THE CANADIAN HEALTH INFO-STRUCTURE:
A CONCEPTUAL OVERVIEW

**Background Paper for the February 1998
National Conference on Health Info-Structure**

Prepared by
The Arlington Consulting Group

For
Health Canada, Office of Health and the Information Highway
and
Alberta Health, ...

November 1997

TABLE OF CONTENTS

I.   PURPOSE OF A CONCEPTUAL OVERVIEW

Canadians have established one of the best health system in the world and have set themselves the objective of developing the healthiest population in the world. To achieve this goal, several key service and program challenges must be addressed. Among those challenges, all jurisdictions have recognized the need to improve the use of health-related information at all levels, i.e. governments, institutions, professionals, and consumers.

Support for the development of a Canadian health info-structure was announced in the February 1997 Federal Budget. This support is part of the response to recommendations made by different organizations such as the National Forum on Health in its Final Report, the Canadian Network for the Advancement of Research, Industry and Education, and the Information Highway Advisory Council. It is also the result of consultations held across the country by Health Canada in March of 1996 to start assessing the needs and hopes of the different stakeholders as the Information Highway develops. It is widely recognized that the establishment of an integrated health info-structure in Canada is required to enable wider and better use of health-related information.

In preparation for this paper, several key documents released over the last five years were reviewed to identify health-related initiatives that have occurred or are occurring to take advantage of advanced information technologies. These initiatives were reviewed, in particular, from the perspective of potential action that the federal, provincial and territorial governments might undertake in the future to achieve common goals.

This conceptual overview has been prepared as a background document for the National Conference on Health Info-structure which will be co-hosted by Health Canada and Alberta Health in Edmonton, Alberta, on February 8th, 9th, and 10th 1998.

II.   HEALTH DECISION-MAKING IN CANADA - A CHALLENGE, AN OPPORTUNITY

The ultimate goal of all health jurisdictions in Canada is to improve and maintain the health status and quality of life of all Canadians. In order to effectively reach this goal, all the actors involved in the health sector are looking increasingly for more timely, accessible and reliable information to support improved decision-making. The National Forum on Health in its final report to the federal government, *Canada Health Action: Building on the Legacy*, concluded that:

> "[....] a key objective for the health sector should be to move rapidly toward the development of an evidence-based health system, in which decisions are made by health care providers, administrators, policy makers, patients and the public on the basis of appropriate, balanced and high quality evidence. In doing so, the potential role of information technology should be explored."

Currently, there are a number of reasons why evidence-based decision-making is not routinely used to improve decisions in the health system, including:

- lack of relevant information which applies to the decision at hand;
- lack of access to relevant information at the time at which the decision must be made;
- lack of consensus regarding the use of conflicting information;
- lack of comprehensive longitudinal information tracking the results of specific treatments over time; and
- difficulties in selecting appropriate and relevant information from overwhelming amounts of data.

The establishment of a health info-structure that provides complete, accessible and comprehensive data will support improved knowledge and decision-making, whether those decisions affect the overall structure and functioning of the health system, or the diagnosis, treatment and care of an individual.

The use of **accessible**, **reliable** and **consistent** information will not only improve decisions at all levels, but also will support a focus on continuous improvement and improve accountability at all levels.

III. DEFINITION OF A CANADIAN HEALTH INFO-STRUCTURE

In order to achieve the vision of an evidence-based health system in Canada, it is clearly necessary to not only change the culture of the health system and the way that decisions are made, but to develop a supporting system of information that facilitates this new way of doing business. Thus, an evidence-based health system is the combination of people, institutions, and the decision-making tools and processes that result in effective health outcomes. In this sense, information and communications technologies are a major enabler of improved decision-making.

There are a number of statements used to describe this new vision for health decision-making. CANARIE (Canadian Network for the Advancement of Research, Industry and Education), for example, outlines a vision for a Canadian Health Information Highway as:

> "The Canadian Health Iway will be a virtual information "centre" that is created and used by communities and individuals across Canada. It will be open and accessible, yet assure sufficient confidentiality and privacy to assist decision-making by health professionals and patients; support research and training; facilitate management of the health system; and respond to the health information needs of the public. The Network will be an agent of change for the health system and contribute to improving the health of Canadians. It will also foster the development of globally competitive Canadian technologies and services."[1]

