



National Conference on Health Info-Structure

February 8-10, 1998

Final Report

**Report of the National Conference
on Health Info-Structure**

Prepared by

Marc Lee

Organizing Committee for the National Conference on Health Info-Structure

Alberta Health (Edmonton)

Mary Gibson
Linda Miller
Liz Broad
Sandi Guebert

Health Canada (Ottawa)

Andrew Siman
Jerry Lee
David Delcorde
Bob Ellis
Pierre Levasseur
Linda St-Amour

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Preface

The National Conference on Health Info-Structure was held February 8 to 10, 1998 in Edmonton, Alberta, hosted by Health Canada and Alberta Health. It was the second of three national conferences sponsored by Health Canada; the others were PharmaCare and Home Care — looking at future directions for Canada's health system.

The purpose of the conference was to advance the development of a national strategy on using information and communication technologies to modernize the health system. The goals of the conference were:

- to present a forum for the broad investigation of issues in information management and technology and health;
- to set national priorities and to identify action plans to deal with these priorities;
- to facilitate communication and information sharing among key players (e.g., different levels of government, researchers, private sector organizations and consumers); and
- to share “lessons learned” from other sectors and explore how they can be applied to building an information technology infrastructure in the health sector.

Unlike conventional conferences that are largely directed toward exchanging information through presentations, the National Conference on Health Info-Structure was very much action-oriented. Delegates worked in small groups to focus their expertise and experience on developing recommendations for setting priorities and acting on key issues.

The conference was the first of its kind to explore the linking of health and information and communication technologies. It was a chance for people from different backgrounds to share lessons learned, information and thoughts on the development of Canada's health info-structure, and to discuss the process for moving forward.

The conference included opening and closing plenary sessions. Between these sessions, participants broke into four sub-plenary themes: Policy Issues, Information Management, Technology and Applications, and Stakeholder Issues. Each theme then broke further into workshops to discuss particular dimensions of the issues and priorities. Quotes from the various theme workshops are included throughout this report to highlight key points.

This report synthesizes the ideas and outputs of the conference. Recommendations made at the conference appear in boxes and, again, as Appendix C.

Background papers, information on Health Canada's current activities and on the Advisory Council on Health Info-structure (ACHI) are available on-line on Health Canada's web site at <http://www.hc-sc.gc.ca/ohih-bis>. The list of members of the Advisory Council (at the time of the conference) is given in Appendix D.

Executive Summary

VISIONS OF A HEALTH INFO-STRUCTURE

Canadians care a great deal about their health system. However, restructuring in recent years has provoked fear among ordinary Canadians that the system will not be there for them in the future when they need it. In light of shrinking budgets, governments have strongly emphasized increasing the productivity of existing resources, including using more effectively the huge amount of data and information that the system collects daily.

Many participants noted that networked information sources can improve effectiveness and efficiency within the health system. Visions of building a national health information infrastructure have stressed the potentials and opportunities to leverage advances in information and communication technologies (ICT) to improve health outcomes for Canadians. As Health Minister Allan Rock noted, in the current system we are “thirsting for knowledge, while drowning in information.”

Canadians are not newcomers to the application of technology to the field of health. Indeed, Canadians have been pioneers, with a long track record of experimentation and innovation in response to the challenges Canadian geography poses to practising medicine. For more than four decades, trials and projects have used increasingly sophisticated technologies to offer health services.

Technological advances have allowed Canadians to build on these pioneering experiences. Telehealth systems have demonstrated that they can improve access to health services for people who live in remote or rural areas. These systems enable local physicians to “videoconsult” with specialists in the closest major city, sharing video and medical images. For their part, patients save the out-of-pocket costs and time (including foregone income) associated with travelling to the city. As well, local doctors have better access to courses in continuing medical education.

Similarly, other applications of technology are full of potential to improve health for Canadians. For example, in emergency situations, ambulances can communicate and share information with hospitals, and remotely located patients can be screened for transport to a major centre for treatment. Clinical laboratories have been networked to decrease waiting times for receiving test results. Home care sites and hospitals have used technology systems to co-ordinate logistics and to monitor patients at a distance.

Each of these examples is about the application of already mature technologies to new circumstances and creating new ways of doing things. These innovative uses of modern information and communication technologies point to the possibilities for the future: powerful tools that enable both experts and non-experts to do what was previously impossible.

THE POTENTIALS OF A WIDESPREAD HEALTH INFO-STRUCTURE

Perhaps the best way to improve the health of Canadians over the long run is to provide them with the information they need to take charge of their own health. Consumers are demanding more and better sources of information on health topics. The popularity of World Wide Web sites that provide information on ailments and treatment options are indicative of this demand. In addition, sites that promote healthy lifestyles, whether through fitness, nutrition or meditation, have great potential to improve health outcomes over the longer term. More than just a source of information, the Internet has also played a strong communication role, enabling on-line support groups and promoting consumer activism, previously hindered by distance.

For Canada's Native peoples, there remain fundamental issues to do with health that transcend information and communication technology. Basic inequities still exist and must be dealt with — not forgotten — in any further discussions. Aboriginal communities want to be in control of the implementation of their health info-structure to ensure that it properly meets their needs and works in their interests.

Participants felt that a health info-structure could be a highly useful tool that could improve the health of Aboriginal communities by, for example, providing information that would help Aboriginal people to become better-informed users of the health care system as a whole. Other perceived benefits are better care and clinical decision making and improved access in remote areas through telehealth. A health info-structure could also be a means of disseminating traditional knowledge, based on a more holistic model of health, which is another reason why local possession and ownership are important.

Health care professionals, already the most knowledge-intensive workers in the health system, may have a great deal to gain from new information support tools. Family doctors and nurses encounter a wide range of clinical problems across all ages, races and socioeconomic groups on a day-to-day basis. Applications that prove effective in providing health professionals with necessary and appropriate information, in a timely manner and user-friendly format, can help them achieve better outcomes.

Better information sources are equally important for administrators and policymakers. During recent budget cuts, many administrators had to make decisions on how to reallocate resources with little evidence of how these program trade-offs might affect health or service to the community. Performance indicators of various types could help in these instances and lead to cost-saving strategies that allocate resources more effectively. Similarly, researchers in Canada need better access to raw data that can then be converted into new knowledge.

Improvements in the health system that benefit practitioners, administrators and researchers are ultimately improvements that benefit Canadians. Better information management is vital to allaying the concerns — such as growing waiting lists — that Canadians have about their health system. It means getting the right information to those that need it in a timely and accurate manner, and in a format that is easily comprehensible.

Canada is well poised to take advantage of the integration of information and communication technologies and health. We are already leaders in both fields. In Canada, the ICT sector is a \$65-billion-a-year industry that employs more than 400,000 Canadians. And Canadians are leading users of new communication technologies, with penetration rates of telephones, cable TV, computers and the Internet among the highest in the world.

The challenge for Canada is to merge one of the world's best health systems with an infrastructure that remains at the cutting edge of innovation. If we are successful, there will be an economic benefit: we will be able to sell our expertise to others around the world, thereby creating jobs for Canadians.

ENSURING PRIVACY: THE NEED FOR PUBLIC CONFIDENCE

Conference participants felt strongly that while visions of a health info-structure are full of potential to improve the quality of health care in Canada, some critical issues must first be dealt with. Probably the greatest area of concern surrounds the privacy and confidentiality of personal health information.

Information is a fundamental commodity in an economy increasingly based on the use and application of knowledge. Personal health information may be one of the most valuable of all, with large sums of money at stake in its commercial use. At the same time, participants recognized that the current state of health information protection can be improved.

While potential violations of privacy were a major concern to the conference delegates, they also recognized society's "need to know". Most Canadians would have little difficulty

with the idea that there are legitimate uses for health information that can improve the quality of care in the health system for individuals and society in general. At stake, however, is a core issue: the right of individuals to both control information about themselves, and give their consent before anyone else can gain access to it.

Those attending the conference came to a broad consensus that while personal health information may be collected for one purpose, it must not be used for unauthorized, secondary purposes — whether by governments or universities, or companies seeking profits. There is a need to forge a social consensus among Canadians that would acknowledge this principle of having control of information that pertains to them.

A social consensus would also need to spell out the conditions under which this individual right to privacy would be superseded by society's need to know. A key concept that could help to move toward this consensus is the principle and practice of *informed consent*. This principle would let people decide for themselves the conditions (such as emergency situations or general research) under which information might be used.

Agreement that a national health info-structure would share only aggregated, non-identifiable data would also ease privacy concerns. Another view was that identifiable data may need to be shared, but that those who handle this information can maintain its confidentiality by being sworn to secrecy. Clarification of the health info-structure's requirements with regard to sharing identifiable data is a necessary next step for all groups of data users.

Ultimately, a successful approach to privacy protection will require harmonization and integration across different jurisdictions, with a degree of flexibility to meet particular needs. Other areas are also equally important to developing an effective approach to sharing data, such as guidelines and protocols, as well as technological solutions such as Public Key Infrastructure (PKI), a physical network and policy framework for sharing secured information. Most important though, is to have a process that is open and inclusive, and which engages all interested parties, in particular the public.

OTHER IMPLEMENTATION ISSUES FOR A HEALTH INFO-STRUCTURE

While issues surrounding privacy and confidentiality were clearly the top priority of delegates, they identified a number of other issues. Each is a potential impediment to achieving the visions of a health info-structure.

Role of the Private Sector

Any discussion of the role of the private sector is broader than the scope of privacy and confidentiality. Participants recognized that the private sector has a major contribution to make in the development of Canada's health info-structure. Participants were concerned that the nature of the private sector's involvement in building the health info-structure might undermine health care as a public good. Participants supported an ongoing, inclusive dialogue on this issue, as well as the disclosure of existing public-private relationships.

Quality Health Information

Developing high-quality consumer health information can pose some challenges. There may be illusions that for every problem, there is an ultimate, single answer to how it should best be treated. This is not necessarily the case.

Participants felt that, ultimately, consumers must be able to choose. Several participants suggested that the health information system must be used to communicate alternative models of health, particularly for Aboriginal populations. Some also argued that health information should focus on developing the general health and well-being of Canadians rather than on treatment only.

Because of these complexities, it may neither be possible nor advisable to render objective, clear-cut directions to information sources. A better role for government might be to point to sources of credible information and facilitate collaboration between various groups or organizations. However, the extent to which the government and others must accept liability for the consequences of the on-line information is in doubt. All of this will affect the nature of content consumers ultimately have access to.

Development of Knowledge and Measures

Much work is required to define health outcome measures, including quality indicators, to assist policy makers, the public and others in evaluating the performance of the health system.

Participants noted the difficulty of measuring outcomes in this complex and demanding area. First, there is a large range of possible variables that can influence an accurate assessment. There will likely be disagreement on which variables are and are not important, including the degree of contextual and qualitative information. Second, there must be ways of defining measures for those outcomes. A core set of indicators or benchmarks needs to be defined. In addition, developing meaningful, institutional “report cards” is a genuinely complex task.

Challenges in Implementing Telehealth

Telehealth illustrates the need to rethink procedures and institutional structures when new possibilities become available. While telehealth has helped to “shrink” distance, the health system is still rooted in geographic spaces.

Telehealth raises a number of issues, such as the remuneration of professionals at a distance, ensuring clear lines of responsibility and accountability, accreditation methods for telehealth sites, education and funding.

Multi-User Considerations

The challenge of implementing a health info-structure is to meet the diverse information needs of a variety of different players in the system, including the public, health professionals, researchers, administrators and policy makers. A critical prerequisite is that all interested groups define their needs and priorities. They must be involved in the design of applications that may affect them.

Implementing these tools successfully also means recognizing the daily realities of those who use them. Of particular concern are economic considerations, which include equipment and upkeep costs. In addition, implementing new technology and applications must be accompanied by sufficient training to ensure that users are able to use them to full advantage.

BUILDING BLOCKS: STANDARDS

Conference participants stressed that if Canada is to have a health info-structure that strengthens information sharing and communication, it will be because effective, agreed upon standards have been put in place. While provincial health information systems are already being built and developed, by working together, there are synergies to be realized. Participants identified a number of priority areas for the short- to medium-term standards development.

Common Core Content

Common content across provincial health information systems can lead to standardized data sets for use in research and planning at a national level, including the development of evidence-based guidelines. Common content would assist periodic exchanges of information across provinces and could be done to facilitate research without recourse to a fully integrated national network. Participants also supported the implementation by 2001 of the ICD-10 version of the International Classification of Diseases coding system.

A Network-of-Networks Approach

With provinces already moving ahead with their health infrastructures, a call for a “grand design from above” simply would not lead to a workable, fully integrated national system. Rather, participants stressed that the focus should be on developing regional and provincial infrastructures or systems that meet agreed upon standards. Indeed, large-scale interoperability among provincial networks might pose privacy threats.

Participants supported further exploration and discussion of areas that could be addressed as “national applications”. Participants also expressed doubts on the extent to which maintaining national-level databases would be desirable. Some supported the idea of national databases, for example for surveillance of disease and outbreaks or, at a minimum, a national dataset of demographic and medical information. Others preferred a more decentralized framework.

Security of the network is a design principle of particular importance. For access to sensitive electronic data, sophisticated techniques to identify users and guard against unauthorized access are a primary requirement. A key area for development is the simplification and standardization of informed consent and a process by which it can be managed efficiently and effectively. A PKI may provide a platform for these functions.

Accelerating Standards Development

Standards must be widely deployed and adopted or accepted by users to be effective. Participants also recognized the need for accelerated development of standards. To this end, it was recommended that the Canadian Institute for Health Information (CIHI) take a lead role in developing national standards and, in the case of ICD-10, to have the authority to implement it.

The need for consensus across a broad range of players, in particular the provinces, highlights the difficulty of the task. Building on its existing work, CIHI should be the point of engagement for a process involving all interested groups. Deputy Ministers have a role to ensure that provincial standards bodies work with CIHI, and that they execute an aggressive implementation schedule. Furthermore, for CIHI to effectively implement its decisions, additional funding may be necessary.

