoplasms to

form. Again, this kind of future progress is exemplified by close coupling of informatics and oncology [4,5]. Beyond even these discoveries (and we do not know how far beyond) lie answers to the great mysteries of brain function. These explorations also will be closely coupled with informatics. Imagine how medicine and informatics will be transformed by gathering evidence for the means and location of basic neuro functions such as memory! Imagine our wonder as better biological understanding of intelligence is won. It seems to me inevitable that medical informatics will be able to seize these opportunities to return to our partnership in the fundamental scientific advances of molecular biology and especially of genetics and neurobiology. In this, I wish you well.

References:

1. Vice President Gore launches free MEDLINE: superhighway of medical information becomes a freeway. NLM Newsline 1997;52(2-4):1, 2, 11.

2. *Grémy F. Preface: Medical informatics as a set of human sciences? Why not? In: Van Bemmel JH, McCray AT, eds. 1994 IMIA Yearbook of Medical Informatics. Stuttgart: Schattauer Verlag, 1994:1-3.*

3. *Rienhoff O. Preface. In: Van Bemmel JH, McCray AT, eds. 1996 IMIA Yearbook of Medical Informatics. Stuttgart: Schattauer Verlag, 1996:1-2.*

4. Pennisi E. A catalog of cancer genes at the click of a mouse [news]. Science 1997;276:1023-4.

5. Stephenson J. Scientists revel in new research tool: an online index of cancer genes [news]. JAMA 1997;278:1221, 1223-4.

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