However, the phrase *information highway* has been used in many ways by a variety of authors and researchers. Often the focus is heavily placed on the supporting technology rather than on the use of the information. For example, Watanabe[2] identifies a variety of definitions, suggested by a number of authors, for the information highway including:

- an integration of telecommunications, computers, and broadcasting;
- a physical network of copper lines and fibre optics, of cables and satellites, of ATM switches, of bauds and bandwidth, of analogue and digital signals;

---

[1] CANARIE. "Towards a Canadian Health Iway: Vision, Opportunities and Future Steps". September 27, 1996

[2] Watanabe et al. "Building Canada's Health Information Highway: A Health Information Infrastructure"

- technology of modems, compression-decompression, networks, video-on-demand, direct-to-home (DTH) and direct broadcasting services (DBS);
- a process of interactive two-way, point to point or multipoint, still-images or real time, text-based or multimedia;
- applications such as Internet, e-mail, bulletin board services (BBS), image transfers, tele-medicine, distance education and consultations, video on demand; and
- the expanding world of virtual reality, or riding the FreeNets and commercial networks to libraries, museums and databases through pathfinders and navigators, gopher, Mosaic (World Wide Web) that allows you to access the content through the highways and the airways.

A broader approach is taken through the definition of a *health information infrastructure*. CHII (Centre for Health Information Infrastructure) uses the following definition:

> "Health information infrastructure is defined as that series of technologies, products and services that will provide the framework for an interconnected and interoperable network to link hospitals, clinics, research institutions, community health centers, other health related institutions, and the home."[3]

Health Canada and Alberta Health, as co-sponsors of the National Conference, have coined the term *health info-structure* to broaden and clarify these two definitions. The term health info-structure includes four key factors:

- the supporting technological framework, including cameras, scanners, telephones, fax machines, computers, switches, disks, video and audio platforms, cable wires, satellites, optical fiber, microwave nets, televisions, monitors, etc.;
- the available information whether in the form of text, sound, images, data, stored in the many different archival facilities, and the applications and software needed to access, manipulate, organize and digest it;
- the governance, management and use of information, including the standards to ensure interoperability, interconnectivity, reliability and security of systems, and the physical, technological and legal means to

---

[3] Centre for Health Information Infrastructure. "HealthScape`95 - Charting Health Information Infrastructure". December 1995.

protect the privacy, confidentiality and security of personal information; and

- the people and organizations involved in creating the information, developing the applications and systems, constructing the facilities, and those using this infrastructure to deliver, maintain and improve health-related services for the benefit of all Canadians.

In order for the health system in Canada to be organized and managed better to deliver health services, technology is a critical underpinning and an underlying enabler. However, it is the use and management of information that will change the system.

IV. RATIONALE FOR THE DEVELOPMENT OF A HEALTH INFO-STRUCTURE

The development of a health info-structure will enable people at all levels to access the right information, at the right time, to further their own use. The rapid development and wide scale implementation of information technologies in a wide variety of sectors has provided the capability to achieve the vision of increased use of evidence-based decision-making processes. At the same time, the increasing pressures to contain and reduce costs in the health system sector have made the information technology developments a potential agent of change for the health system sector. "The evidence on which health system providers base their decisions is crucial to improving the management and cost efficiency of the health system. The development of a national health information system accessible to all those in the health system will ensure that accurate, up-to-date information is on hand when it is needed."[4]

All jurisdictions in Canada have recognized the need for the development of a health information infrastructure to support decision-making in the health sector. However, a comprehensive health info-structure is beyond the capabilities of even the largest single jurisdiction. What is required is a national strategy with all health jurisdictions, agencies, associations and consumer groups playing active roles in the development process. Without this national strategy, individual jurisdictions will duplicate development in other areas, and gaps will proliferate that will be difficult to fill. Incompatible systems and data elements will make aggregation and comparison of information difficult, if not impossible. The need for comparative information across all jurisdictions highlights the necessity for agreed upon standards and approaches to be established early in the development process.

In addition, the competing information needs of the various stakeholders in the health system in Canada requires a broadly-based forum to ensure that the development process meets the needs of the widest variety of end-users in a timely fashion. The action orientation of the National Conference on Health Info-structure will ensure that:

---

[4] Health Canada Fact Information Sheet, February 1997.

- information systems development remains focused on the desired end result – a national culture of evidence-based decision-making in the health sector;
- a wide variety of stakeholders are involved in the development process; and
- the challenges, barriers and issues in the development of a national health info-structure are identified at an early point in the development process for action by the appropriate players.