CONCLUSION: MOVING FORWARD

Participants strongly agreed that the health system is a public good, as noted in the Final Report of the National Forum on Health. In the rapid change brought on by information and communication technology and its implementation in the health system, the public wants assurance that the health info-structure will strengthen, rather than weaken, the public-good aspect of the health system. To this end, there must be a consensus regarding the vision of Canada's health info-structure.

Participants expressed an additional concern that spending on the health information system would come at the expense of other elements of the health system. If health budgets are capped, and additional expenditures on information communication technology are desired, these resources would have to come from other areas. Thus, participants recommended that health info-structure projects be funded by new money.

The task ahead is a massive one and clearly requires leadership. Participants called on Health Canada, given its position as a national body, to take on this leadership role. Health Canada should continue to bring the key stakeholders, particularly the public, to the table. At the same time, health is a matter of provincial jurisdiction. Health Canada can play a key role in collaborating with the provinces through a number of mechanisms, including the Committee of Deputy Ministers.

The Advisory Council on Health Info-Structure will also be a focal point for discussions. With a year remaining in its mandate, the Council will consider recommendations from participants.

The process for moving forward is important. The call from conference delegates is for broader consultation and engagement of all stakeholders. The issue is not *who* must be involved; it is that *all* must be. And a process of ongoing participation and dialogue will be required to integrate all their views.

Most important is that the public be engaged and feel that it is a part of the process. Some kind of mechanism for ongoing public input is required to ensure accountability to Canadians. However, there is a wide range of opinion as to what form this input might take.

In addition, there is a need for action to move forward. Provinces are already rolling out their information systems. Time is of the essence to achieve an integrated health info-structure. To this end, participants suggested both areas for action in the near term, as well as areas that require further deliberation.

In some respects, this conference should be seen as part of an ongoing dialogue. It brought together Canadians with a wide range of backgrounds and views. The richness of perspectives, the range of discussions and the importance of the health system to Canadians attest to the need for an inclusive process as we move forward.

I. Visions of a Health Info-Structure

Recent Perspective

Canadians care a great deal about their health system. When asked about how Canada should spend its "fiscal dividend", now that the federal government has balanced its books, and with the provinces soon to follow, health is consistently ranked at, or near, the top of the list. In public opinion polls, when asked about what they regard as key symbols of their nation, Canadians have often cited their health system above the Canadian flag, the Parliament Buildings and hockey. The importance of the health system to Canadians cannot be overstated. Conference participants reflected the views of all Canadians in noting that health is a core element of our high quality of life. The health system is a key part of Canada's "social infrastructure," a network of services and support that helps bind us together as a nation.

Canadians have adapted remarkably well to the geography of the country. With a population thinly spread across the second largest country in the world, they have bridged vast distances with infrastructure. Railroads and canals, followed by highways and airports, have reduced the impact of distance and brought Canadians closer together. In modern times, the telecommunications infrastructure has enabled new means of sharing experiences and information with those far away. A noteworthy application is found in the area of health, with the development of a health info-structure. This theme, of forging linkages to overcome distances, is a very Canadian one.

However, the health system has undergone a great deal of change in recent years. Provinces have sought to lower the costs of delivering health services, their largest single budget item. Efforts to strengthen health promotion and education have been accompanied by the desire to eliminate waste in the system. Most visible for Canadians have been hospital closures and growing waiting lists as cuts have occurred. And they fear that more is to come, which may undo a health system that they cherish.

Times of change offer both threats and opportunities. While spending has been cut back, there is still a great deal of money in the system. As a percentage of the Gross Domestic Product, Canada's expenditures on health compare favourably when benchmarked against other industrialized nations. While pouring more money into the system will not necessarily yield a higher quality of care, there linger many sentiments that we can make better use of the resources we already have.

What the health system does have in abundance is information. At its roots, health is about applying information and accumulated knowledge to making patients better and, ideally, preventing them from getting sick in the first place. Herein lies the opportunity.

The development of modern information and communication technologies has meant an exponential increase in the speed and a sufficient drop in the cost of the processing, storage and transfer of information. By connecting information hubs into networks, the Internet has grown from being an obscure tool for researchers in universities to a household word, with Canadians of all ages and groups logging on in steadily increasing numbers. A global network of networks, the Internet is pervasive in its application. It affects almost all elements of life, from education to entertainment to business.

Throughout the 1990s, many have picked up on these trends in information and communication technologies and remarked on their potential for being applied in the field of health. Telemedicine and telehealth are valuable examples of technology contributing to improve the delivery of health care services. Building on the shared resource of information, the concept of a health information infrastructure has grown in prominence and has come to mean the creation of *intelligent connections* to improve the quality of, and access to, health care.

Paving the Way to the Canadian Health Info-Structure

The National Forum on Health, CANARIE and the Information Highway Advisory Council are three important organizations that have paved the way for the development of a Canadian health info-structure.

National Forum on Health

In its report, the National Forum on Health concluded that in an evidence-based health system, sufficient, useful evidence is available for all health systems and health care decisions. Information systems and technology are state-of-the-art. Decision makers at all levels of the health system can gain access to relevant and timely information on population health strategies and both medical and non-medical health determinants. Information is integrated and readily accessible from all health sectors and from other sectors that affect health. Incentives and tools are in place to ensure that the best evidence is used. Decision making is accountable and transparent. An effective and efficient health system exists which contributes to improved health status and quality of life.

CANARIE

In its vision paper "Towards a Canadian Health Iway", CANARIE sees the Canadian Health Iway (CHI) as a virtual "information centre" 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; it will support research and training and facilitate management of the health system; and it will respond to the health information needs of the public. The CHI will be an agent of change for the health system. It will contribute to improving the health of Canadians and foster the development of globally competitive Canadian technologies and services.

Information Highway Advisory Council

The final report of the Information Highway Advisory Council envisions a national health information infrastructure as:

- allowing timely on-line diagnostic consultations, improving the quality of care and reducing costs;
- providing care closer to home, eliminating the cost of unnecessary transportation;
- providing essential health services to currently under-served populations;
- providing on-line information to enable consumers to make informed decisions about personal health and health interventions; and
- promoting the development of a national, standardized, longitudinal health information database accessible to researchers and policy makers.

Context of the Conference

The National Conference on Health Info-Structure marked the first large-scale national meeting of a broad range of key groups with an interest in the development of a Canadian Health Info-Structure (CHI). It provided an opportunity for experts to collaborate in developing recommendations, setting priorities and defining what must be done in developing the CHI. The conference also allowed delegates to communicate and network, to build awareness of the viewpoints of other stakeholder groups and to share information on challenges, current activities and opportunities for collaboration. In general, it also served to generate a positive atmosphere for moving ahead with developing the CHI.

Leading into the Conference, Health Canada and Alberta Health used the term “health info-structure” to include four key areas:

- the supporting technological framework, including cameras, scanners, telephones, fax machines, computers, switches, disks, video and audio platforms, cable wires, satellites, optical fibre, microwave nets, televisions, monitors, etc.;
- existing information (whether in the form of text, sound, images or 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 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.

Participants at the conference expanded on previous visions of a health info-structure. Federal Minister of Health Allan Rock led by stressing the untapped potential of information to modernize the medicare system. By harnessing technology, Minister Rock noted, people’s health records could be as portable as their medical health coverage is now. The most current health research and clinical applications could be used as the basis for making more effective health decisions, and consumers could make better choices by having easy access to health information. Finally, the talents of top specialists could be available to people in Rankin Inlet or Goose Bay as easily as they are to people in Vancouver or Edmonton.

Alberta Minister of Health Halvar Jonson built on these comments by citing work done toward developing Alberta's WellNet health information system. Alberta is working to build an integrated, responsive system that will deliver services more efficiently, and which is based on a vision of "better information for better health". Current projects include a pharmaceutical management information system, integrated telehealth services, and assisting health authorities to implement regional systems according to an overall strategic blueprint. This blueprint is based on using technology to link existing systems so that information can be shared appropriately, while protecting privacy.

Before delegates began their deliberations, a Vision Panel set the tone for the conference. Panellists tried to define some common themes of a health info-structure vision, based on existing ideas about a health info-structure and their own experiences. They also raised concerns and comments about some key issues, as noted below:

Dr. Tom Noseworthy, Co-Chair of the Advisory Council on Health Info-Structure, drew upon his own experiences as a physician in rural Newfoundland about 20 years ago to offer his hopes for Canada's health info-structure. He recalled placing a burr hole in a seven-year-old child's skull to release a subdural haemorrhage, and being walked through this operation by a neurosurgeon 250 miles away, talking via a nurse on the telephone in the adjacent room. His vision for the future includes a two-way interactive communication network to enable rural physicians to communicate directly with specialists.

Dr. Noseworthy noted that many times as an intensive care unit physician, he had been unsure about — or did not know — a key piece of information, and had to "fly by the seat of his pants". His vision includes decision-support tools and user-friendly guidance systems that can draw from the best literature in the world in these situations.

He remarked that health information is important for all users of the health system, including consumers, administrators, policy makers and researchers. Decisions on budget cuts should be made with the best possible information about impacts. Researchers should not be excessively delayed in their ability to have access to data. For the general public, profiles could be published of the health of Canadian communities, possibly as part of a national "health atlas" based on population health data.

Dr. Noseworthy added that privacy is, without reservation, the number-one priority for any health info-structure of the future. Strong efforts are needed to prevent fraudulent access to health information and its fraudulent use. Moreover, the current situation with regard to privacy leaves much to be desired, and more work to improve the protection of personal health information is generally required at all levels of the health system.

Michael Decter, former Deputy Minister of Health in Ontario and current Chair of the Board of the Canadian Institute for Health Information, stressed the new possibilities for the health system in light of Moore's Law — that the speed of processing data doubles every 18 months. Processing power is no longer a barrier. What is needed are applications to take advantage of this power.

Technological advances enable information sources to be better leveraged, in key areas such as setting policy. For example, in Ontario, 9% of people in hospital beds could be elsewhere, such as in long-term care facilities or at home. New allocations of funds should therefore support these other areas, rather than go back into hospitals. Furthermore, a broad range of overall information — on adverse consequence rates, physician records, consumer reports — that would be useful for a number of users does not exist today.

Mr. Decter noted three priorities regarding a health info-structure. First, significantly more investment is needed in information and communication technologies at every level. Current expenditures are about 2% of the health budget, which is insufficient when benchmarked against private sector expenditures. Second, the people who use the technology must be well trained. Otherwise, the technology will not be used effectively, or its use could meet with resistance from users. Finally, there is tremendous potential in the concept of “report cards” that could provide accountability information to the public and policy makers alike about various facets of the health system.

Dr. Ian Heath, from the Australian Department of Health and Family Services, reflected on the Australian experience in developing a health info-structure. Australia's population is relatively concentrated along its east coast, just as Canada's population is concentrated along our southern border with the United States. Australia is also federated, with strong jurisdictional powers resting with its states. Its health care system, like ours, is a mix of public and private sectors.

Some elements of the Australian vision of a health info-structure are common to Canada's. Dr. Heath elaborated a vision of having the right information available at the time and place where care is delivered; improved distribution and accessibility of care; a more efficient care system, linking providers and funding bodies; improved data on treatments, outcomes and costs; and widely available consumer health information.

Australia has made some progress toward realizing this vision. It, for example, completed a National Health Information Agreement in 1993 to improve access to uniform health information by community groups, health professionals, government and non-government organizations. It also developed a Health Information Model as a framework for managing health information. In addition, several initiatives to develop data and connectivity

standards are underway. A key challenge in carrying out this work has been to keep consumers in the loop, in particular with regard to privacy issues, access to their own records and access to the health system.

Mr. Alan Nymark, Associate Deputy Minister of Health Canada, summarized the key points of discussion at the closing of the conference. He described the enthusiasm of the participants for collaborative approach among governments, health professionals, the private sector and, very importantly the public. He went on to identify three overriding themes: confidence, balance, and doability. Privacy is paramount to achieving confidence. Balance is meeting the real needs of the various stakeholders and the public is at the core of these stakeholders. Doability is marrying the genius of medicare with the excellence in communications. Going forward rests on collaboration, on-going participation, the involvement of all stakeholders is immense, and the most important of all are those who foot the bill at the end of the day - the public.

While the convergence of health and information and communication technologies promises much, achieving these broad goals of a health info-structure will not mean that health problems in Canada will mysteriously vanish. But it does suggest a healthier population that receives a very high standard of care when they do need to use the health care system. Reaching this point will not be a simple task, as subsequent chapters will indicate. Conference participants discussed many of the important issues and policy questions and made recommendations as to how to address them. The number of stakeholders is immense, and the most important of all are those who foot the bill at the end of the day — the public.

II. The Potentials of a Widespread Health Info-Structure

Those attending the conference widely supported a broad definition of health info-structure that encompasses a variety of information and services, particularly services that empower consumers. Indeed, the potential for all stakeholders to benefit from improved access to health information is enormous. This view parallels the call by the National Forum on Health for "the establishment of a culture of evidence-based decision-making...[where] decision makers at all levels — health care providers, administrators, policy makers, patients and the public — will use high-quality evidence to make informed choices about health and health care."

A key principle underlying a health info-structure is that all types of health information be *shared*. To do this effectively, it is imperative to put the information in the proper format and make it easy to understand. If information is not user-friendly, it cannot contribute to and support improved health care. In most instances, information must be tailored to the needs of different audiences, which necessitates differing levels of detail and, often, different information.

Within the health system, networked information sources can be leveraged to improve effectiveness and efficiency. Health Minister Allan Rock noted that in our current system, we are "thirsting for knowledge, while drowning in information". Most components of a health info-structure are already present. But they are isolated within organizations and institutions — a patchwork of unconnected projects, whose value would increase immensely if part of a coherent whole.

