

Advisory Council on Health Info-structure



***Connecting for Better Health :
Strategic Issues
Interim Report***

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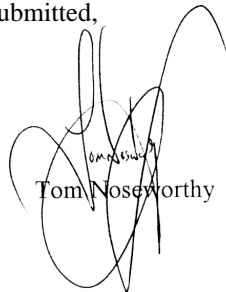
On behalf of the members of the Advisory Council on Health Info-structure, we are pleased to submit to you our interim report, *Connecting for Better Health: Strategic Issues*.

This report represents the progress to date of the Advisory Council on a number of key issues central to the development of a strategy for a health infostructure in Canada. The Advisory Council, in the past year of its mandate, has heard from stakeholders on the need for a national health infostructure, and the potential the infostructure could play in improving the health of the people of Canada.

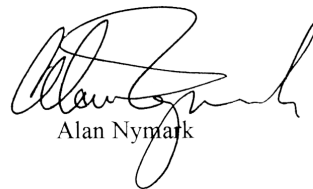
As we endeavour to expand and modernize medicare, it becomes crucial that the health system utilize existing and emerging information and communications technologies to improve the efficiency and effectiveness in the system. We believe that the advice presented in this report can serve to achieve this goal.

The Advisory Council will continue its work into the last phase of our mandate. We hope that this report will stimulate further inputs to our deliberations, as we work towards presenting our final recommendations to you early in 1999.

Respectfully submitted,



Tom Noseworthy



Alan Nymark

Connecting for Better Health: Strategic Issues

Interim Report
Advisory Council on Health Info-structure

September 1998

Canada

This interim report was prepared by the Advisory Council on Health Info-structure. The final report is expected in early 1999.

Additional copies are available from:

Health Canada Publications
Postal Locator 0913A
Brooke Claxton Building
Ottawa ON
K1A 0K9
Telephone: (613) 954-5995
Fax: (613) 941-5366

This report can also be downloaded from the Website address:

<http://www.hc-sc.gc.ca/ohih-bis>

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Cat. No.: H49-118/1998

ISBN: 0-662-63773-9

ACKNOWLEDGEMENTS

The Advisory Council on Health Info-structure wishes to acknowledge the work of all those who helped in the production of this report, but specifically the ongoing contribution of the following individuals:

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PREFACE

Information is power. Until recently, extensive health information has been available mainly to a limited number of decision makers within the health sector. The new information and communications technologies used in a health infostructure offer the promise of significant change. Over the next few years, high-quality information on health and the health-care system will become available to individuals and to all providers in the health sector. This information will offer all citizens the opportunity to take a more active role with respect to their own health and make possible a health care system which is dramatically more responsive to individual needs and more accountable to Canadians

Canada's health care system faces many real challenges as the millennium approaches – a lack of coordinated, community-based services beyond the hospital door, a lack of systematically gathered data on health determinants and the outcomes of decisions by health care providers, managers and policy makers, and a growing restiveness on the part of a public determined to take control of its own health and hold the health care system accountable. Many even question its sustainability.

An important part of the solution to this malaise will be the development of new ways of thinking about health information – how we create it, how we

analyse it, how we use it. Health information systems can ensure the coordination and often integration of today's diverse health care services so that a person can move seamlessly through them. Sound and timely information on health determinants and the outcomes of previous decisions can allow health care providers to make better decisions in their patients' interests. A better understanding of the health impacts and costs of previous actions can enable health policy makers and managers to make the evidence-based decisions needed to sustain the health care system. Most important of all, better health information will allow the general public to engage more fully in the ongoing debate about health policy and hold the health care system to account. As consumers, they will be able to make informed choices about the treatments and services that truly meet their needs. This report is about how such information can be created, distributed and used by the public and all stakeholders in the health sector.

The Advisory Council on Health Infostructure was established to develop a strategy for implementing a nation-wide health information infrastructure – infostructure, for short. Our final report is due in early 1999, but we want to bring out this interim report now for three reasons.

First, we as a Council wish to inform Canadians about our progress and improve public understanding of a health infostructure – its nature, its promise and the issues it raises. Second, we want to involve as many Canadians as possible in discussion of these issues. Accordingly, this report is our invitation to you to express your views and concerns. Finally, our deliberations thus far have revealed several imperatives that demand strategic action in the short term. This report brings these to the attention of the federal government.