V.   PRINCIPLES FOR A CANADIAN HEALTH INFO-STRUCTURE

A set of principles is required to guide the development of the Canadian health info-structure. Although no single author or document provides a comprehensive set of principles, the following proposed set of principles draws from a number of works in the health information field.

Determinants of Health Focus - The health info-structure should be grounded in a "determinants of health" model, balancing the emphasis on health and non-health factors that influence the health of Canadians.

Evidence-Based Decision-Making - The health info-structure should support decision-making by all stakeholders in the health system by providing all Canadians affordable, timely and user-friendly access to the information services and products they need, when they need them, in the official language of their choice.

Consumer-Focus - The health info-structure should facilitate individual Canadians taking increased responsibility for his/her own personal health and well being and facilitate informed choices regarding personal health and treatment.

Professional Support - The health info-structure should facilitate evidence-based decision-making by health professionals, leading to a more effective and efficient health system.

Effective Service Delivery - The health info-structure should facilitate effective, efficient service delivery and promote the horizontal and vertical integration of service delivery systems.

Private and Secure - The health info-structure should ensure that an appropriate balance is found between protecting the privacy and confidentiality of individual health information, while maximizing the use of such information for administrative, research and evaluation purposes.

National Partnerships - The health info-structure should provide nation-wide coverage through financially viable, public, private and multi-partner initiatives.

Coordinated Development - The health info-structure should be based on commonly agreed to standards and definitions, while emphasizing the unique role of each jurisdiction and organization.

Leading Edge Canadian Technology - The health info-structure should use leading edge technology that supports the growth and development of the Canadian economy by promoting the development of Canadian technology, applications and services.

Open Architecture - The health info-structure should be based on technology sustainable standards that are vendor independent and that encourage multi-vendor participation.

Distributed Management - The health info-structure should be guided by an accountable distributed management structure that ensures fair competition, practical standards and assures quality content.

VI. PURPOSES AND USES FOR A CANADIAN HEALTH INFO-STRUCTURE

There are six critical areas where a national health info-structure is seen to hold the most promise: clinical decision-making; consumer and provider education; policy, management and administration; research and development; wellness/public health/population health; and economic development. Key examples of desired purposes in each of these areas are provided below.

Clinical Decision-Making

Clinical decision-making encompasses those areas where individuals or providers are attempting to make a specific decision regarding individual health. The key decision-maker in this process is the individual health system client. From the individual's point of view, access to a variety of information is required to:

- assess level of wellness;
- improve health and well-being;
- promote the health of self and family;
- prevent accidents and illness for self and family;
- determine whether a personal health "problem" exists;
- discover the most appropriate way of accessing health services, if required; and
- select an appropriate provider in a convenient location.

Information to support these purposes must be available directly to the individual without any necessary involvement of a provider.

Once the individual enters the health system, information must be available to both the individual client and the provider. The key technological advance in this area would be the electronic health record. Electronic health records would support provider linkage to patient records from a multitude of locations and facilities, ensuring full knowledge of the patient's condition and medical history. Quick and accurate access to this information would be invaluable to a provider, and, in emergency situations, may even provide lifesaving guidance. Evidence-based decision-

making support tools (linking providers to information on leading-edge appraisal and screening tools, or effectiveness and best practices for specific patient procedures and/or conditions) would assist in both diagnosis and selecting the most appropriate form of treatment. For providers in remote or isolated locations, the ability to use telemedicine technology to link to specialists in larger centres, or to view medical images at a distance would be an invaluable support to the remote delivery of health services. Inter-provider linkage would facilitate sharing knowledge on the best practices for prevention, screening, quality control, and treatment of a variety of conditions and diseases

Consumer and Provider Education

Access to a Canadian health info-structure would provide clients and consumers with home-based consumer health information products and services. In the area of wellness and health promotion, there is already a significant amount of information available through a variety of sources on the Internet. It is also possible to purchase a variety of personal and technical health and medical supports through companies that have an Internet sales capacity. However, consumers have no easy way of identifying the wheat from the chaff, nor do they have information of the relative effectiveness of many of the products, since there is little quality control on some sites. Improvements in this area could be a key function of the health info-structure.