A successful, well-integrated health info-structure means a healthier population that receives a high standard of care when they do need to use the health care system. It offers an opportunity to renew the focus on the five principles of the *Canada Health Act* — accessibility, universality, comprehensiveness, portability and public administration.

Empowering Consumers and Patients

One way to improve the health of Canadians over the long run is to provide them with the information they need to take charge of their own health. Consumers are demanding more and better sources of information on health topics. Sites on the World Wide Web that promote healthy lifestyles through, for example, fitness, nutrition or meditation, have great potential. They echo the National Forum on Health's call for a shift in emphasis from health *care* toward broader notions of *health* itself, including determinants of health such as socioeconomic conditions and health promotion initiatives. Giving people information to make "healthy" choices is a win-win situation that decreases the burden on the health

system, and allows resources to be used more effectively, while improving the health of Canadians.

RECOMMENDATIONS

- Health information must include the “knowledge” which individuals want and need in order to be able to make better choices about their health. This includes tangible consumer information on health outcomes beyond medical records and patient data (e.g., best practices, advocacy tools, comparative information on institutions, costs of services).
- Multiple access methods to the information should be allowed in order to ensure balanced and equal access to health information. Address the following priorities: multicultural needs; economic status (affordability); inaccessibility of electronic technology (hardware and training); and making use of existing, quality health information in non-electronic media.

— *Stakeholder Issues Theme*

- There should be national leadership from Health Canada to proactively provide guidance to consumers on quality recommended sites for health information.

— *Information Management Theme*

Participants also supported making disease-specific information available to people who want to learn more about particular ailments and the various treatment options. Currently, a significant amount of this type of health information is available on the Internet. However, not all of it is accurate or useful, and it may ultimately cause more harm than good. Participants felt there was a clear government role in helping consumers sift through the information maze.

Another force for empowerment is the idea of “report cards.” These could provide information to consumers so that they can make better choices among providers in the

health system itself. Ideally, these proposed report cards could strengthen accountability, provide better and more transparent information to consumers, and give them a measure of access to the policies and the inner workings of the system. Like a form of *Consumers' Reports* for health care, report cards could enable consumers to check waiting lists or obtain comparative results for different procedures in different hospitals. They could also measure things like rates of complications from surgery and readmissions to hospital following a particular treatment.

There are also new and different ways of using information and communication technologies to improve Canadians' health. For instance, the Internet has a great potential to create on-line support groups. Canada already has a number of success stories with, for example, groups relating to breast cancer, smoking and birthing. These groups enable those suffering an ailment or condition and those close to them to share information and experiences. Internet-based tools also support consumer activism through facilitating better information sharing and communication across widely dispersed communities of interest. These tools can increase the power of consumers relative to other players in the system. Examples include the movement for midwifery in Canada and sharing information on alternative birthing practices.

Each of the broad categories of consumer health information — information on actions that promote healthy lifestyles, information about various health conditions and treatment alternatives, and measures on the performance of the health system itself — in addition to on-line collaboration can be tools of empowerment for Canadians. Conference participants strongly supported any developments that improve access and knowledge for patients and consumers.

Another promising area for consumers and patients is telehealth. For patients, the biggest advantage of having services delivered at a distance is the saving in time and costs (including foregone income), of making what is often an overnight or longer trip to the city. Telehealth has improved access to rural and remote areas during trials, and has the potential to do so on a country-wide basis.

Addressing Aboriginal Concerns

Information and communication technologies offer much potential to improve health in Native communities by providing better health information and services, including telehealth. They cannot, however, address all fundamental issues. Basic inequities still exist and must be dealt with, not forgotten, in any further discussions. This initial concern is an overarching one.

While large differences exist between the Aboriginal and non-Aboriginal communities, differences also exist between the Aboriginal communities themselves. Different levels of health and health care are evident. For example, status Indians and Inuit are covered by federally funded prescription drug programs and other medical services not already covered by the province or territory, while non-status Indians and Metis are not. In a roll-out of a health information system, determining who is defined as “Aboriginal” or “First Nations” is critical.

RECOMMENDATIONS

- The discussion of health technologies should take into consideration the issue of basic health inequities between different Aboriginal populations.
- To address the issue of trust, the community should have governorship and ownership of the system and information.
- Health information systems should be sufficiently flexible to accommodate cultural and community sensitivities.
- There should be community involvement in system design and development.
- Any changes should not prejudice existing treaty rights and fiduciary relationships.

— *Stakeholder Issues Theme*

Any changes as a result of introducing health info-structures to Aboriginal communities must not exacerbate these differences. Furthermore, any changes must not prejudice existing treaty rights and fiduciary responsibilities.

While diversity precludes combining all Aboriginal peoples into one homogeneous group, Aboriginal communities have unique needs that must be accommodated. Cultural differences must be taken into account in training providers of health care and sharing information. Linguistic differences must also be considered, given that there are more than 50 distinct language groups with multiple dialects, which may mean added cost for

translating information. Another special requirement is the need for a higher degree of flexibility around health care providers and who has and needs access to health information. In many instances, nurses are the primary point of contact with the system, providing services usually associated with physicians.

Participants expressed concern that Aboriginals might not own or control repositories of Aboriginal information. Aboriginal communities want to control the implementation of their health info-structure to ensure that it properly meets their needs and works in their interests. Trust is a fundamental issue in terms of how the health info-structure will be implemented. Trust is particularly important in relation to the privacy issue, a key consideration in implementing the First Nations Health Information System. The lack of ready trust is rooted in historical relations with the federal government. Thus, it is important that communities become involved in system design and implementation. A key challenge in designing the health info-structure is to ensure that community needs are met, because for most people, the health system is what they see in their community.

In spite of these concerns, participants felt that a health info-structure could be a highly useful tool that could improve the health of Aboriginal communities by, for example, providing information that would help Aboriginal people to become better-informed users of the health care system as a whole. Other perceived benefits are better care and clinical decision making and improved access in remote areas through telehealth. A health info-structure could also be a means of disseminating traditional knowledge, based on a more holistic model of health, which is another reason why local possession and ownership are important.

Indeed, the health info-structure initiative could well learn some important lessons from the Aboriginal experience. When rolling out health information systems to Aboriginal communities, the Medical Services Branch of Health Canada actively consulted with the communities, an approach that could be adopted for various provincial health-information networks. The First Nations Health Information System should not be considered in isolation, but as an important element of the larger Canadian health system.

Assisting Health Professionals

Traditionally, health professionals have played a lead role in treatment because of their highly specialized knowledge. The training of physicians and other health professionals demands that they absorb large quantities of information and use available information and tools to meet the health needs of patients.

Health care professionals may have much to gain from new information support tools. Family doctors and nurses, for example, are the first line of interaction between the health system and patients. They encounter a wide range of clinical problems across all ages, races and socioeconomic groups on a day-to-day basis. Accordingly, applications that provide physicians with appropriate information, in a timely manner and user-friendly format, will help them achieve better outcomes for their patients.

Physicians, for example, may at times lack a key piece of information, or they might want to clarify a treatment approach. In these circumstances, decision-support tools and disease-guidance systems that draw upon relevant literature and the best available evidence offer great potential for improving the quality of patient care. Such tools and systems could alleviate the information overload that many health professionals experience. One report noted that general practitioners would have to read 19 articles a day, 365 days per year to keep up with developments in their field (Radford, 1995, cited in National Forum on Health, Volume II, Creating a Culture of Evidence-Based Decision Making p.15). Thus, it is important that the health info-structure generate new knowledge rather than simply collect more data.

RECOMMENDATIONS

- Existing efforts to define information needs and priorities among stakeholders should be co-ordinated.
- The following two achievable outputs should be pursued: evidence-based information to guide service providers; and accountable information to the public.
- Funding should be provided for demonstration projects to evaluate the impacts of different ways of delivering evidence to practitioners.

— *Stakeholder Issues Theme*

In addition to using information, health professionals also function as key *providers* of information. Any information that is shared at higher levels ultimately derives from that gathered at lower levels. Thus, it is imperative that health professionals have the time and the training to collect data in an accurate and comprehensive manner.

Another example of health professionals sharing their knowledge is telehealth. Telehealth, which certainly affects consumers and patients, also holds much promise for health professionals. Conference delegates noted that the application of information and communication technologies to health care also opens the door to new ways of delivering health services. Indeed, Canadians are among the early pioneers of telehealth and technology, with a long track record of experimentation and innovation in response to the challenges Canadian geography poses to practising medicine.¹ For more than four decades, trials, pilots and projects have used increasingly sophisticated technologies to offer health services. In 1956, Dr. Feindel, a Saskatoon neurosurgeon, used a closed circuit television system to transmit live electrocorticography tracings. Two years later, Dr. Jutras, a Montreal radiologist, pioneered teleradiology. Small-scale experiments and trials such as these continued for almost 40 years, involving a small group of researchers supported by government subsidies and research and development grants.

Technological advances have allowed Canadians to build on these pioneering experiences. Telehealth² has emerged as a key application area of Canada's health info-structure and is perhaps the most mature. Telehealth technology has now been demonstrated in trials across the country, in application areas such as direct care, consultations, diagnosis, treatment and Continuing Medical Education (CME) for rural and remote physicians.

The primary function of telehealth is to enable local physicians in rural and remote areas to consult with specialists, who usually live in the major cities. Canadian expertise through trials extends to radiology, cardiology, dermatology and psychiatry consultations. Using information and communication technologies has shown itself to be effective in removing the barrier of distance. Telehealth has improved access to services, while containing costs. For example, using a telecommunications infrastructure, turnaround times for analysing radiology images can be dramatically reduced.

While physicians benefit from having access to timely advice from experts, they can also have access to CME, again saving money and reducing the time spent away from their practice. Because the same infrastructure can be used for both remote consultations and

¹ For a good overview, see House and Elford, *Telemedicine Experience in Canada*, 1996.

² The term "telehealth" is a potentially confusing one. Originally, it meant the use of telecommunications to provide health services at a distance. Recently, however, the term has been used to describe the broad application of information and communication technologies to the field of health. This report reverts to the original connotations of the term, referring to services delivered at a distance, such as remote consultations and CME.

CME, the two applications are inevitably linked and can serve to share the costs of implementation. Telehealth has also contributed to reducing feelings of isolation on the part of remotely located physicians and to providing a technology-supported back-up system.

Supporting Secondary Users of Information

Data collected by health professionals will feed into both the work of researchers and the decisions of administrators and policy makers. Participants felt that a more accountable, efficient health system, where resources are better targeted to the public's needs, would ultimately benefit Canadians. For example, during recent budget cuts, many administrators had to make decisions on how to reallocate resources. However, they had little evidence for predicting how these program trade-offs might affect health or service to the community. Performance indicators of various types could help in assessing these effects and lead to cost-saving strategies that allocate resources more effectively.

There is also a critical role for health information in setting, monitoring and adjusting health policy. The right information could, for example, enable comparisons to be made among jurisdictions and allow the health impacts (or lack thereof) of various policies and programs to be reviewed. Armed with better information, policy makers could better assess how budget cuts affect health from the outset.

The policy-making function of health information can also extend beyond the health system. Quantitative and qualitative data from the health system can be used to make more "healthy" public policy in a variety of areas. For example, the knowledge that isolated elderly people tend to die much younger than those who are not alone could promote policies that would encourage better social support for the elderly.

Canadians will also benefit from better research. Researchers are key users of the data gathered by the health system. Yet, they are often frustrated by the current system, which makes access to data difficult. A health info-structure, however, will greatly improve the accessibility of data which, in turn, will help researchers to test the effectiveness of a variety of procedures.

RECOMMENDATIONS

- A national health info-structure should be based on existing provincial/territorial data resources and include a standardized core data set.
- Focus on key indicators linked to the principles of the *Canada Health Act*.
- The health information info-structure should strengthen the public administration of the Canada health system.
- Electronic warehouse storage should be perceived as ideal for giving individuals access to their own health data and hence enhancing portability and promoting individual responsibility for wellness.

— *Policy Issues Theme*

Positioning Canada as a World Leader

Modern information and communication technologies are powerful tools. Used innovatively, they could enable both experts and non-experts to do what was previously impossible. Health Canada, for example, is currently developing a national database to track epidemics and diseases by geographic region. Internationally, telecommunication tools have been used to meet the unique needs of developing countries, such as combatting “river blindness” in West Africa.

Canada is well poised to take advantage of the integration of information and communication technologies and health. We are already leaders in both fields. In Canada, the information and communication technologies sector is a \$65-billion-a-year industry that employs more than 400,000 Canadians. And Canadians are leading users of new communication technologies, with penetration rates of telephones, cable TV, computers and the Internet among the highest in the world.

III. Ensuring Privacy: The Need for Public Confidence

Delegates attending the conference felt strongly that although visions of a health info-structure have much potential to improve the quality of health care in Canada, some critical issues must first be addressed. Probably the greatest area of concern surrounds the privacy and confidentiality of personal health information. In the many workshops at the conference, virtually all participants cited the privacy issue as the potential "deal-breaker" for the development of Canada's health info-structure.

Although doctor-patient confidentiality has a long-standing legal and philosophical tradition, the advent of powerful information systems adds a new layer of complexity. Among the participants, there was fear, uncertainty and doubt about how electronic systems will treat and store sensitive personal health information. Canadians do not want to lose the control they now have in the confidential relationship between doctor and patient. They do not want to sacrifice their privacy to achieving the vision of the health info-structure.

Key Definitions³

Privacy, confidentiality and security are common terms that may be used somewhat interchangeably. While there are no standard, universally accepted definitions, the consensus on these terms is that:

- *Privacy* encompasses the values of individual autonomy, freedom and dignity. It can be defined as the right to be left alone, remain anonymous and free from intrusion; control information about oneself; withdraw from the influences of the environment; be protected against physical or psychological invasion, or against the misuse or abuse of something legally owned by an individual or normally considered by society to be his or her property.
- *Confidentiality* is a tool for protecting privacy. It reflects confidential status conferred on sensitive information that mandates specific controls on that data, which include closely monitoring and strictly limiting access and disclosure. It is about choosing to provide information, but expecting that it will be kept secret.
- *Security* encompasses all of the safeguards in an information system including hardware, software, personnel policies, information practice policies, disaster preparedness and oversight of all these areas. The purpose of security is to protect both the system and the information it contains from unauthorized access from without and misuse from within.

