B.5. Health Informatics - Who Leads, Who Represents?

Information systems and particularly information technology are often seen negatively, and without a full appreciation of their essential role in healthcare delivery. Given that information is at the heart of healthcare and is essential for the management processes and the fact that science and technology are being harnessed widely by other segments of the society to improve upon paper-based methods, it is a matter of major concern that there is a lack of shared vision and leadership for IS&T in the health sector. There is a lack of focused research programs and structured evaluation, and many academic units are struggling for funding and little opportunity is taken to learn from overseas experience or developments. Even where there are national initiatives, such as in moves to support professional education and operations-support applications, projects and their development are generally uncoordinated and we are still far from common policies or standards. The losers are the public as consumers, health, and other professionals directly involved, and the informatics industry.

Meanwhile, the rapidly changing relationship between the functional capacity and price of modern technology is increasingly seen as the way to improve production processes while saving time and money, with wider benefits, including better quality of communication and thus, for the health sector, of care. Notwithstanding all the problems and constraints mentioned, Health Informatics is becoming an everyday part of healthcare practice, but often in a piecemeal and managerially led way. Consequently, those with a direct interest in constructive and ethical use of Health Informatics in clinical care and in advanced use of technology are less than happy with the current environment. To solve the major development and acceptance problems the following issues must be addressed by the health informatics community:

- Coordination amongst policy makers
- Poor use of IS&T by the health sector
- Patchy success in solving complex issues
- Leadership and cooperation
- Variety of stakeholders and their agendas
- Divergent priorities
- Need for independent associations.

1. Absent coordination amongst policy-makers

There is continual tension between policy-makers at the national and local levels, healthcare organizations, health professionals, and systems suppliers. Important initiatives to circumvent those problems exist, but are often felt not to achieve their full potential. Frequently each of the technical, administrative, and operational constituent parts of public, and sometimes also private, health organizations have their own information management and technology strategy, with little coordination on identification and agreement of underpinning common principles or priorities. Moreover, liaison with the academic, research, and industrial communities appears to be at arm's length rather than closely integrated.

2. Wide use, poor usefulness, of IS&T

Other service industries such as banking, commerce, and travel have already gone much further than healthcare in the widespread harnessing of information technology to provide better and cost-effective services. New patterns of communication and information are almost entirely dependent upon information technology, and the use of Internet and Intranet systems shows great promise, as do many health telematics applications. Nevertheless, many domestic households have more powerful computing and telecommunications infrastructure than many clinical departments. Although health informatics is becoming a part of healthcare practice and few diagnostic departments could function nowadays without computer technology, poor utilization of IS&T by the health sector poses a great challenge.

3. Patchy success in solving complex issues

Healthcare raises a greater range of more taxing issues than most other areas of information technology application. These issues range from the representation of illness and the clinical needs and treatment objectives of patients, through the maintenance of confidentiality and avoidance of abuse where large volumes of highly personal and potentially financially valuable information are concerned. Many countries, e.g., the United Kingdom, the United States, France, Sweden, Holland, and others, have been very active not just in pioneering and deepening the use of health IS&T, but also in tackling innovatively some of the core issues related to standards development and implementation and the representation of clinical concepts. Yet at the same time there is much to be done regarding practical implementation, quality control aspects, structured evaluation methodologies for IS&T, and the education of health professionals in informatics.

4. Need for leadership and cooperation

Health informatics offers major opportunities to support efficient and high-quality healthcare. It also has a potential to repeat past failures or introduce new risks. It is a surprising and worrying paradox that this fundamental area of healthcare science and policy has a limited number of leading organizations and very few common meeting points for debate. The major international technical cooperation organizations have approached the issue in a fragmented, uncoordinated, and technically deficient manner. Many projects sponsored, designed, or funded by such agencies have a narrow perspective, and some were technically unsound and failed to take advantage of the available technological opportunities. Exceptions to this sad state of affairs are the international and national health informatics scientific and technical associations of which the International Medical Informatics Association (IMIA) is a prime example — unfortunately they have limited influence over most decision-makers, who continue to be uninformed about IS&T.

This leadership vacuum has heightened the tension between leading individuals of the clinical professions, whose vision is on informatics as a tool for the clinician, one that may engender

parochial approaches, and national policies aimed at providing an efficient informatics infrastructure, which can be perceived as being bureaucratic or having a hidden agenda.