OUR ORIGIN

The Advisory Council on Health Infostructure originated in the growing recognition in Canada and abroad that the application of new information and communications technology in the health sector has the potential to make a significant contribution to people's health and the quality and efficiency of health care.

As early as 1991, the National Task Force on Health Information set out a broad strategic direction for the development of a national health infostructure. The Information Highway Advisory Council (IHAC), in *Connection Community Content: The Challenge of the Information Highway*, its September 1995 report to the federal

government, recommended an "Advisory Council of all stakeholders" to address "the challenges of implementing a health information infrastructure and identify applications that would benefit all Canadians as well as improve effectiveness and efficiency." The Canadian Network for the Advancement of Research, Industry and Education (CANARIE) expanded on this in 1996. The National Forum on Health, in *Canada Health Action: Building on the Legacy*, its 1997 report to the Prime Minister and Minister of Health, called for the establishment of "a nationwide population health information system...to support clinical, policy and health services decision making, as well as decision making by patients and the public at large." In the February 1997 budget, the federal government committed \$50 million over three years to developing a strategy for a national health infostructure.

In the summer of 1997, the federal Minister of Health established the Advisory Council on Health Infostructure to give him strategic advice on the development of a national strategy for a Canadian health infostructure. Our 24-member Council includes representatives from a wide range of stakeholders from the health sector¹.

¹ Annex A contains a list of Council members and their backgrounds.

OUR MANDATE

We have been asked to consider how information technologies and systems could best support and promote better and more informed decision making by individual Canadians, health professionals, administrators, researchers, planners and policy makers. Our focus is a client-centred health infostructure that, while respecting privacy concerns, meets the specific needs of all these groups. Our work is not just to strengthen health care but also to increase public understanding and encourage action on the broader, non-medical determinants of health. Although our primary mandate focusses on health, we have been asked to elucidate and analyse the economic and industrial opportunities presented by the development of a health infostructure.

In more specific terms, our mandate is to:

- ◆ develop a Canadian vision for a health infostructure and identify its basic shape and the essential needs it should serve;
- ◆ establish national priorities for action to improve the capabilities of a Canadian health infostructure in meeting the needs of specific categories of users;
- ◆ identify and prioritize issues, challenges and barriers to the effective use of information technologies and systems in a Canadian health infostructure, with a view to recommending coordinated approaches and solutions;
- ◆ generate an agenda for action by stakeholders to advance implementation of the most vital components of a health infostructure, including a long-term strategy to achieve a Canadian consensus for building it, and advise the federal Minister of Health on specific actions to move this agenda forward; and
- ◆ advise on international developments in this area.

OUR PROCESS AND YOU

To carry out this mandate, we divided into working groups on vision and analytical framework, key policy issues, health information for the general public, and technology/applications. In practice, we discovered that the activities of these four working groups overlapped, encouraging useful debate and a cross-pollination of perspectives that advanced our work.

From the outset, we realized that no government acting alone would be able to create a national health infostructure. Cooperation of a high order among

federal, provincial and territorial governments is central to this endeavour. But even governments acting together will not be sufficient to carry forward this agenda. Success will also depend on the active involvement of the general public in all its diversity and the full range of stakeholders in the health sector – from health professionals, administrators, policy makers and researchers to hospitals and community health organizations to non-governmental organizations and private industry.

In recognition of this need for broader involvement in the issue, the Council took part in February 1998 in a National Conference on Health Info-Structure in Edmonton, co-sponsored by the Government of Alberta and the federal Government. Participants included 300 representatives of the public, stakeholders, industry and federal, provincial and territorial governments.

The Council joined with the Canadian Institute for Health Information and Statistics Canada in interviewing some 500 health stakeholders about their information needs. Council staff have also been working actively with a recently established forum of Chief Information Officers for federal, provincial and territorial health departments.

To encourage further discussion of these matters, we are releasing this interim report on our preliminary thinking and recommendations. We urge you or your organization to respond with your own thoughts and views, your own recommendations for the shape of a national health infostructure for Canada. The issues raised touch on the future health of all Canadians. Your input can help ensure that the new information and communications technologies serve that over-riding objective.