³ These definitions of privacy, confidentiality and security were taken from *Ensuring Privacy and Confidentiality on Canada's Health Iway*, produced by CANARIE, December 1997, p.7.

The Privacy Threat

Canadians have become much more aware of privacy and confidentiality issues in recent years. Privacy is a very emotional issue, frequently cited as a top area of concern in discussions about the Information Highway. It is considered a fundamental value by most Canadians. Privacy is also considered a human right in Canada, as evidenced by both the *Canadian Charter of Rights and Freedoms* and the Quebec Charter.

Ultimately, it is these perceptions that rule the day, and that may indeed undermine public confidence and trust in the health information system. Without the confidence of Canadians, the health info-structure will never fulfil the potentials discussed in the previous section. As noted in the federal Privacy Commissioner's 1996-97 Annual Report: "[a] Canadian health information system could either stand or fall on the extent to which it incorporates privacy, patient autonomy and informed consent."

"The credibility of a national strategy hinges on public confidence that privacy will be protected....[Citizens] should not have to worry who can see their files or how information will be used. They deserve that protection and I am determined to ensure that Canadians receive it."

— *Allan Rock, Minister of Health*

Information is a fundamental commodity in an economy increasingly based on the use and application of knowledge. Personal health information may be one of the most valuable of all, with large sums of money at stake in its commercial use. Sophisticated new technologies make possible data mining, electronic profiling and database linking. These tools already enable marketers to target potential customers with even greater accuracy, to which anyone receiving junk mail and telemarketing calls can attest.

Important to any discussion about the use of personal health information is the role of the private sector. The private sector will sell applications, hardware and software for the health info-structure, just as it currently supplies specialized medical equipment. However, participants were concerned about private companies being involved in collecting, handling and processing data.

Several conference delegates were concerned that insurance companies might have access to billing information. This could adversely affect patients through higher insurance premiums. Another concern was that cost-cutting pressures could have implications for

privacy if, for example, data management and processing were contracted out. Whether contracting out these functions would be undesirable, or whether some form of "bonding" (as is the case for companies handling money) might be appropriate are key questions. Further discussion is required on what restrictions and regulations might apply with respect to any involvement of the private sector in the health system.

Companies also want access to information to perform research. Finding cures for diseases can be highly profitable. Indeed, Canada may be viewed as an attractive place to find such information because our system does not have the fragmentation of the American system, where information hoarding is a much bigger problem. Because the private sector plays a role in delivering health care, whether in traditional areas such as pharmacies, or in new areas such as home care, the notion that personal information might be available to someone else who could be free to sell it to the highest bidder is a troublesome one.

The same concerns extend beyond the private sector to government and universities as well. University and government labs are also engaged in a variety of research activities. Their publicly funded status does not eliminate the potential for the abuse of sensitive information. It is possible that governments, for example, could sell information or transfer it from one department to another. Participants also wanted to protect against "function creep", where new uses of information are developed that are different from the original reason for collection. For example, the question arises whether personal information, once collected, should be accessible to law enforcement agencies some time in the future if they can make a compelling argument for such access.

At the same time, reports of dangers in a networked world mask the fact that the current state of health information protection is far from rock-solid. Visiting a hospital health-record department would leave doubts in most people's minds about sufficient measures to ensure there is no abuse. So while contemplating how best to resolve these issues as they relate to a health info-structure, we must keep in mind the need to improve the existing situation as a starting point.

Sharing Health Information and Informed Consent

One element of the privacy issue is who should have access to information. While potential violations of privacy were a major concern for participants, they also recognized society's "need to know". Most Canadians would have little difficulty with the idea that there are legitimate uses for health information that can improve quality of care for individuals and society in general. As is the case with financial information they provide to the bank or government, people are generally willing to divulge health information, as long as they believe that it is secure and will be kept confidential.

At stake, however, is a core issue — the right of individuals to both control information about themselves, and give their consent before anyone else can gain access to it. Currently, in the case of both public and private sectors, people do not trust that the rights of individuals to control information about themselves will be respected. Conference participants did not want Canadians to lose control of such information for other uses unknown to them — even in the context of the health info-structure — not only by outsiders such as private sector companies, but by the health sector itself.

Specific parameters and criteria must govern access to information to define “need to know”. A key concept that could help to control access is the principle and practice of *informed consent*. The question becomes "With whom am I willing to share my personal information?" — assuming that appropriate distinctions are made between proper and improper uses of this information.

In an emergency situation, our concern is *improving* the flow of information and access to it. For example, most people would want a hospital doctor to have ready access to information that could be critical to saving a patient's life — information, for example, that someone is allergic to certain medications, one's relevant medical history and perhaps even important items from the family history. Any undue delays or incomplete information are potentially life-threatening. However, the situation changes dramatically when someone inside or outside the system could gain access to this information for purposes not directly related to a patient's health. In these circumstances, even where intentions are benign, the potential for abuse may be significant.

Simple and standardized procedures for getting consent are essential to developing an effective process of informed consent in an electronic world. In other words, procedures must be clear, and patients must truly understand what they are signing or consenting to. These procedures must define the uses of data and under what conditions it will be used.

Currently, the law guarantees patients' access to their medical records, laboratory results and medical images. However, the case is not as clear with regard to electronic medical records. Patients require access to their medical records — in whatever format — to verify their contents and correct any erroneous information. But not everyone knows this, and the process for gaining access to health information should be made clear.

RECOMMENDATION

- With respect to privacy, the consent management process should be simplified and standardized, preferably using electronic rather than paper media. The individual consent management process should distinguish between treatment, information sharing for research purposes and information sharing for other (e.g., administrative, judicial, police) purposes.

— *Information Management Theme*

Toward Solutions

Striking a balance between sharing information — yet ensuring confidentiality — is no simple task. It is essential to take into account various interrelated factors such as legislation, technology, education, risk assessment, organizational policies and codes of conduct. Privacy protection in Canada is a shared jurisdiction between federal and provincial governments. The challenge is that the laws, regulations, policies and voluntary measures applicable to privacy in the context of the health info-structure are a patchwork.

Lessons can also be learned from Canada's Aboriginal people. With agreement of the Medical Services Branch of Health Canada, in many cases either band councils or individuals themselves control the data.

Federally, the *Privacy Act* covers the protection of personal information in the public sector. The federal government announced that the Ministers of Industry and Justice will be bringing legislation forward to extend the protection of personal information to the private sector. However, this legislation will apply only to the federal private sector (i.e., areas of federal jurisdiction, with regard to the Constitution), leaving a big gap that must be filled by provincial legislation. Most provinces have privacy laws that apply to the public sector. Quebec is the only province that has comprehensive personal information protection for both public and private sectors.

RECOMMENDATIONS

The underlying principle of the recommendations is based upon Dr. Tom Noseworthy's Vision presentation which stated: "Privacy is without reservation the number-one issue. If we cannot secure health information systems and guard against invasion of privacy, and if we cannot offer confidentiality and prevent fraudulent access to and use of health information, we should stop now and entomb health information in impenetrable silos."

- There is a need to establish a uniform, consistent level of privacy protection across Canada.
- There is a need to begin to build on standards already in existence in Canada, recognizing that Quebec already has legislated data protection standards in both its public and private sectors.
- There is a need for an open and transparent public debate/discussion involving all stakeholders, especially the general public, to discuss a national strategy on Privacy, Protection and Security based on a recognition of an individual's right to privacy. The discussion should be transparent about the role and involvement of the private sector.
- Given the number of existing players involved in the Health Iway and potential new players, there is a need for a mechanism to co-ordinate the ongoing efforts of a National Strategy.

— *Policy Issues Theme*

- Comprehensive privacy legislation should be enacted to cover both the public and private sector, under the guardianship of the federal government. Include the following:
 - consent must be required for access to personal medical information and ownership of that information must remain with the individual; and
 - the public guardian must ensure the application of strict conflict of interest guidelines regarding health information.

— *Stakeholder Issues Theme*

Ultimately, a successful approach to protecting privacy will require harmonization and integration across different jurisdictions — with a degree of flexibility to meet particular needs. However, it is unclear whether specific changes are necessary in the forthcoming federal privacy legislation, or whether the articulation of a federal policy framework of principles to guide provincial legislation would be sufficient.

The confidentiality of health information is well established in Canada through a myriad of laws and regulations, in addition to codes of ethics administered by health professional bodies and colleges. In an electronic environment, privacy issues loom over how information is collected and stored and how agents in the system interact. Thus, clinical protocols, guidelines and codes of conduct are important elements to fill in the gaps that cannot be addressed by legislation and technology alone.

Nationally, there is a need to develop core principles governing practices for collecting, storing and distributing health information. There was discussion that the Canadian Standards Association (CSA) *Model Code for the Protection of Personal Information*, a Canadian voluntary code developed in response to the need for a harmonized approach to data protection, was an excellent starting point. The Code is based on internationally recognized data protection principles, namely the Organization for Economic Co-operation and Development *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data*, to which Canada subscribed to in 1984.

The CSA Principles are:

1. *Accountability* — An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.
2. *Identifying Purposes* — The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.

The CSA Principles are: (continued)

3. *Consent* — The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate.

Note: In certain circumstances personal information can be collected, used, or disclosed without the knowledge and consent of the individual. For example, legal, medical, or security reasons may make it impossible or impractical to seek consent. When information is being collected for the detection and prevention of fraud or for law enforcement, seeking all consent of the individual might defeat the purpose of collecting the information. Seeking consent may be impossible or inappropriate when the individual is a minor, seriously ill, or mentally incapacitated. In addition, organizations that do not have a direct relationship with the individual may not always be able to seek consent. For example, seeking consent may be impractical for a charity or a direct-marketing firm that wishes to acquire a mailing list from another organization. In such cases, the organization providing the list would be expected to obtain consent before disclosing personal information.

4. *Limiting Collection* — The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.
5. *Limiting Use, Disclosure, and Retention* — Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfilment of those purposes.
6. *Accuracy* — Personal information shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used.
7. *Safeguards* — Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.

The CSA Principles are: (continued)

8. *Openness* — An organization shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.
9. *Individual Access* — Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.
10. *Challenging Compliance* — An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.

The conference recognized that developing standards for privacy and confidentiality is a priority, particularly in creating an independent, non-government (but government-sanctioned) "agent" to grant access to data by those who need it, while preventing access by those who do not.

The conference called for an open and transparent debate and discussion on privacy issues. The process must be inclusive of all stakeholders. A key agency to engage is the federal Privacy Commissioner. There was some debate about the Commissioner's role in any discussions of privacy and the info-structure. One suggestion was that the Privacy Commissioner be appointed to the Advisory Council on Health Info-Structure. Others felt that ongoing consultations may be more appropriate.

Participants felt that the public is the most important stakeholder of all. Instilling public trust and confidence in the health system demands, as a next step, an inclusive process of education, communication and consultation that engages the public and allows it a voice in the discussions ahead. Some mechanism is required to keep the public involved in the ongoing development of policies with regard to privacy and confidentiality.

IV. Other Implementation Issues for a Health Info-Structure

While the need to develop a social consensus around privacy and confidentiality was clearly their primary concern, participants identified a number of other priority issues. Each is a potential impediment to fulfilling the visions of a health info-structure. These issues include the role of the private sector in the health system; ensuring quality health information, the development of knowledge and measures, challenges in implementing telehealth, and multi-user considerations.

Role of the Private Sector

Any discussion of the role of the private sector is broader than the scope of privacy and confidentiality. Participants recognized that the private sector has a major contribution to make in the development of Canada's health info-structure. This contribution includes developing systems and applications that will allow for better health care delivery. Participants were concerned that the nature of the private good. This concern also existed in regard to the role being played by commercial interests in developing the framework for a health info-structure.

Conference participants generally supported the notion that population health information be held in the public domain. Concerns exist about private sector ownership of intellectual property in the health info-structure. Fees to use the health info-structure may pose a barrier to accessing health information. If intellectual property remains in the public domain, it could be more broadly accessible. Nevertheless, with governments turning to "cost recovery" to cover the cost of their services, there is concern that even in the public domain, access fees might appear.

Further discussion and debate will be needed to alleviate concerns about the appropriate role of the private sector in a single-payer, publicly funded system, and to define the principles for governing or managing the relationship between the public and private sectors as the health info-structure evolves. One recommendation from participants was that there be system-wide disclosure of public-private relationships in the health system. This disclosure should extend to pharmacies, drug and insurance companies, physiotherapists and other non-system health professionals who are also considered private sector.

RECOMMENDATION

Accountability to the public through system-wide disclosure of the public-private relationships in the information system should be strengthened.

— *Stakeholder Issues Theme*

Quality Health Information

Developing high-quality consumer health information can pose some challenges. As is true for other media, legitimate concern exists about the quality of the health information on the World Wide Web. For physicians, information of questionable quality may entail spending extra time with patients to counter any misinformation. At the other end, consumer advocates have expressed similar concerns regarding potential bias introduced by pharmaceutical companies advertising their products to health professionals. There may also be several different schools of thought (and, therefore the possibility of conflicting or inconsistent information) on how best to treat certain conditions. For example, there are many treatment methodologies for back pain — physiotherapy, massage therapy, chiropractic and acupuncture to name a few — and various combinations of these treatments.

Also important to consider are different models of health. Eastern traditions, for example, do not stem from the same biomedical perspective that predominates in the West. The same is true of traditional Aboriginal models of health care. There is no clear consensus on how to accommodate these "alternative" health treatments, such as acupuncture and homeopathy, that have become increasingly popular in the West, but do not fit into the existing institutional framework of the health system. Furthermore, with regard to assessing alternatives, the tests, in Western scientific terms, may be constructed too narrowly.