5. Variety of stakeholders and their agendas

(a) The direct care professions

Many professional groups, including specialty societies, have established mechanisms to consider informatics issues in their own domains, and approaches taken have varied from objective reviews of data-related issues, standards, application systems, to the consideration of educational needs. However, there is a tendency towards medical computing special interest groups, which focus primarily upon practitioner-designed stand-alone systems, that undoubtedly have intrinsic value, but when developed in isolation are not conducive to integrated policies or standards. We have seen that each health professional body now has an interest group in informatics, but the majority are largely unfunded and with a restricted number of active associates. Perversely, in a supposed era of integrated and seamless healthcare there is no vehicle for these professional interests to come together to develop a common interprofessional view, or to explore common ground.

(b) Academic bodies

Academic units for health informatics undertake research as well as teach. Although well respected in their specialist areas, in general, they suffer difficulties in obtaining funds as a result of the generally low recognition of the importance of health informatics. Obtaining funding is particularly difficult as informatics falls right across the boundaries between medicine, physical science, economics, and social sciences. Therefore, most strategic research projects — those which would identify informatics solutions and evaluate their effects upon healthcare — have no natural prime funding source, no master vision, no overall control, and no coordination. This is in contrast to most other areas of healthcare development, where academic units and the clinical professions work in tandem, and routes to research funding are clear. Similarly, information and informatics do not feature high on the research and development agenda at the national or regional level in most countries.

Some progress on the professional education side is being made in determining informatics components of the medical undergraduate and postgraduate curricula but these are, in nearly all instances, quite separate from real project development and operation.

(c) IS&T professionals and the industry

Most professional associations for IS&T are active in seeking to raise the status and the education of IS&T professionals. They should develop much stronger links with health professional interests. The unhelpful perception by many health professionals of IS&T technical personnel being "administrative", in the pejorative healthcare interpretation of the term, needs to be broken. Health professionals must recognize the importance and contribution of the information specialist profession in ensuring the sound implementation and operation of informatics systems, whilst informaticians must be

conspicuously in tune with the health professionals' requirements and understanding of their anxieties.

Finally, but importantly, the hardware and software supplier industry is active and innovative, and does have a trade association function. Unfortunately, in any free market situation, suppliers are nearly always seen as being motivated by self-interest to a greater degree than is actually the case, and there is a strong argument for strengthening links with health-focused supplier bodies over generic policy, standards, and development issues.

6. Divergent priorities

Examples abound to prove that healthcare informatics in most countries is fragmented and without leadership. Certainly, it is holding back the better and safer application of modern technology in the interests of good healthcare. It also creates destructive suspicion and tension when cooperation and coordination would be more appropriate. Because opportunities for discussion of divergent and sometimes outright conflicting priorities are few, there is no open objective forum for analysis, research, or debate, and above all there is a lack of patient representation. A coming together for the common good, and the creation of a shared vision and voice for health informatics development and use, are greatly needed.

One must focus on alliances between suppliers, academic units, and care providers, without overlooking the importance of splitting the commissioning of research, the pursuit of innovation, and independent evaluation, as in the pharmaceutical science model. Issues of common learning versus proprietary interests, and of balancing commercial confidence and published concepts, must be adequately considered, and the overall legal and ethical implications must be addressed.

7. Need for independent associations

What is missing throughout is the common ground, organizational and intellectual, where health professional health informaticians, suppliers, and other interested parties can come together in a noncompetitive and nonconfrontational setting to constructively advance the science and ethical principles of health informatics.

Healthcare computing conferences and related exhibitions are important contributions, but they have limitations as policy and developmental settings, particularly in a science-based field. The equivalent of the respected American Medical Informatics Association (AMIA) does not exist in most countries. Such professional and technical associations can provide an open and influential analysis and debating forum. In Latin America and the Caribbean there are active health informatics associations, particularly in Brazil, Argentina, Uruguay, Mexico, and Cuba, but the number of associates and representation across the stakeholders' spectrum is still rather limited.

At the international level, the International Medical Informatics Association (IMIA) is an effective organization that is addressing the key issues here discussed. Working groups cover not only the traditional interests such as nursing informatics and data security, but also the need for better

evaluative methodologies, the impact of informatics upon healthcare organizations, and how appropriate expertise can be transferred from developed to developing countries.