The current Internet already allows for the creation of virtual communities of individuals with similar health issues providing mutual support and information, particularly around specific diseases and conditions. Not only does this allow consumers to become more educated about health and health conditions, but also provides direct support and training for providing home-based care to family members. A more formal approach to the educational aspects of home-based care may be a welcome addition for many clients. In addition, any kind of improved "road-map" to where to find the many resources available would ease the process for many non-technical individuals.

Universities and colleges experimenting with distance learning have an excellent foundation to use the health info-structure to provide technology-assisted continuing education, to support the maintenance and improvement of professional skills for many providers. An information

bank of clinical practice guidelines can assist providers to improve the quality of the care provided, while peer-based professional development activities facilitated by a health info-structure could link directly to improved quality assurance and accountability of providers.

Policy, Management and Administration

In this era of rapid and overwhelming change in the health sector, evidence-based decision-making offers the promise of assisting in the management of change by ensuring that key health decisions are soundly grounded in the best available information. When making critical choices, such as exploring alternate delivery systems, weighing options like facility versus community-based care, or determining the most cost-effective health programs, information is critical. The health info-structure could be the main source of information on best practices and comparative costs and benefits of alternatives.

Local information sources linked into overall information networks would become a timely source of the most relevant information for monitoring various aspects of the health system operation, including the monitoring of the economical use of facilities, service event patterns and health resource management systems. More importantly, the growing ability to monitor performance standards, health outcomes and resource utilization would result in improved accountability of the health system, especially if that information was provided to the public through provision of information on results and costs.

Health system administration (including financial, purchasing, payroll and human resource management) would be improved if decision-makers had rapid access to detailed information regarding current trends in expenditures and resource usage. For providers, the possibility of on-line claims and payments processing would speed payments for goods and services consumed by the health system.

The on-going evaluation of health services and the overall health system facilitated by improved information availability will allow organizations and jurisdictions to respond rapidly to changing circumstances, leading to overall improvement in the quality of health delivery systems. The sharing of best practices will simplify the search for options to facilitate cost

reduction in the health delivery systems, and generally improve the planning processes for health and community services.

The very nature of the possible info-structure linkages would facilitate the establishment of on-line policy forums, ensuring that the best knowledge and information could be brought to bear on challenging policy questions. This facilitation of open planning and consultation processes involving a wide variety of individuals and groups, including community agencies, in a variety of locations would significantly alter communication patterns within the health sector.

Research and Development

Current research and development in the health field suffers from the difficulties involved in linking data over space and time. Epidemiological research would be strengthened by the existence of easily accessible longitudinal data banks that could be used for a variety of purposes. Anonymous data included in these banks would protect the privacy of individuals, while maximizing the usefulness of the data for research purposes. On-line access to health data banks for researchers and other health professionals would be invaluable for determining the effectiveness of a variety of treatments over the longer term.

Electronic publishing of health information and research, with searchable indexes, would broaden the audience for key research findings, as well as increase the timeliness of that research. Not only would access by health professionals be facilitated, but the cost to providers of obtaining that information (through subscription fees, purchase of articles, etc) could be significantly reduced.

One field that would benefit by improved access to information would be in the area of development and tracking of outcome measures. Developing the linkages between inputs, processes, outputs and outcomes, and quantifying the impact of contextual variables would increase knowledge of the effectiveness of the health system. In particular, measures of wellness, related to a determinants of health model, would allow for improved tracking of population health.

Wellness/Public Health/Population Health

It is critical that organizations and jurisdictions be able to better monitor the overall health of various populations for epidemiological purposes, as well as to monitor the impact of the overall health services system. A Canadian health info-structure would facilitate both collection of information on population health status and the public reporting of the health status of various groups and geographic areas. Comparative data, with other countries, genders, or cultures, would help to identify key areas of differences and similarities, as well as facilitate the setting of publicly agreed-to benchmarks for the health system.

The ability to access data banks coupled with on-line real-time data on infectious diseases would significantly assist in the area of disease surveillance, allowing tracking of the dissemination and preventing the spread of infectious diseases as quickly as possible.

Information on public health issues could be quickly and effectively disseminated through a health info-structure, providing information of direct use to both providers and the general public. Whether the key question is on-going monitoring of air and water quality or the inspection records of a meat-packing plant or a restaurant, improved access to this information would assist individuals in daily decision-making.