Essentially, however, consumers must be able to choose. Several participants suggested that the health information system must include and communicate information on alternative treatment models, particularly for Aboriginal populations. There was also some argument for focusing on providing health information on general health and well-being, rather than on treatment alone.

The conference participants felt that the role for government might better be to point to information sources deemed credible. This role may be like a "seal of approval" that Health Canada could grant as a form of accreditation to assist consumers in assessing the validity or credibility of information. However, such an approach raises concern over potential liability. While government should work closely with others to provide information, the extent to which it must accept liability for the consequences of that on-line information is in doubt. All of this will affect the information that consumers ultimately have access to.

Development of Knowledge and Measures

Standards are also key to developing new knowledge. They could include guidelines for maintaining the quality of consumer health information, or possibly for evaluating recommended web sites. In addition, much work is required to define outcome measures, including quality indicators. These are critical to helping stakeholders such as policy makers and the public assess the performance of the health system. Notably, this area is also the most complex and demanding.

The health system has tried to focus on the outcomes it achieves for a given level of expenditure. Evidence-based decision making that flows from outcome measures will become more important, given that health expenditures are the largest single component of most provincial budgets, and that as the population as a whole begins to age, more demands will be placed on the system. However, achieving the goal of linking expenditures and outcomes in an accountability framework is made more complicated by both the sheer size and complexity of the health system, and the major restructuring and reductions that are occurring in a number of provinces.

Participants noted the difficulty of measuring outcomes. First, a range of variables is important to consider in creating an accurate picture. Disagreement will likely arise over what variables are and are not important, including the degree of contextual and qualitative information necessary to properly assess outcomes. Moreover, the spectrum of outcomes involved (both health-related and process-related) is very broad and includes quality of care, access to care and economic costs. Health-related outcomes can include disease-specific results, such as improvement in clinical symptoms or signs, or generic results, such as the overall quality of health and life. In addition, process-related outcomes include utilization of the service, technical performance, the quality of decision making, the presence of adverse effects and the degree of satisfaction among patients and physicians.

Second, there must be ways of defining measures for those outcomes — a core set of indicators or benchmarks must be defined. Developing meaningful institutional score cards is a genuinely complex task. For example, in order to compare the record of two hospitals relating to post-operative mortality of heart bypass patients within, for example, three months of surgery, one would need to standardize for a host of conditions. These include the age distribution of patients, the extent of pre-operative damage that they sustained, post-operative care received at home, and their diligence in taking post-operative rehabilitation courses.

Standards are important at a national level, so that effective comparisons can be made. But the foundation for valid comparison is good management and data collection at the local level. Because the provinces deliver health care and collect data, the information used by the national health info-structure has to be the information that provincial and local health managers generate and, subsequently, use in their own decision making.

A final consideration in developing performance measures at an individual or institutional level is resistance to having results publicized. People and institutions do not want to be seen as inadequate compared to others. In the case of an institution, poor results might affect its funding. Given the complexity of health factors and the need for large amounts of contextual information to interpret results, health care providers are concerned about how measures will be derived and used.

In addition, regulations may be necessary to prevent spurious quality claims in Canada. Looking to the example of the United States, nothing prevents a health facility in that country from advertising a superior quality of care, regardless of the evidence. Any implementation of performance measures must be sensitive to these considerations.

Efforts to achieve these performance measures come at a time of cutbacks in health spending. Participants felt that, to the greatest extent possible, existing information should be used first. Then any gaps should be filled. Activities should build on Health Canada's National Population Health Clearinghouse initiative, which will be launching summer 1998. The initiative will leverage existing health networks and databases to provide access to high-quality health promotion content for both the public and health intermediaries.

At a national level, co-ordination of efforts across jurisdictional powers and professions is required to define information needs and priorities. In addition, the costs of achieving these outcomes must be determined. Ultimately, there has to be a payback for these efforts, in cost savings or in better quality of care.

Challenges in Implementing Telehealth

Telehealth illustrates the need to rethink procedures and institutional structures when technology offers us new ways of doing things. For example, telehealth has helped to eliminate or reduce the barriers of distance. However, the health system is still rooted in well-defined geographic spaces. The system's geographic orientation has posed some challenges and is a barrier to implementing telehealth because of the essentially non-geographic character of the latter.

Another significant challenge is to develop a system for enabling consulting physicians to get paid for the services that they deliver through telehealth technology. The challenge arises because physicians have traditionally been able to bill only for the face-to-face services they provide to patients. Still another challenge is to resolve any problems relating to provincial licensing, for example when a telehealth consultation crosses provincial boundaries. Similar difficulties may occur within provinces (and even internationally) when a physician with privileges in one hospital consults with another hospital where he or she does not have privileges.

Participants noted several other ethical, legal and social issues that could arise in circumstances surrounding telehealth. Poorly handled, these issues could affect the success of telehealth initiatives and act as barriers. Legal issues include ensuring that treating physicians remain responsible for their patients and that consulting physicians are liable for their opinions. As well, accreditation methods are needed for certifying new telehealth sites and ensuring the reliability, safety and effectiveness of the technology. In addition, traditional concerns remain in the new telehealth environment, such as the need to ensure that patients give their informed consent to any procedure recommended, and that privacy and confidentiality are protected. Indeed, roles and responsibilities for all participants need to be clarified.

Education — for example, on the appropriate use of technology — is an important element in telehealth, for both physicians and consumers. Consumers in rural and remote communities may also fear that an on-site professional could be replaced by a computer. Therefore, it is worth emphasizing that telehealth is a means of *supporting* local physicians and retaining local services, not *replacing* them.

RECOMMENDATIONS

- Telehealth should be pursued as a key component of a national health info-structure.
- A co-ordinated federal/provincial/territorial national approach is required in order to leverage expertise and resources, prevent duplication and lead to compatible solutions.
- Support is needed for:
 - proof-of-concept applications;
 - research to illustrate where telehealth can be most effective;
 - the development and delivery of telehealth education and training;
 - the development of clinical standards to ensure the quality and integrity of diagnostic information;
 - regional strategic planning and implementation; and
 - the development of a national telehealth "toolkit" — standards, guidelines, model legislation, codes of practice, public education and technology assessment.

— *Policy Issues Theme*

Funding issues must also be resolved. A large part of the savings flowing from remote consultation accrues to the patient and family in the form of reduced travel costs, rather than to the health system. Yet, it is the system that bears the costs of implementation. Ensuring access to telehealth consultations can be justified on the ground that people in remote and rural areas are already disadvantaged with regard to health services. Under a more regional system, where each region receives a share of the provincial health budget, the funding issue may be complicated for telehealth consultations that cross regional boundaries.

Fortunately, there is much Canadian expertise that can be brought to bear as telehealth is rolled out in Canada. A co-ordinated federal-provincial approach will best leverage expertise and resources, while preventing duplication of effort. This co-ordinated

approach should include key stakeholder groups, and it should ideally lead to solutions that are compatible, though not necessarily identical. Priority areas for moving forward should be identified, where services can best be utilized. Participants also recommended support for the development of telehealth applications, standards and guidelines.

Multi-User Considerations

The challenge of a health info-structure is to meet the diverse information needs of a variety of different players in the system — including the public, health professionals, researchers, administrators and policy makers. The health system already produces a flood of data. An effective health information system must sift through these data and get the right information to the right person at the right time in a user-friendly format. Fundamentally, there are three broad types of information needs:

- *information sharing*, such as in file transfer or e-mail;
- *databases* to store information for personal use, planning and research; and
- *real-time interaction*, such as in a videoconferenced remote consultation, using video, image transfer, voice and text.

An important prerequisite to meeting these needs is for stakeholder groups to define their needs and priorities. Perhaps more importantly, stakeholders must be involved in the design of applications pertaining to them. To this end, communication must be improved between stakeholder groups and the private sector players developing the computer systems and applications. It must be clear that new technologies actually benefit the provider and meet their needs, while improving the quality of care.

Successful implementation must recognize the daily realities of user groups. Health professionals, for example, must remain focused on immediate concerns relating to their patients. They often face practical constraints in adopting a technology whose benefits may be realized only in the longer term. Of particular concern are economic considerations, which include equipment and upkeep costs.

Implementing new technology and applications must be accompanied by sufficient training to ensure that users are able to take full advantage of the system's capabilities. Developing a health info-structure takes more than deploying expensive equipment. It must appropriately involve and consider the people who will use the technology. Without adequate training, new technology will not be implemented effectively and may encounter resistance from those who are supposed to use it.

Users may tend to think only in terms of their own information needs, rather than about their obligations to report. Health professionals are also vital to data collection, so getting data must always be considered as being part of their work. If data collection is too time consuming, or if health professionals believe that the data collected are not relevant to their practice, they may not be overly supportive. A key challenge is to ensure that those who collect the data are included in the process. Without appropriate incentives to collect valid data, data could be incomplete or inaccurate.

V. Building Blocks: Standards

Conference participants stressed that if Canada is to have a health info-structure that improves information sharing and communication, it will be because effective, agreed-upon national standards have been put in place. National standards are the foundation upon which the national health info-structure rests. Without them, Canada will have only a patchwork of provincial systems. No patient-based health information system can work without standards for content, technology and data collection.

The best example of the effective application of standards is the Internet, the global “network of networks”, all of which use a common suite of protocols. The evolution of these standards is perhaps one of the greatest achievements in the entire computing and communications field. Standards provide a platform for exchanging information, even though the systems on either end may be quite different.

Provincial health information systems are already being built and developed at different paces and with different purposes. Nevertheless, by working together, there are synergies to be realized. Participants identified a number of priority areas for the short- to medium-term that touch upon standards, common core content, a network-of-networks model, and speeding up standards development.

Common Core Content

Participants supported common content across provincial health information systems. Such standardized data sets could be used for research and planning purposes at a national level, including the development of evidence-based guidelines. These guidelines would assist in exchanging information among provinces and could help to facilitate research without the need for creating a fully integrated national network. Standardization requires consistency of coding, nomenclature and identifiers.

In Ontario, a number of studies looked at what information would have to be collected every time a patient has an encounter with the health system. Each study found that only 10 pieces of information were needed — totalling only 80 characters of information. These included: location, date and time of encounter; name of the agency and who delivered the service; name of the patient; the service provided; quantity; referral information; and diagnosis. For all of these, standards already exist or could easily be developed, which suggests that creating such a “minimum national data set” would not be an excessively complicated problem.

Participants also discussed another priority area — standards for content. The ICD-10 version of the International Classification of Diseases (a coding system) was agreed to in principle by federal and provincial Health Deputy Ministers in 1995. It was recommended that this version be implemented by 2001.

A Network-of-Networks Approach

Where necessary or desirable, networks must be able to share information and functions. With provinces already moving ahead with their health infrastructures, a call for a grand design from above simply would not lead to a workable, fully integrated national system. Rather, participants stressed that the focus should be on developing regional and provincial systems, with adherence to agreed-upon standards, as a “glue” to bind the networks together for certain agreed-upon activities.

The network-of-networks approach underlies discussions of the development of the Information Highway and is equally relevant to a health info-structure. A core principle is the notion of "distributed accountability," where provinces manage their networks according to the needs of their citizens. Clarity is required here, as the network of networks should not suggest broad interoperability among provincial networks, something that might be seen as posing a privacy threat.

At a minimum, participants felt that certain standardized data should be shared occasionally across provinces. Others suggested that a number of areas exist that could be addressed as “national applications”. How far standards should reach into these other areas is not clear. Participants felt that further exploration and discussion of national applications was necessary. Telehealth, for example, is an application area where standards and applications could be developed collaboratively for use in a number of provinces. Certainly, provinces should work together within a framework of national co-ordination to the extent they feel it desirable to share experiences and costs for other applications. However, provinces may wish to tailor such applications to meet their own needs.

Participants also expressed doubts on the extent to which maintaining national databases was desirable. Some supported the idea of either national databases for surveillance of disease and outbreaks or, at a minimum, a national dataset of demographic and medical information. Others preferred a more decentralized framework around local systems and databases. Ultimately, flexibility at the provincial or regional level in response to specific needs must be respected. Noting the privacy concerns mentioned previously, there is a perception that developing national, public databases containing information on all Canadians might be a concern.

RECOMMENDATIONS

- Information sharing should be on an interprovincial basis and led by the Federal/Provincial/Territorial Deputy Ministers of Health with outside involvement (e.g., Canadian Institute for Health Information) (CIHI). The process should be directed at identifying and sharing common issues and opportunities, and reaping the benefits of working together.
- A project directed at defining a process to set national initiatives should be undertaken and: be highly consultative; emphasize what should be rolled up to a higher level; vest leadership in existing federal/provincial/territorial bodies with clear accountabilities for decision making; base the process on learning from current national initiatives; be comprehensive; and include a feedback loop.

— *Technology and National Applications Theme*

Security of the overall network is a fundamental design principle of particular importance. For access to sensitive electronic data, the development of sophisticated techniques to identify users and guard against unauthorized access is of primary concern. A key area for development is the simplification and standardization of informed consent and a process for managing it effectively and efficiently. These would provide for authentication and verification functions, allowing access where required and denying access where it is not.

A Public Key Infrastructure (PKI) may provide a platform for these functions. A PKI is a physical network and policy framework for sharing secured information. The notion of *trust relationships* is a key element of a PKI system. Through *certificate policies*, levels of security can be defined as a basis for the secure exchange of data, even though the parties exchanging these data may not have met each other. The Canadian government PKI model, for example, defines four levels of security.

Certificate policies in PKI provide for classes of activity across diverse communities that have information-sharing needs and common security requirements. The PKI has great potential to accommodate the complex demands on the network, where a great many users with different needs must be accorded appropriate levels of access and security.

Accelerating Standards Development

Participants also recognized the need to speed up the development of standards. To this end, it was recommended that the Canadian Institute for Health Information (CIHI) take a lead role in developing national standards and, in the case of ICD-10, have the authority to implement them.