1. INTRODUCTION

For many Canadians, the health care system is so important it has become a defining feature of their nationality. Being a Canadian means having access to the publicly administered, single-payer health care system which forms Medicare.

In the last two decades, the health care system has grown ever more complex and diverse – less able to keep its component parts working together and more opaque to Canadians ever more worried about its sustainability. We believe a key part of the solution lies in the development and use of information. The technologies to allow this are already starting to become available and are being deployed in the health sector.

This report is about how investments in these technologies and knowledge management should be shaped strategically to sustain Medicare, to improve our collective health, to enable the integration and strengthening of health care services, to strengthen their accountability to Canadians, to allow individuals to take control of their own health. Your comments, opinions and suggestions will be critical to seizing this opportunity in a wise and effective fashion.

SUSTAINING HEALTH CARE WITH INFORMATION

From the 1960s to the 1980s, growth in Canada's health care system was spectacular and mainly meant growth in the number of acute care facilities such as hospitals. Then in the 1980s, driven by fiscal restraint and a realization that people needed more alternatives to acute care, Canada's health care system began to move toward an increasing pluralism – from a system dominated by acute care in hospitals to dependence on an ever wider variety of services and health care professionals, many of them community based.

This transformation is only partly complete, with the result that these new services are often poorly coordinated and in some cases have not yet come into existence. With reform only half achieved, patients have been left to find their own way through a labyrinth of services. Health care providers, policy makers and managers continue to face difficult decisions affecting the health of individuals and Canadians as a whole, often with little systematically gathered empirical data on the outcomes of earlier decisions. Not surprisingly, Canadians express worry and fear about their future access to quality care and the sustainability of the health care system. As health consumers, they demand the tools to take control of their own health. As citizens, they ask for meaningful input

to health policy.

Council believes that new and better information, shaped to meet all these requirements, will be critical to meeting these challenges and sustaining the health care system as we enter the 21st century. Health information systems will enable coordination and integration of today's many health care services so that a patient can move seamlessly from one to another. With sound and timely information on health determinants and outcomes of previous decisions, health care providers will be able to make informed decisions in their patients' interests. With better understanding of health impacts and costs of previous actions, policy makers and managers will be able to make the evidence-based decisions needed to carry forward reform and sustain the health care system. Better health information will allow the general public to engage more fully in the health policy debate and hold the health care system to account. As consumers, they will be able to shop around knowledgeably for the health care providers and services that meet their needs.

This report is about how such information can be created, distributed and used by the public and stakeholders in the health sector. The technologies to do so are already becoming available.

THE NEW TECHNOLOGIES

Over the last 25 years, the capabilities of computer and communications systems have grown astonishingly. The power of computers has doubled at least every 18 months, while the capacity and affordability of communications systems have risen dramatically. And the two technologies have converged, producing powerful applications for the shared creation, analysis and transmission of information on a national, even global, basis. The Internet and the personal computer are the phenomena most often associated with this change, but they are not the only ones.

As a result, distance and geography are now less of an obstacle to economic development, social intercourse, learning or volunteer work. These technologies are making information more widely available to everyone, thereby presenting opportunities to become more informed and improving the chances for wiser decisions in all aspects of our lives – from business to government to education to the daily routines of life.

In much the same way, new technologies - some already developed, some under development now - promise to contribute to improvements in health care and the health of Canadians.

POTENTIAL HEALTH BENEFITS

Council believes the health sector should seize this opportunity on behalf of Canadians, although it is important to understand that technology itself is rarely the complete solution to anything. For benefits to be realized, deliberate policy, input from the public and stakeholders, and the social values at the core of Canada's health sector should shape the application of these technologies. Seizing this opportunity will thus be a long-term process, but one that should begin immediately so that benefits can be realized as soon as possible.

What are these potential benefits? At the most general level, they revolve around the potential of technology to connect Canadians and members of the health sector in a timely fashion with each other, with better health information and with better health care. In all these ways, the technology can be utilized to contribute to improving our collective health.

Potential benefits fall into three broad categories:

1. Direct Benefits to the Public

Information technology promises to make the health care system much more accountable to the public. The Internet already allows patients, caregivers and citizens to communicate more effectively with each other in their

efforts to make health care providers and the system itself more responsive.