The role of a health info-structure in raising awareness regarding wellness issues is still to be determined. However, for individual consumers accessing the information network, an improved focus on wellness, rather than illness, would be possible through the provision of accessible, user-friendly information on health promotion and prevention. Information tailored to specific ages, genders and cultures would be possible, including a specific focus on children accessing the information directly through school or at home.

Economic Development

Although not the focus of the development of a Canadian health info-structure, a significant 'by-product' would be the creation of opportunities for Canadian companies to develop health content and health education services, as well as core networking and software technologies. Significant government investment in the information network could result in Canada's health technology companies building a competitive international advantage in many areas. For example, Canada's geography lends itself to the

development of a myriad of telehealth applications that would be of value to any sparsely settled country at any time, or for any country in times of crisis when the need for a health system is critical, such as natural or man-made disasters like floods. The on-going development of the Canadian health info-structure would provide a compelling reason for Canadian companies to invest in research and development of health technology and services in order to become globally competitive.

VII. CHARACTERISTICS OF THE HEALTH INFO-STRUCTURE

Canada's technological infrastructure is ready for the development of the Health Info-structure, with universal telephone service coverage with a penetration rate of 98% national fibre-optics routes, and 95% digitization of telecom networks. The backbone of the Iway is the Internet and its rapid explosion. Canada has one of the highest rates of Internet usage in the world. Approximately 3.5 million Canadians currently access the Internet – growing at approximately 10% per month in Canada and internationally. However, this does not mean that all technological barriers have been dealt with.

> "It is likely that the majority of Canadians will not be "hooked up" until the turn of the century, particularly in the remote regions of the country. It is also likely that some traditional media will always be preferred by certain target groups and will have to be maintained."[5]

Medical information comes in many forms: print and graphics, sound, and an assortment of imaging technologies. The advent of cable modems speeds up transmission of medical images, eliminating another barrier to the extension of telehealth.

Large-scale networks capable of linking facilities and community based providers of health services already exist. For example, CANARIE is in the process of linking OCRINet (Ottawa), LARGNet(London), ONet (Ontario), WNet (Prairies), RNet (British Columbia), RISQ (Quebec) and ACORN (Atlantic Provinces) which will permit traffic from coast-to-coast.

It is critical to note that this development of a health info-structure is happening in most developed countries. The international nature of the Internet means that, for example:

- it will be as easy for an individual practitioner to consult with the Mayo Clinic or Johns Hopkins as with the local university;

---

[5] Centre for Health Information Infrastructure. "Situational Analysis for the Development of a Canadian Health Information Infrastructure". March 1996

- consumers can obtain information on tobacco cessation from Norway or the UK as well as from Health Canada or any provincial health department; and
- disease surveillance information from the Center for Disease Control in Atlanta will be as available to researchers as from the local provincial/territorial public health department.

This has massive implications for health in Canada. Given the rapid change in the technological arena, the need for early coordination is paramount. Considering the open, multinational nature of the Internet, this coordination may be required at international, as well as national levels.

VIII. KEY STAKEHOLDERS IN THE DEVELOPMENT OF A HEALTH INFO-STRUCTURE

The Canadian Institute for Health Information (CIHI) has developed a framework[6] to support the development of a Canadian health info-structure. This framework analyzes the health information requirements of all health stakeholders, to ensure that the health information system supports their requirements for planning, evaluating, and delivering health services. In this framework, the key groups of stakeholders are identified as governors, managers, providers, clients, researchers and educators. The following table describes these stakeholder groups in more detail and identifies the key information requirements of each group.

Role	Description	Sample Information Requirements
Governors	**Persons needing to choose among competing courses of action for the purpose of approving public policy. Includes elected and senior appointed officials in public, quasi-public and private organizations responsible for overall health system outcomes, programs and delivery systems.**	**Characteristics of population being served, status of that population's health, definition and monitoring of key outcomes of the health system, best practices for fostering healthy public policy, etc.**
Managers	**Persons managing health service programs/services and their outcomes, and/or persons managing financial, human, capital asset, material or information resources.**	**Cost-effectiveness of alternate health programs and delivery systems, efficiency of current health programs and services, results achieved from current service delivery systems, comparative performance information, etc.**
Providers	**Persons providing health services to clients, including support services which enable health service delivery Includes health service providers, support individuals and volunteers in public, private sector and voluntary organizations. Also included would be professional groups and organizations.**	**Information to support determination of diagnosis and course of treatment, assistance in assessing client needs, monitoring of outcomes of services, etc.**