CIHI has already been addressing standards issues in health, working with other standards organizations and the key stakeholders in the field, including the provincial Ministries of Health. Six working groups were established in spring 1997 to address the variety of standards issues in the field:

Health Information Model: includes the development of a data model and the elements required for an electronic patient record;

Terminology, Classification and Nomenclatures: development of health management indicators using standards for classifying data;

Security, Privacy and Quality: standards for health information security, privacy and information integrity;

Information Exchange Protocols: standards for information exchange, applications and communications protocols;

Advanced Health Technologies: standards for advanced technologies such as videoconferencing, document scanning, diagnostic imaging and patient cards; and

Health Identification Systems: standards for linking provincial health information systems and the formation of a national health identification cross-reference facility.

The need for consensus across a broad range of players, in particular the provinces, highlights the difficulty of the task. Building on its existing work, CIHI could be the point of engagement for involving all stakeholders. Its renewed role would be to build a way forward, so that when change is required it is accepted rather than rejected.

Deputy Ministers have a role to ensure that provincial standards bodies work with CIHI and that they execute an aggressive implementation schedule. Furthermore, for the Institute to be able to effectively implement its decisions, additional funding may be necessary.

Although broadly supported by participants, the consensus on this issue was not unanimous. Some participants had concerns that CIHI may not have full support across Canada, and that there are other standards organizations in Canada that might play a strong role. While some participants noted the need to include the private sector in CIHI's

standard-setting activities, others were uncomfortable with the existing private sector role in the Institute.

RECOMMENDATIONS

- There is a need for a common core content in provincial/territorial health information systems for research and planning purposes.
- The Canadian Institute for Health Information (CIHI) should become a national standards development organization.
- The process should be accelerated; funding is a prerequisite.
- At the next meeting of provincial Deputy Ministers of Health, there should be a declaration of devolution to ICD standards, presumably to CIHI, and funding for provincial implementation.
- There should be a dialogue with all stakeholders.
- The Canadian Council on Health Services Accreditation (CCHSA) should expand its accreditation process to take into account quality indicators, at least at the regional level.
- A body should be designated to ensure a process for the secure transportation of information and authentication of sender and receiver.

— *Information Management Theme*

VI. Conclusion: Moving Forward

Priority Areas for Action

Key areas include those discussed in previous chapters: achieving a social consensus that balances individual rights to privacy and society's need to know; confidentiality of personal health information; increased availability of health information to assist in decision making by consumers, health professionals and other users; getting acceptance around common standards for data sets, information transfer and applications; and adopting a "network-of-networks" approach.

All of this points to a vision of a health info-structure. While the introduction of this report described some of the possibilities and noted the visions of others, a generally agreed-upon vision of Canada's health info-structure does not yet exist. A role for the Advisory Council on Health Info-Structure could be to help create such a vision and to define what the components of a national system might look like.

Participants strongly identified with the notion of the health system as a public good, as noted in the Final Report of the National Forum on Health. The public wants to ensure that the health info-structure strengthens — not weakens — the public-good aspect of the health system. Some participants were concerned that the process for moving forward may be driven by those who have financial stakes in the outcome, and that the price to pay for a health info-structure may be an erosion of privacy.

Another concern of participants was that spending on the health information system would occur at the expense of other elements of the health system. Participants recommended that if health budgets are capped, and if work on a national health info-structure is to continue, health info-structure projects should be funded by new money.

A Strong Co-ordination Role for Health Canada

The task ahead is a massive one and clearly requires leadership. Participants called on Health Canada, as a national body, to assume this leadership role. Health Canada should continue to bring the key stakeholders, particularly the public, to the table.

At the same time, health is a matter of provincial jurisdiction. Health Canada can play a key role in collaborating with the provinces, through a number of mechanisms, including the Committee of Deputy Ministers. At this level, the necessary consensus on issues and implementation can be forged. As noted by Halvar Jonson, Alberta Minister of Health and Conference Co-Sponsor, the provinces want Health Canada to take a lead co-ordinating role.

Areas for national action and co-ordination that cut across provincial and territorial boundaries include tracking health trends; researchers looking for cures and pursuing guidelines for evidence-based decision making; administration and policy making around the organization and funding of health services; development of national and provincial strategies to improve health; more efficient health systems with resources directed to where they are needed most; and reporting on the health of Canadians and the performance of the health system.

RECOMMENDATION

- The National Advisory Council on Health Info-Structure should articulate a vision of what the health information system is going to be, including its structure/framework, function, scope and fundamental guiding principles.
- The health info-structure should be funded with new money.
- Health Canada should reassert its leadership role in the development of a national health information system, including:
 - bringing key stakeholders together for discussion;
 - developing standards, particularly on information for the public;
 - enforcing the current reporting data requirements from provinces, as mandated; and
 - leading the coordination and strengthening of health information resources, first focusing on existing resources.
- A national health information system should be developed by a national body and include the following:
 - integration of existing resources;
 - new money for new resources;
 - broad representation; and
 - Health Canada to have the lead responsibility.
- New funding is required to do what has to be done.

— *Stakeholder Issues Theme*

The Advisory Council on Health Info-Structure will also be a focal point for discussions. With a year remaining in its mandate, the Council will consider recommendations from participants.

An Inclusive Process

The call from conference participants is for broader consultation and engagement of all stakeholders. The issue is not *which* stakeholders must be involved, it is that *all* must be. And ongoing participation and dialogue will be required to integrate the views of all interested parties.

The most important stakeholder is the public. Canadians are concerned about the fate of the health care system — a system that is a source of national pride, and which they have witnessed being downsized and cut back in recent years. They fear further cuts and declines in the quality of service. And while they see potential benefits from a national health info-structure, they have legitimate concerns about how this info-structure will be implemented.

RECOMMENDATIONS

- The public should be engaged in an ongoing broad consultation process at the federal and provincial levels on health info-structure to address the following priorities: public education; public participation from the start on decision-making bodies; and designation of health information as an integral part of the Canadian public health care system.
- An ongoing mechanism should be established to ensure that the public can provide input into the development and administration of a health info-structure to address the following priorities: accountability to the public; and custody of the info-structure to remain in the public health care system.

— *Stakeholder Issues Theme*

- A broader public consultation should be pursued.
- Individual stakeholder groups should work in collaboration with each other and the public. A spokesperson with strong communication skills is required.
- The benefits of collaboration should be identified.

— *Policy Issues Theme*

It is critical that the public be fully involved in the process. Some kind of mechanism that provides for public input on an ongoing basis is required as a means of ensuring accountability to Canadians. However, there is a wide range of opinion as to what form this mechanism might take. Suggestions included a broad public consultation process, a national conference on privacy and confidentiality issues and a greater degree of public participation on Advisory Councils. Still more complicated is the task of determining who represents, and speaks for “the public,” a term that encompasses a wide variety of opinions and perspectives. Many organizations — government included — wear the mantle of “the public” when speaking, yet have agendas specific to their interests.

There is a tension between the need to move forward, and the need to be inclusive of all stakeholders when confronting pressing issues. Provinces are already developing their info-structures, and time is of the essence in achieving an integrated health info-structure.

In some respects, this conference should be seen as part of an ongoing dialogue. It brought together Canadians representing the spectrum of stakeholder groups, with a wide range of backgrounds and views. It provided an opportunity to exchange opinions, to share experiences, and to promote better understanding of how others see the unfolding info-structure. In this sense, the conference was more exploratory than prescriptive. The richness of perspectives, the range of discussion, and the importance of the health system to Canadians attest to the need for an inclusive process as we move forward.

Appendix A

Speaking notes for Allan Rock, Minister of Health, at the National Conference on Health Info-Structure Edmonton, Alberta, February 9, 1998

Ladies and gentlemen good morning. I want to begin by expressing, on behalf of the Prime Minister and the Government of Canada, a warm welcome to all of those here today for taking the time and showing the interest in this important subject.

This is the second of three national conferences that are being held this year to look at specific ways in which we can modernize medicare.

A few weeks ago in Saskatoon we met to talk about pharmacare. In early March we'll be in Halifax at a national conference on home and community care. And it's appropriate that we meet in Alberta to discuss information technology.

Under the leadership of Minister Jonson and the stewardship of Dr. Tom Noseworthy, Alberta is in many ways showing the way forward through its Wellnet program, combining people and organizations to establish important linkages in the use of information.

I must say I very much enjoyed working with my partner and friend Halvar Jonson in planning and organizing this conference. Our officials have worked to assemble an outstanding faculty of moderators and speakers and I want to thank Halvar and his very capable officials for such a successful collaboration.

I'm delighted to see here at this conference some of my colleagues from the Parliament of Canada - Members of Parliament Reg Alcock from Winnipeg, Dr. Rey Pagtakhan from Winnipeg, and Dr. Carolyn Bennett from Toronto.

You know, on all those occasions when people have stopped me to speak about issues on their minds, I can't recall a single occasion when a Canadian has come over to me and asked urgently about health infostructures.

Now, they ask me about waiting lists for surgery, they talk about the state of our emergency rooms, they're worried about referrals to specialists.

But the truth is, an intelligent, systematic and integrated use of information technology will be a fundamental requirement if we're going to succeed in solving the problems that are at the top of people's minds - whether it's better management to overcome the problem

of waiting lists, overcoming service gaps in rural and remote areas, or innovations like pharmacare and home care.

This is more than a question of mechanics and processes. It is about information as a driving force for positive change. And it is about values - including protecting the privacy of our personal health information.

Today, I want to help set the tone for your work by suggesting what I believe Canada could achieve with the right health information structures, second, offering my view of where we are now and finally, noting some of the key issues that I hope you will help us resolve during your deliberations.

This exercise over the next couple of days must also be about values, including the value we place on privacy, because we might as well acknowledge at the outset that we will not have the broad support of Canadians for the innovations we have in mind unless we can give them full and credible reassurance that their privacy concerns can and will be accommodated.

I believe that a common vision is developing about the end goal towards which we should all be working. Simply stated, we want to harness information technology to create a coherent system that will collect, integrate and provide access to reliable and consistent information for use in health promotion and health care - from clinical decisions to laboratory research, from policy development to disease prevention, and from hospital management to quality control.

And the case for moving toward the achievement of that goal now is very strong. Every health policy analysis, and in particular the National Forum on Health's report, recommends that we foster in Canada a culture of evidence-based decision-making. But how can we make evidence-based decisions without the evidence?

Every government, every regional health authority, every hospital knows that to meet rising demands with finite resources we must manage wisely. But how can we manage what we do not measure?

There will be competing needs and conflicting interests to reconcile. The broad and varied representation at this conference will help us identify them and work towards their resolution. There will be technical problems to solve. There will be legal issues to debate. There will be economic barriers to overcome. But the value and the importance of the prize we seek makes all of that well worth undertaking.

You know in many ways the work is already well-started. In every province of Canada, in scores of hospitals, in leading universities, the public and the private sectors have invested in the creation of infrastructure to accumulate and analyse health-related information. But too often these separate systems stand in isolation. They speak to the issues but not to each other. They reflect part of the story but so many subjects remain unrecorded.

And the result? A patchwork of unconnected projects, each with its uses but with a value that would increase a hundred-fold if they formed part of a coherent whole. And even when data is captured, it's sometimes unavailable to those with the capacity to analyse and understand it. And so we too often find ourselves drowning in information, while thirsting for knowledge.

The Forum recommended the Government of Canada take a leadership role to bring about a national information system. It did not call for unilateral action. Rather, it called for collaboration with the provinces, territories, other partners and the private sector.

There is a substantial basis for this cooperation. Just as with Alberta Wellnet, other provincial governments are planning or implementing health information systems and networks. Many challenging projects are bringing together disparate hospital systems with those of public health organizations, doctors' offices, pharmacists and the private sector.

So what vision is it that we're pursuing in Canada? What do we want from technology as the servant of the health sector? How can we put its wonders to work to produce a more efficient, effective health care system?

Well I suggest that our end goal should be a nation in which complete, accessible and comprehensive information will support improved knowledge and decision-making, whether those decisions involve the overall structure and functioning of the health system or the diagnosis, treatment and care of an individual.

To support improved knowledge and decision-making, consider the many ways that information management through technology can and often already is supporting improved knowledge and decision-making.

Consider an elderly woman who comes into the emergency room of a hospital. Other doctors at another hospital miles away know her medical history well but the staff in this emergency department do not. Within minutes the information is electronically shared, making it unnecessary to take a prolonged history, allowing caregivers to rule out irrelevant possibilities, to avoid allergies to medication, to focus on the real problem.

Imagine a family physician who ponders which is the more desirable of two alternative therapies in the treatment of a middle-aged man. As she considers her options she programs her laptop with the patient's particulars and learns that an assessment of outcomes in the Canadian population shows that one treatment has a clear statistical edge when the problem presents itself in the patient's age group.

Think of a patient who is discharged from hospital following surgery. The home-care worker downloads the patient's history, outcome and course of medication in hospital onto a computer, saving hours of manual copying or patient interviews, avoiding errors of transmission or understanding.

Picture a doctoral candidate doing research at the University of Alberta medical school, who wants to assess the incidence and the trends in the epidemiology of a given infection. At the touch of a button, nation-wide data appears with regional variations adjusted for gender, age and occupation.

These and other wonders are now within our reach. Some of them occur daily in a few favoured locations.

Our goal must be to make them commonplace in Canada. And there are more possibilities. For instance: Hospital administrators learning best practices and cost consequences before making a choice about a new management system; patients in rural and remote areas having images read and conditions diagnosed by specialists in a distant city; consumers wanting to check waiting lists for elective surgery or comparative results for certain procedures as performed in different hospitals and, consulting a virtual consumer's report on health care and making their choice based on quality.

Remember, for the most part the technology already exists. The key is in its application and integration of the data, and in sharing it, enabling the full potential of that technology to be realized.

I hope, and I expect, that this conference will bring us closer to the day when such things are commonplace by finding ways to remove barriers that stand in our path, and by producing a list of concrete steps to take if we are to walk the path toward our destination.