Greater public access to data on health policy will strengthen these efforts. The technology can also be used to give people more and better health information, including directories and report cards on health care services and programs. This information will allow Canadians to become more informed consumers of health services and products, and take greater control of their own health.

2. Improved Health Care Services

Applications of telecommunications and information technology are critical to the seamless integration and coordination of the plethora of health care services characterizing today's health sector. Such applications allow the electronic sharing of vital information, when required, among hospital services, laboratories, diverse health professionals, community health institutions and homecare providers who may be serving a particular patient. Such capability is particularly important in this era of regionalized and integrated service delivery, operating from several geographic locations.

These applications can electronically deliver health care services and expertise into underserved rural and remote areas or meet the growing need for health care services in the home. Furthermore,

pharmaceutical databases can make sure both health professionals and patients are better informed about drug effects and interactions.

Continually updated decision support systems and electronic health records, easily and confidentially accessible by physicians and health providers, can improve both quality of care and efficiency by eliminating unnecessary or redundant tests and procedures. At the same time, a health infostructure can provide, independent of geographic location, further training and information access for health care providers, enabling maintenance of competence in this era of rapid change in medical knowledge.

The electronic exchange of health care information across provincial and territorial boundaries permits portability by allowing patients from one province to authorize instant but confidential access to health records by a health care professional in another province. Such exchanges lay the basis for provision of telehealth services across jurisdictional boundaries.

3. Benefits to Health Researchers, Managers and Policy Makers

The new technologies can be used to develop and deliver, subject to appropriate privacy safeguards, better information in support of decision making by health managers and policy

makers, as well as to open new frontiers for health researchers. The resulting information and discoveries can serve both to strengthen health care and accountability to the public by the entire health system and health care professionals.

Researchers will arrive at potentially new and fundamental understandings of health determinants – with possibly vast implications for improving health and reducing health care costs. The availability of better information to managers could well allow better control of costs and improved financial and administrative accountability throughout the health sector. Policy makers will make better decisions as a result of access to statistical information illuminating in an unprecedented way the impact of different health policies on the health of Canadians. Similar information will be made available to the public. Such data might also be used to illuminate the impacts on health of economic, social and environmental policies outside the traditional health care domain.

CHAPTER KEY

The federal government has set in motion several initiatives to strengthen Canada's health system. Some address development of Canada's health infostructure. As Annex B shows, provincial and territorial governments are also taking important steps in this area. However, there is a clear need for a strategic focus to all these disparate

efforts.

Chapter 2 delineates a vision and strategic framework for how these efforts can be shaped to serve the goals of Canada's publicly financed single-payer health care system. **Chapter 3** highlights the specific challenges to using the infostructure to empower the public, strengthen health care and create strategic information resources for accountability and improvement of the

health system. **Chapter 4** addresses the broader strategic issues which must be faced in developing the infostructure. As well, it brings forward interim recommendations for immediate action. **Chapter 5** invites further input from all concerned with the health of Canadians and the sustainability and improvement of Canada's health care system.

2. ENVISAGING A CANADIAN HEALTH INFOSTRUCTURE

As yet, neither Canada nor any other country in the world has fully and effectively taken advantage of information and communications technology in the health field. Governments and their health sectors are investing heavily in information networks and services, but still struggling to figure out how they can best be used. Most of Canada's provincial governments and the federal government have launched ambitious projects to take advantage of this opportunity. These initiatives should provide the foundation for a national approach, but only if these applications are shaped by a common strategic vision.

A term now used to describe these applications and the people managing and using them is "health infostructure" – a shortened version of "health information infrastructure." Here we look at some defining elements of this infostructure before delineating a vision of what we believe it should be. Then, we set out a broad strategic framework and look at the most critical factor for fulfilment of this vision – effective Canada-wide collaboration across the Canadian public, governments and stakeholders in the health system and the private sector.

THE QUESTION OF DEFINITION

Most experts agree that the heart of a health infostructure is health information – its development, analysis, adaptation for different purposes, communication to the appropriate user, and employment to improve health, health care and accountability throughout the health system. Another key concept is improved communications – among the various players within the health system, among the general public, and between both groups.