---

[6] Canadian Institute for Health Information. "Canadian Health Information Framework: Working Document". 1995

Clients	Persons who have received or may in the future receive health services, either to improve their own health or their family's health, or to assist them in providing services to someone else. Includes clients, families, significant others, informal care givers, and advocacy groups.	Information to make informed health choices, including whether the health system is required, alternate practitioners and courses of treatment, likely outcomes of alternate courses of treatment, etc.
Researchers	Persons conducting fundamental or intervention research or evaluation	Information to support the study of health determinants, their impact on the demand for health services, contribution of health services to the overall health of the population, information to evaluate effectiveness and efficiency of health services, etc..
Educators	Persons providing formal education programs/services in the health sciences and related courses of study, and persons providing practical learning opportunities in health service delivery organizations.	Information to help in identifying education requirements, developing and evaluating learning objectives, curricula and formal education programs.

Looking at roles from an organizational perspective, it becomes obvious that any one organization may carry a number of different roles in different parts of the organization. Thus, most organizations require a wide variety of information which crosses the role descriptions given in the above table.

Within the discussion on key stakeholders and what is required to be done by whom, it should also be noted that they private sector is a key player in the delivery and funding of health services.

There is one additional 'stakeholder' group that provides a technical support function for the other key roles in the development of health information systems: health informatics/technology organizations. These organizations may be publicly funded, such as CANARIE, CIHI, etc. or may be private-sector for-profit health information companies such as SmartHealth or IBM. The role of these organizations is to lead the technological side of the development in cooperation and partnership with other key stakeholder groups and organizations, tailoring the technology to best meet the information needs and desired processes.

IX. CURRENT INITIATIVES

Initiatives related to the development of a health info-structure are occurring across Canada to take advantage of the emerging Information Highway. These initiatives are extremely diverse and range from projects aimed at assessing the feasibility of remote diagnostic for instance, to long term endeavour to establish fully networked health services across provinces.

Federal Health Initiatives

The federal government announced a $50 million investment to promote and stimulate the development of a health info-structure in Canada that will support the emergence of an evidence-based decision-making culture. As part of its contribution to the building of the health info-structure, Health Canada will put a special emphasis on areas where it plays a particular role already on a national basis. To this end, Health Canada's objectives in the near future are:

- start developing the means to establish a national health surveillance system;
- put in place the base for setting up a national population health clearinghouse; and
- as part of the devolution process, provide a health information management system to over 500 First Nations health facilities.

Provincial/Territorial Initiatives

There are two major approaches being taken by the provinces and territories in moving towards health information systems:
- development of a health information network strategy to create a core provincial infrastructure, around which a wide variety of service and client-based applications are being developed and delivered. Examples include: HealthNet/British Columbia, alberta we*ll*net, the Saskatchewan Health Information Network, the Manitoba Provincial Health Information Network, PEI's Island Health Information System, New Brunswick's Wellness Network, etc.; and
- provincial funding of regional and local consortia of health providers and private sector stakeholders to promote local initiatives. Examples include the Ontario Network Infrastructure Program and Inforoute Quebec.

It should be noted that initiaves currently under way in Canada are not all at the same level of development. In fact, some initiatives are more advanced than others, and some are likely more feasible and potentially more effective than others.

X.   BARRIERS AND CHALLENGES TO CHANGE

There is increasing movement to a consumer-based, wellness model of health in Canada, grounded in a determinants of health model. However, three key issues act as barriers to applying evidence-based decision-making as a tool to transform the health system in this way:

- growing gaps in evidence-based knowledge, which are impeding the health system's capacity to produce "health";
- the increasingly critical gaps in the health system's ability to track what is happening to its' components; and
- mounting health system costs competing inefficiently for a shrinking health system dollar with little or no comparative cost-effectiveness information regarding the efficacy of alternate treatments, effectiveness of service delivery alternatives, etc.

The health info-structure offers promise to address these barriers. However, there are a number of issues and challenges that must be dealt with if evidence-based decision-making is to become an integral part of the health system culture in Canada. These issues are identified below under the four general headings that will be the focus of the National Conference on Health Info-structure in February 1998; policy issues, stakeholder issues; information and standards issues; and technology/applications priorities.