Clearly, one challenge is the need to protect individual privacy. Few subjects are as sensitive as our personal medical histories. And each of us has the perfect right to have that privacy respected in full and without exception.

That's not only a legal entitlement -- it's a matter of personal dignity.

At the same time there are many in the health sector who are concerned that stringent privacy rules can impose unreasonable limits on access to the information they need. They believe that valuable research might be impeded, that the usefulness of information might be diminished if it's shrouded or masked to conceal private information.

I understand those concerns. But I believe that we can find solutions to that dilemma - that the very technology that will enable us to master information can hold the key to its protection.

And once methods are found, we should consider how those safeguards should be expressed - through national guidelines, through Canadian or provincial legislation. I want this conference to debate this issue openly, to show the way forward on the issue of the privacy.

There are solutions, and we can't let that problem stand in the way of the important goal that we seek.

Technology can play a major role in helping address the privacy concerns. One example under development at the federal Department of Health is called Spatial Health Information Exchange or SPHINX. This integrates data from various sources to help us monitor certain health surveillance priorities. The software is designed to strip away personal identifiers and ensure privacy. And we're now starting a pilot project to see how it works in partnership with Alberta Health.

A second issue -- what kind of system should we be aiming for?

One possible approach is a sort of a Trans-Canada Highway for health information. Like its namesake, it would be a unifying route composed of the individual health info-highways of the provinces and territories - a network of networks connected and widely accessible. Is that the model we should choose? Is it the most efficient? Are there others? What can we learn from experiences in other parts of the world? And regardless of the preferred model, how can we establish a common approach to information gathering so that we are collecting the same kinds of data, in the same kinds of ways, using common standards?

Many of these issues are now being considered by the Ministerial Advisory Council on Health Info-Structure that was appointed last summer by Health Canada. That Council is looking at these questions and examining options. It is also trying to find a way to ensure that the public has a role in these deliberations because in my mind it is essential that we remember that the public - consumers - must be part of these deliberations and must buy into the conclusions. So, the Advisory Council is trying to find ways to make the public an integral part of the process.

Many of the members of that Council are here at this conference and I take this opportunity if I haven't had the chance to greet them personally to express my gratitude for the enormous work they've contributed to that effort.

A third issue is money. The potential spending on health information could be very substantial. And yet, how do we know that our spending will produce the best results? The private and public sectors alike are full of stories of technology investments that fell far short of their promise?

How can we make the right decisions and help the public better understand the importance of these investments? As we calculate the cost, let's not forget to include the benefit because by acting on some of these opportunities we'll reduce costs in the health care system very significantly.

Let me conclude by suggesting that this important work offers us the opportunity to produce a truly Canadian success. Canada is known to people around the world for many things. Two of them bring us here today. The first is leadership in medicare. The second is pre-eminence in the development of communications technologies. A generation ago we created a medicare system that offers all Canadians access to medically-necessary services based on their need, not their ability to pay.

Over many years we pioneered telecommunications products and services that have led the world while enabling us to overcome the barriers of distance in a vast land. We've learned how to use technology to link a people broadly dispersed across an immense country.

Well, the time has come to bring those strengths together.

We can make our health information as portable as our health insurance.

We can link communities so that they learn from each other.

We can develop tools that bring the latest information and services to health providers and consumers alike.

We can use better health information and better use of technology to improve the medicare system we have and to enable us to build the one we want to leave for our children.

We can collect and exploit data to guide our efforts to assess levels of wellness, to promote health, to prevent illness, to establish strategies and priorities in that effort.

It seems to me that the time has come to start building that system on a national, a Canadian scale. The time has come for us to make clear plans and to act on them.

As we'll hear from Dr. Mandil at lunch, this is not just a Canadian preoccupation - it's a global challenge. And it presents us, not only with an opportunity to make a real humanitarian contribution, but also an economic opportunity of unparalleled scope.

So I encourage you over the next two days to establish challenging goals for our nation, to develop a workable and ambitious agenda for the future and above all to show Canadians how we will harness our modern technologies to build a better and healthier Canada for the 21st century.

Thank you.

Appendix B

Speaking notes for Halvar Jonson, Alberta Minister of Health, at the National Conference on Health Info-Structure Edmonton, Alberta, February 9, 1998

Good morning. On behalf of the Alberta government, I am pleased today to welcome you to this National Conference on Health Info-structure.

Minister Rock, delegates, organizers - you are all here because there is consensus growing around the need to develop a national health information infrastructure within an integrated health system.

As you have just heard, this is a priority at a national level. It is equally a priority at the provincial level. Because ultimately, it becomes incumbent upon all of us to create an innovative form of integration architecture, with common data sets and standards, that suits the health needs of all Canadians.

That's why this conference is so important. We are here to set priorities, and to identify action plans, aimed at advancing the development of a national health information system.

This conference is an opportunity to investigate the issues in information management technology and health.

It is also an opportunity to talk face-to-face -- and to share information between key players.

By communicating and sharing what we know collectively, we can learn the lessons of others, and apply them to building an information management technology infrastructure in the health sector.

In Alberta, the groundwork has been laid. Through health restructuring, Alberta's health system continues to improve as the regional health authorities, health professionals and the provincial government work together to build an integrated, responsive system that meets the needs of Albertans.

The next step in our vision is to develop an integrated information management system - using the current technology - to enable a more effective and efficient delivery of health services.

Let me give you an example of our vision to help bring it into focus.

Consider this: A young child living in Yellowknife experiences severe breathing problems. Her mother calls 9-1-1.

- The 9-1-1 operator contacts a doctor, who connects to a health information system and, with the mother's permission, accesses the child's records.
- The physician learns, through the network, that the child has a history of asthma and also has serious reaction to certain drugs.
- Through a pharmacy network, the doctor checks out the drugs she is currently taking and rules out drug-related problems.
- Again, through the network, the physician contacts a specialist in Edmonton, and they agree to airlift the girl to an Edmonton hospital.
- When the child arrives, hospital staff already have all her previous health history and know her current symptoms. There is no delay in treatment.

This kind of scenario is not possible in Canada today. There is currently no easy way to link across provinces and territories - nor even between facilities within our province - in a timely and comparable way, to access the child's health information, or to contact specialists, or to transmit important information between sites.

At this conference, we need to tackle the challenges that a national health information management system entails.

- We need to discuss what core nation-wide components are required to be in place in order to have such a system.
- We must talk about how we can collect the data, and how legitimate users of the system can safely share it without breaching the public's right to privacy.
- We need agreement on processes and mechanisms to ensure planning is done in a coherent way.
- We have to address issues of ensuring compatibility and inter-operability of information.

Advances in technology have provided us with unique opportunities - and challenges - to modernize the health delivery system through information management.

In Alberta, as in other provinces, we are moving on those opportunities. We are also confronting the challenges.

Alberta WELLNET

In Alberta, as in other provinces, we are developing a provincial health information system. We call it Alberta WELLNET. The name really says it all.

Alberta WELLNET's mandate is to create an integrated health information system to support health and health care in the province.

The vision for WELLNET is simple : Better information for better health.

Among the many projects that we're working on now are a pharmaceutical management information system, integrated telehealth services, and assisting health authorities to implement regional systems within the context of an overall strategic blueprint.

The Strategic Blueprint

WELLNET's strategic blueprint is the foundation upon which our network will be built. It sets out the basic elements - mission, principles, and overall design.

There are several key concepts underlying the strategic blueprint.

One is that we will not tear down the old systems, but we will use technology to link existing systems and build gateways so that information can be shared appropriately.

Health information will stay where it is now - in physician's offices, hospitals, clinics, and health authorities.

Concept number two is that privacy is paramount. I cannot state strongly enough that whatever system is put in place, Albertans can be confident their privacy will be protected.

We are in the process of developing the Health Information Privacy Act, with input and guidance from health stakeholders, the privacy commissioner, and other interested Albertans, to address issues of concern.

The requirements and rules set out in the legislation will be built directly into the detailed development of Alberta WELLNET.

The outcome we expect is a province-wide health information system providing access to health information by the right people, for the right reasons, and only when they need it.

We also expect that our system will tie in with the national health information structure.

THE BENEFITS OF A NATIONAL HEALTH INFORMATION STRUCTURE

The benefits of a national health information structure are clear.

They cut across all aspects of the health system, from individuals who receive health services directly, to those who provide front line care.

It will benefit people who track health trends, researchers looking for possible cures, and administrators making decisions about organizing and funding health services.

The benefits of a national health info-structure are also tangible. For the health system as a whole it will mean:

- better information and greater reliance on clear evidence to guide decisions in health
- the ability to take as long term view, tracking the health of Canada's population and developing both national and province-wide strategies to improve health
- more efficient health systems, with resources directed to where they are needed most
- continuous improvements in the health of Canadians and the quality and management of the national health system
- regular reports with up-to-date information on the health of Canadians and the performance of the health system

For individuals, it will mean they can be confident that physicians can access their health information where and when it's needed, especially in emergency situations.

It will also mean faster reporting of test result; reduced duplication of tests; and elimination of the need to repeat basic health information to a number of health care providers and organizations, within and beyond provincial boundaries.

It is early in the game, but not too early to see how vital national health information network is to the future of healthcare delivery.

Now, as we embark on two days of workshops and discussions, I encourage you to consider your role in the development of a national health information system.

All governments, stakeholders, and individuals must work together to create a system that works - and at the same time, protects our personal health information.

Even though, today, we do not yet have a fully integrated health information system, I believe we are not far from that goal.

I am also sure that as a country, we are on the cutting edge - and that our work today will be the envy of other nations within the decade.

In conclusion, I would like to thank you for participating. This conference is an opportunity to learn not only from the successes of others, but also from their difficulties and challenges.

This is an opportunity for all partners in the health system to be leaders in the development of a health information network that will indeed guarantee better information for better health.

Thank you.

Appendix C

Summary of Recommendations

THEME: POLICY ISSUES

Workshop: Privacy, Security and Confidentiality

The underlying principle of the recommendations is based upon Dr. Tom Noseworthy's Vision presentation which stated: "Privacy is without reservation the number-one issue. If we cannot secure health information systems and guard against invasion of privacy, and if we cannot offer confidentiality and prevent fraudulent access to and use of health information, we should stop now and entomb health information in impenetrable silos."

- There is a need to establish a uniform, consistent level of privacy protection across Canada.
- There is a need to begin to build on standards already in existence in Canada, recognizing that Quebec already has legislated data protection standards in both its public and private sectors.
- There is a need for an open and transparent public debate/discussion involving all stakeholders, especially the general public, to discuss a national strategy on Privacy, Protection and Security based on a recognition of an individual's right to privacy. The discussion should be transparent about the role and involvement of the private sector.
- Given the number of existing players involved in the Health Iway and potential new players, there is a need for a mechanism to co-ordinate the ongoing efforts of a National Strategy.

Workshop: Critical Success Factors — Measuring Performance Along the Way

A broader public consultation should be pursued.

Individual stakeholder groups should work in collaboration with each other and the public. A spokesperson with strong communication skills is required.

The benefits of collaboration should be identified.

A national health info-structure should be based on existing provincial/territorial data resources and include a standardized core data set.

Focus on key indicators linked to the principles of the *Canada Health Act*.

The health information info-structure should strengthen the public administration of the Canada health system.

Electronic warehouse storage should be perceived as ideal for giving individuals access to their own health data and hence enhancing portability and promoting individual responsibility for wellness.

Workshop: Telehealth

Telehealth should be pursued as a key component of a national health info-structure.

A co-ordinated federal/provincial/territorial national approach is required in order to leverage expertise and resources, prevent duplication and lead to compatible solutions.

Support is needed for:

- proof-of-concept applications;
- research to illustrate where telehealth can be most effective;
- the development and delivery of telehealth education and training;
- the development of clinical standards to ensure the quality and integrity of diagnostic information;
- regional strategic planning and implementation; and
- the development of a national telehealth “toolkit” — standards, guidelines, model legislation, codes of practice, public education and technology assessment.

THEME: INFORMATION MANAGEMENT

With respect to privacy, the consent management process should be simplified and standardized, preferably using electronic rather than paper media. The individual consent management process should distinguish between treatment, information sharing for research purposes and information sharing for other (e.g., administrative, judicial, police) purposes.

There is a need for a common core content in provincial/territorial health information systems for research and planning purposes.

The Canadian Institute for Health Information (CIHI) should become a national standards development organization.

The process should be accelerated; funding is a prerequisite.

At the next meeting of provincial Deputy Ministers of Health, there should be a declaration of devolution to ICD standards presumably to CIHI and funding for provincial implementation.

There should be a dialogue with all stakeholders.

The Canadian Council on Health Services Accreditation (CCHSA) should expand its accreditation process to take into account quality indicators, at least at the regional level.

A body should be designated to ensure a process for the secure transportation of information and authentication of sender and receiver.

There should be national leadership from Health Canada to proactively provide guidance to consumers on quality recommended sites for health information.

THEME: TECHNOLOGY AND NATIONAL APPLICATIONS

Information sharing should be on an interprovincial basis and led by the Federal/ Provincial/Territorial Deputy Ministers of Health with outside involvement (e.g., Canadian Institute for Health Information (CIHI)). The process should be directed at identifying and sharing common issues and opportunities and reaping the benefits of working together.

A project directed at defining a process to set national initiatives should be undertaken.

- be highly consultative;
- emphasize what should be rolled up to a higher level;
- vest leadership in existing federal/provincial/territorial bodies with clear accountabilities for decision making;
- based the process on learning from current national initiatives;
- be comprehensive; and
- include a feedback loop.

THEME: STAKEHOLDER ISSUES

Workshop: Priorities and Needs of Policy Makers/Administrators

The National Advisory Council on Health Info-Structure should articulate a vision of what the health information system is going to be, including its structure/framework, function, scope and fundamental guiding principles.

New funding is required to do what has to be done.