Policy Issues

The development of an integrated Canadian health info-structure requires that a number of policy issues of common interest to all stakeholders be addressed. For example, the way different jurisdictions address the protection of individual privacy through legislation and the security safeguards established to protect the confidentiality of health-related information are central to the capacity to develop a Canadian health info-structure. Also, if the technology is to ensure secure exchange of information through telecommunications, the policy regarding an effective management infrastructure for certification/validation and authentication of different users will need to be decided. The development of new mechanisms for coordination of the overall health system with its myriad of players to focus on mutual cooperation towards a common end and agreement on the "common end" are critical. Some of the more specific challenges that exist in this area include:

- the legal and policy issues related to remote practice of health professionals within and across jurisdictions;
- the common positions on the advisability of remote diagnostics, consultations, treatments, monitoring in response to increased technological capacity and within this context the advisability of various options;
- information sharing between jurisdictions with different approaches to client confidentiality, including the development of protocols for information sharing across jurisdictional boundaries; the interprovincial and international portability of health information to ensure that there are no barriers with regard to access to a health system for clients outside their "home" jurisdiction;
- regulatory barriers in health (e.g., regulations affecting clinical applications and remuneration for health services) can act as a barrier to some telehealth practices both within and between different provinces and territories; and
- copyright and intellectual property issues impacting free flow of information between sectors and stakeholders and mechanisms for on-line purchase of copyrighted or proprietary material.

Stakeholder Issues

Stakeholder barriers and challenges relate primarily to Health Info-structure characteristics that will fundamentally change the way that stakeholders carry out their functions within the health system. The challenges of creating new ways to coordinate activities through new distributed leadership and management paradigms will alter the way organizations and individuals relate to each other. New tools for planning, delivering and evaluating health system components will be required as new information, and ways of dealing with that information become available. Technologically based ways of ensuring that the privacy, security and confidentiality of client data are protected will be critical in obtaining client support for the development of a health info-structure.

Specific risks, barriers and challenges that are of concern to one or more of the stakeholder groups include:

clarification of the leadership roles in the development of the Canadian health info-structure to support development of new and creative options;

- further development of planning infrastructure (e.g., role clarification, funding mechanisms, etc.), building on the federal/provincial/territorial management superstructure that is already in place;
- building and maintaining appropriate partnerships intersectorally and intrasectorally, including enhanced public/private collaboration;
- innovative financing and funding mechanisms, both for the planning and development of the health info-structure and the ongoing operation thereof;
- enhanced communication and information sharing, perhaps through the establishment of a national clearinghouse coupled with funding for demonstration pilots and projects to facilitate the information system developmental process;
- proactive communications with regard to public perceptions which focus on how a health info-structure will improve the quality of work and how privacy/confidentiality/security of health information will be enhanced by technology;
- the development of mechanisms to prevent and reduce overlap and duplication in developmental activities to ensure effective expenditure of scare resources;
- a process for establishing overall priorities, with a set of principles to underlie the establishment of those priorities, across stakeholder groups with different needs and priorities to appropriately allocate scarce resources to high priority needs;
- consumer concerns regarding the privacy and confidentiality of individually identifiable information and balance between individual privacy protection and research and administrative use of information; how to ensure that privacy and confidentiality is maintained, but that consumers understand these protections and have some recourse if privacy is breached;
- an independent audit and accreditation body to conduct oversight and compliance activities;
- required change to attitudes and behaviours of providers and clients that result from the current mind-set of health professionals and consumers. As noted by the National Forum on Health, what is required is a fundamental culture change, which is difficult to achieve;
- related to this culture change, the significant implications of consumer empowerment and the resulting impact on personal responsibility for the management of personal health will likely change the relationships between providers and consumers in a very basic way, shifting the current locales of information based "power" in the health system; and

- lastly, even after a shift in climate towards a culture of evidence-based decision-making in health, there is the issue of the education and training of stakeholders throughout the entire health system to use the rapidly changing and developing technology.

Information and Standards

There is already a wealth of health information available to providers, clients and researchers via the Internet. However, much of this information is of questionable relevance and accuracy, is uncoordinated and difficult to find, and is difficult if not impossible to link together. The Canadian health info-structure has not yet been fully defined in terms of content, information and tools to be included, although some preliminary work is underway in this area through CIHI. Some of the challenges that exist in this area include:

- detailed cost-effectiveness analysis for decisions regarding large, longer-term investments in the health info-structure;
- the development of evaluation and measurement tools for pilot and demonstration projects to support the development of these cost/benefit business cases at a relatively early stage;
- establishment of commonly accepted audit and evaluation criteria, standards and protocols for informatics projects to ensure comparability and connectivity of information developed in a variety of locales on different technological platforms;
- definition of commonly agreed to minimum data sets to facilitate national and international comparisons for all health sectors;
- identification/development of a policy framework and principles to guide the drafting of provincial legislation including rules and guidelines based upon a common understanding of values and ethics;
- consensus on key definitions (e.g. need to know, control and ownership of records, what constitutes health information, etc.);
- mechanisms for identifying best practices across all health sectors as a necessary baseline for comparing the effectiveness of alternate approaches to deliver services;
- related to this issue, mechanisms to ensure universal access to essential material, including both access to appropriate technology to obtain relevant information as well as minimizing financial barriers for all Canadians;
- mechanisms for translating information between at least the two official languages are only one component of ensuring that information is

provided in a culturally sensitive fashion; there is also the issue of ensuring that the information is actually relevant to the particular culture, gender and geographic location; and

- information comes in all grades of reliability, accuracy, appropriateness and relevance (particularly on the Internet, "crackpot" medical theories and unproven folk medicine "cures" share cyberspace with respected medical journals and professional discussion groups); therefore there is the issue of required mechanisms, first to ensure quality control of the content of the Canadian health info-structure and second, to assist consumers to judge the quality of information which can be obtained through a variety of sources.

Technology/Application Priorities

The technological "backbone" of the Canadian health info-structure is under development. One of the clear principles for this development, noted earlier, is the need for open architecture and multi-vendor platforms. This raises a number of technological issues and challenges:

- the issue of building capacity in the system by building on the knowledge and know-how with respect to the development of appropriate information systems, building and/or linking these systems and the appropriate protections, as well as building the knowledge and capacity to use these systems;
- technical performance and network standards, including interconnectivity and interoperability of systems, to ensure system compatibility across jurisdictions;
- the harmonization of health nomenclature and data definitions to ensure comparability of information across systems;
- mechanisms to share experiences to ensure that gaps and duplication in development do not occur e.g. a number of jurisdictions are exploring the potential use of smart cards and other portable health technologies for consumers and providers;
- technical security standards for networked systems, developed in line with commonly agreed to privacy and confidentiality access standards; and the need to build an infrastructure for privacy and security that meets international standards;
- current networks may not be able to handle the increased "traffic" generated by a national health information system, particularly given the "image-rich" nature of much health information; planning for

network enhancement and deployment of technology across organizations and jurisdictions may involve new approaches to funding and network control and maintenance; and

- regulatory barriers in telecommunications (e.g., regarding effective competition and pricing and packaging of services) may be inconsistent with the approaches that would be desirable in the construction of the Canada health info-structure.

The pace of development of health information systems at the federal, provincial, territorial and local levels in Canada is staggering. The use of technology by clients, providers and the voluntary sector is rapidly growing. The challenges and issues identified above are being dealt with on a day to day basis by all jurisdictions in Canada to move towards an evidence-based decision-making system in the health sector. The challenge of the National Conference will be to discuss these key issues and to identify priority action and responsibilities.

XI. SUMMARY

The National Conference on Health Info-structure in February 1998 is a first and critical step in the development of a national strategy and framework, and the development of implementation and action plans. The action-orientation of the conference will focus on the identification of issues and selection of priority areas for action, i.e. *what* is required to be done, by *when* must it be completed, *who* are the stakeholders, and *how* will it be done and by whom. The National Conference is an excellent opportunity to facilitate the development of an integrated Canadian health info-structure by focusing on several key questions:

- Which ventures taking place across Canada are considered high priority from the perspective of helping to maintain and improve the health of Canadians?
- Which ventures taking place across Canada would benefit from and/or require collaborative action?
- Given agreement on ventures requiring collaborative action, what needs to happen, in what sequence, with what strategy, with whom and within what time frame?

This conceptual overview of the definition, purpose and rationale for a Canadian health info-structure, its characteristics, the needs and roles of the stakeholders, and the issues, challenges and barriers to be faced is intended to provide a common understanding and background to conference participants to assist in their deliberations.

The primary goal of the health sector in Canada is the improvement and maintenance of the health of all Canadians. Adopting a culture of evidence-based decision-making will ensure that this goal is achieved in the most effective way possible. A national health info-structure supporting an effective decision-making process offers the best hope for turning that goal into a reality.