Health Canada should reassert its leadership role in the development of a national health information system, including:

- bringing key stakeholders together for discussion;
- developing standards, particularly on information for the public;
- enforcing the current reporting data requirements from provinces, as mandated; and
- leading the coordination and strengthening of health information resources, first focusing on existing resources.

Existing efforts to define information needs and priorities among stakeholders should be co-ordinated.

Accountability to the public through system-wide disclosure of the public/private relationships in the information system should be strengthened.

Workshop: Priorities and Needs of Health Service Providers/Researchers

A national health information system should be developed by a national body and include the following:

- integration of existing resources;
- new money for new resources;
- broad representation; and
- Health Canada to have the lead responsibility.

The following two achievable outputs should be pursued: evidence-based information to guide service providers; and accountable information to the public.

Funding should be provided for demonstration projects to evaluate the impacts of different ways of delivering evidence to practitioners.

Workshop: Priorities and Needs of the Public

The public should be engaged in an ongoing broad consultation process at the federal and provincial levels on health info-structure to address the following priorities:

- public education;
- public participation from the start on decision-making bodies; and
- designation of health information as an integral part of the Canadian public health care system.

The health info-structure should be funded with new money.

An ongoing mechanism should be established to ensure that the public can provide input into the development and administration of a health info-structure to address the following priorities: accountability to the public; and custody of the info-structure to remain in the public health care system.

Multiple access methods to the information should be allowed in order to ensure balanced and equal access to health information. Address the following priorities:

- multicultural needs;
- economic status (affordability);
- inaccessibility of electronic technology (hardware and training); and
- making use of existing, quality health information in non-electronic media.

Comprehensive privacy legislation should be enacted to cover both the public and private sector, under the guardianship of the federal government. Include the following: consent must be required for access to personal medical information and ownership of that information must remain with the individual; and the public guardian must ensure the application of strict conflict of interest guidelines regarding health information.

Health information must include the “knowledge” which individuals want and need in order to be able to make better choices about their health. This includes tangible consumer information on health outcomes beyond medical records and patient data (e.g., best practices, advocacy tools, comparative information on institutions, costs of services).

Workshop: Priorities and Needs of Aboriginals

The discussion of health technologies should take into consideration the issue of basic health inequities between different Aboriginal populations.

To address the issue of trust, the community should have governorship and ownership of the system and information.

Health information systems should be sufficiently flexible to accommodate cultural and community sensitivities.

There should be community involvement in system design and development.

Any changes should not prejudice existing treaty rights and fiduciary relationships.

Appendix D

Members of the Advisory Council on Health Info-structure (at the time of the conference)

Co-chairs

Dr. Tom W. Noseworthy

Professor and Chair of Public Health
Sciences, Faculty of Medicine
University of Alberta
Edmonton, Alberta

Mr. Alan B. Nymark

Associate Deputy Minister
Health Canada
Ottawa, Ontario

Members

Mr. Richard Alvarez

President and CEO of CIHI (Canadian
Institute for Health Information)
Ottawa, Ontario

Mme Monique Charbonneau

President and CEO of CEFRIO (Centre
francophone de recherche en
informatisation des organisations)
Quebec, Quebec

Dr. Andrew Bjerring

President and CEO of CANARIE
(Canadian Network for the Advancement
of Research, Industry and Education)
Ottawa, Ontario

Ms. Cheryl Doiron

Vice-President Planning and Business
Development
Atlantic Health Sciences Corporation
Saint John, New Brunswick

Ms. Madeline Boscoe

Executive Coordinator
Canadian Women's Health Network
Winnipeg, Manitoba

Dr. Ivan P. Fellegi

Chief Statistician of Canada
Statistics Canada
Ottawa, Ontario

Dr. George Browman

Scientific Program Leader of HEALNet
(Health Evidence Application and
Linkage Network) Professor and Chair
Department of Clinical Epidemiology and
Biostatistics
McMaster University
Hamilton, Ontario

Ms. Debbie L. Good

Associate, Palmer and Shea, Chartered
Accountants
Charlottetown, P.E.I.

Mr. Doug Hull

Director General, Information Highway
Applications Branch, Industry Canada
Ottawa, Ontario

Dr. Mary Ellen Jeans

Executive Director, Canadian Nurses
Association
Ottawa, Ontario

Dr. Wilbert J. Keon

Director General, University of Ottawa
Heart Institute
Ottawa, Ontario
Member of the Senate

Dr. André Lacroix

Chief, Endocrinology Service, Research
Centre, Hôtel-Dieu Pavillion
Université de Montréal
Montreal, Quebec

Mr. John MacDonald

Chief Operating Officer, Bell Canada
Ottawa, Ontario

Dr. Cameron Mustard

Associate Professor, Manitoba Centre
for Health Policy & Evaluation
Department of Community Health
Sciences, University of Manitoba
Winnipeg, Manitoba

Dr. David Naylor

CEO of Institute for Clinical Evaluative
Sciences, Professor, Department of
Medicine, University of Toronto
Toronto, Ontario

Doreen Neville

Chief Executive Officer of the
Newfoundland and Labrador Centre for
Health Information
St. John's, Newfoundland

Dr. Robert Perreault

Chief of Preventive Medicine (HMR)
Public Health Division, Montreal Centre
Montreal, Quebec

Ms. Dorothy Spence

President and Chief Executive Officer
TecKnowledge Healthcare Systems Inc.
Halifax, Nova Scotia

Mr. Bill Thomson

Managing Partner
Sierra Systems Consultants Incorporated

Victoria, British Columbia

Dr. Mamoru (Mo) Watanabe

Professor Emeritus, Faculty of Medicine
University of Calgary
Calgary, Alberta

Mr. John A. Williams

President and CEO of SmartHealth
Winnipeg, Manitoba

Mr. Frank Winter

Director of Libraries
Library Administration
University of Saskatchewan
Saskatoon, Saskatchewan

Appendix E

Conference Principals

Richard Alvarez

Canadian Institute for Health Information
Don Mills, Ontario

Daniele Bertrand

Stentor Innovation Centre
Ottawa, Ontario

Andrew Bjerring

Canadian Network for the Advancement
of Research, Industry and Education
Ottawa, Ontario

Madeline Boscoe

Canadian Women's Health Network
Winnipeg, Manitoba

Sondra Bruni

Consumers' Association of Canada
Winnipeg, Manitoba

Mike Connolly

Information Systems Division
Ontario Ministry of Health
Kingston, Ontario

Michael Decter

Canadian Institute for Health Information
Don Mills, Ontario

Ivan P. Fellegi

Statistics Canada
Ottawa, Ontario

Marie Fortier

Health Canada
Ottawa, Ontario

Valerie Hagerman

New Brunswick Department of Health
and Community Services
Fredericton, New Brunswick

Kathryn Hannah

Sierra Systems Consultants Inc.
Calgary, Alberta

Ian Heath

Information Services Division
Department of Health and Family
Services
Canberra, Australia

David K. Hurst

Oakville, Ontario

Mary Ellen Jeans

Canadian Nurses Association
Ottawa, Ontario

Wilbert J. Keon

University of Ottawa Heart Institute
Ottawa, Ontario

André Lacroix

Centre hospitalier de l'Université de
Montréal
Montreal, Quebec

Salah Mandil

World Health Organization
Geneva, Switzerland

Dave McNaughton

Treasury Board of Canada Secretariat

Ottawa, Ontario

John Mullin
Ministry of Health Government of
British Columbia
Victoria, British Columbia

Andrea Neill
Federal Department of Justice
Ottawa, Ontario

Doreen Neville
The Newfoundland and Labrador Centre
for Health Information
St. John's, Newfoundland

Tom W. Noseworthy
University of Alberta
Edmonton, Alberta

Alan B. Nymark
Health Canada
Ottawa, Ontario

Michael Percy
University of Alberta
Edmonton, Alberta

Denis J. Protti
University of Victoria
Victoria, British Columbia

Carl W. Robbins
Memorial University of Newfoundland
St. John's, Newfoundland

Mamoru Watanabe
University of Calgary
Calgary, Alberta

Michael C. Wolfson
Statistics Canada
Ottawa, Ontario

Jay Wortman
Health Canada

Ottawa, Ontario

Appendix F

Organizations Attending the Conference

Advisory Committee on Population Health (ACPH)
Alberta Medical Association
Alzheimer Society of Canada
Assembly of First Nations
Canadian Association for Community Care
Canadian Association of Chain Drug Stores
Canadian Association of Occupational Therapists
Canadian Breast Cancer Network
Canadian Chiropractic Association
Canadian Coalition for the Prevention and Control of High Blood Pressure
Canadian Coalition on Cancer Surveillance
Canadian College of Health Service Executives
Canadian Confederation of Midwives
Canadian Coordinating Office for Health Technology Assessment
Canadian Council on Health Services Accreditation
Canadian Dental Association
Canadian Diabetes Association
Canadian Drug Manufacturers Association
Canadian Haemophilia Society
Canadian Healthcare Association
Canadian Health Coalition
Canadian Health Libraries Association
Canadian Health Services Research Foundation
Canadian Infectious Diseases Society
Canadian Institute for Health Information (CIHI)
Canadian Institute of Child Health
Canadian Labour Congress
Canadian Life and Health Insurance Association
Canadian Lung Association
Canadian Medical Association
Canadian Medical Protective Association
Canadian Mental Health Association
Canadian Network for the Advancement of Research, Industry and Education (CANARIE)
Canadian Nurses Association
Canadian Organization for the Advancement of Computers in Health
Canadian Paediatric Society

Canadian Pharmacists Association
Canadian Physiotherapy Association
Canadian Policy Research Networks Inc.
Canadian Psychiatric Association
Canadian Psychological Association
Canadian Public Health Association
Canadian Society of Hospital Pharmacists
Canadian Society of Telehealth
Canadian Standards Association
Canadian Union of Public Employees
Care-Link Inc.
Carleton University
Centre de Bioéthique IRCM
Centre francophone de recherche en informatisation des organisations
Centre for Health Information Infrastructure
CGI Information Systems and Management Consultants Inc.
Clinidata
College of Family Physicians of Canada
College of Physicians & Surgeons of British Columbia
Communications & Information Systems Health Sciences Centre
Community AIDS Treatment Information Exchange
Consumer Health Information Service
Consumers' Association of Canada
Dalhousie University
EDM Management Systems Inc.
Friends of Medicare (Alberta)
Government of Alberta
Government of British Columbia
Government of Canada
Government of Manitoba
Government of New Brunswick
Government of Newfoundland
Government of Nova Scotia
Government of Ontario
Government of Prince Edward Island
Government of Quebec
Government of Saskatchewan
Government of the Northwest Territories
Government of the Yukon
Health Care Concepts International
Health in Action

Hollander Analytical Services Ltd.
IBM - Healthcare Solutions
IMS Canada
Information Technology Association of Canada
Innovaction
Institute for Work and Health
Institute of Public Administration
Manitoba Nurses' Union
McGill University
McMaster University
Medialinx Interactive inc.
Medical Research Council of Canada
Memorial University
Meta Strategies Inc.
Métis National Council
Métis National Council of Women
National Federation of Nurses Union
National Action Committee on the Status of Women
National Advisory Council on Aging
National Association of Friendship Centres
Newfoundland & Labrador Nurses Union
Office of the Privacy Commissioner
One Voice, The Canadian Seniors Network
Ontario Hospital Association
Ontario Medical Association
Palmer & Shea Chartered Accountants
Pauktuutit Inuit Women's Association
Paul Gamble & Associates
Pharmaceutical Manufacturers Association of Canada
Registered Nurses Association of British Columbia
Richard Ivey Foundation
Royal College of Physicians and Surgeons of Canada
Saskatchewan Association of Health Organizations
Saskatchewan Union of Nurses
Science Applications International Corporation
Sierra Systems Consultants inc.
Smart Health
Society of Rural Physicians of Canada
TecKnowledge Healthcare Systems Inc.
University of Alberta
University of British Columbia

University of Calgary
University of Saskatchewan
University of Toronto

The above list notes the organizations and businesses invited to the conference. In addition, a number of participants were invited to the conference, not as members of an organization, but as individuals. These individuals included members of the public, experts and academics, and former members of the National Forum on Health.

Appendix G

Background Papers

1. A Health Information Strategy for Canada - A Conceptual View; The Arlington Consulting Group; November 1997 (prepared for Health Canada and Alberta Health)
<http://www.hc-sc.gc.ca/ohih>
2. Preparing Canada for a Digital World; The Information Highway Advisory Council; September 1997
<http://strategis.ic.gc.ca/SSG/ih01650e.html>
3. Health Information Technology in Canada '97: A Review of Ongoing Initiatives; Centre for Health Information Infrastructure; August 1997 (prepared for Health Canada)
<http://www.hc-sc.gc.ca/ohih>
4. Telehealth in Canada - Clinical Networking, Eliminating Distances; The Canadian Network for Research, Industry and Education (CANARIE); July 1997
<http://www.canarie.ca/eng/outreach/health/telehealth/main.html>
5. Canada Health Action: Building on the Legacy; The National Forum on Health; February 1997
<http://www.nfh.hwc.ca/publicat/finvol1/1trans.htm>
6. Towards a Canadian Health Iway: Vision, Opportunities and Future Steps; The Canadian Network for Research, Industry and Education (CANARIE); September 1996
<http://www.canarie.ca/eng/outreach/health/toc.html>
7. Building the Information Society: Moving Canada into the 21st Century; The Information Highway Advisory Council; May 1996
<http://strategis.ic.gc.ca/SSG/ih01103e.html>
8. Connection, Community, Content: The Challenge of the Information Highway; The Information Highway Advisory Council; September 1995
<http://strategis.ic.gc.ca/SSG/ih01070e.html>
9. Access, Affordability and Universal Service on the Canadian Information Highway; The Information Highway Advisory Council; January 1995
<http://strategis.ic.gc.ca/SSG/ih01090e.html>

10. Privacy and the Canadian Information Highway; Discussion paper of the Information Highway Advisory Council; October 1994
<http://strategis.ic.gc.ca/SSG/it00567e.html>