Some argue that an infostructure has four key features:

- ◆ *"the supporting technological framework, including the cameras, scanners, telephones, fax machines, computers..., etc.;*
- ◆ *"the available information, whether in the form of text, sound, images, data..., 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 and technological and legal means to protect the privacy, confidentiality and security of personal information; and

- ◆ “*the people and organizations... creating the information, developing the applications and systems... and those using this infrastructure to deliver, maintain and improve health-related services for all Canadians².*”

This definition emphasizes that a health infostructure is about more than technology or even information. People and policy are also critical.

We do not believe a health infostructure, even the national health infostructure, will be a single entity. It will be built upon the foundation provided by provincial and territorial health infostructure initiatives already being designed or implemented. Each will retain its identity and integrity. The national health infostructure will be an interconnected and interoperable network of networks, but one with stringent confidentiality and security

safeguards to ensure that personal health information is fully protected in accordance with strong and effective privacy legislation and regulations.

We believe it more useful to define a health infostructure in functional terms, especially since, as seen in Chapters 3 and 4, each function relates to different privacy concerns, raises different issues and calls for different information, technology and policy solutions. As well, any definition will be provisional. Both technological and social realities are changing rapidly. As they transform, so too will our vision of a health infostructure.

VALUES AND VISION

The values animating the national health infostructure should be the same values underpinning Canadians’ support for a publicly administered health care system. It is the marriage of these values with a sense of new technological capability that provides the foundation for a vision of the national health infostructure. This in turn provides the basis for a strategy to develop and implement it.

First, a health infostructure should strengthen Medicare as a single-payer, publicly funded health care system guided by the five principles of the *Canada Health Act* – universality, accessibility, comprehensiveness, portability and public administration – within the framework of a strong

² The Arlington Consulting Group, *The Canadian Health Info-Structure: A Conceptual Overview* (Background Paper for the February 1998 National Conference on Health Info-Structure), pp. 4, 5.

federal/provincial/territorial partnership. Developing the infostructure will involve collaboration with industry and health organizations, but only in this context.

Privacy will be a key value in a health infostructure. A fundamental condition for successful health care is the trust patients have that their personal health information will be protected. Otherwise, few would confide in a physician or health care provider. In an age of instant electronic access and dissemination, we believe personal health information must be protected by strong privacy legislation and effective security. While we recognize that privacy is a relative and not an absolute value, we strongly believe that personal health information must be protected from secondary commercial use. We further believe that the burden of proof should be on anyone proposing release of such information without consent to demonstrate that a tangible public good of significant benefit will result, and that no harm can occur to any person as a result of using personal information.

We believe the national health infostructure should be inclusive rather than exclusive. Caregivers, patients, the general public, health care professionals, researchers, administrators and policy makers should participate as users and creators of the information. This information should be relevant, accurate, timely and appropriate to

users – and in a format they can use. It will be critical to the success of a health infostructure that users be involved in its design.

Of particular importance are the values of collective and personal responsibility identified by the Values Working Group of the National Forum on Health. Canadians want to participate meaningfully in decisions about health care policy. They want to take greater responsibility for their own health. Out of concern about the confusing complexity of today's health system, they also ask for an efficient, effective health system that will provide quality care in an accountable manner.³

In light of these values and capabilities, our vision is as follows:

A Canadian health infostructure builds on provincial and territorial infostructures to strengthen the ability of people – individual Canadians, health care providers, health researchers, managers and policy makers – to make informed choices about their own health, the health of others and Canada's health system.

³ National Forum on Health, "Values Working Group Synthesis Report," *Canada Health Action: Building on the Legacy – Synthesis Reports and Issues Papers*, Vol. 2 (1997), pp. 6, 7.

STRATEGIC FRAMEWORK

Strategies help translate visions into reality. In the case of our client-focussed vision, it is important to understand that the means of ensuring this ability to make informed decisions will vary, depending upon the decision maker.

The realities of the Canadian health system at the millennium have shaped this strategy. It flows from a recognition that people are concerned about the health system, want to take more responsibility for their own health, and are demanding greater accountability from the system. It stems from a realization that lack of coordination across the spectrum of health care services is a major source of inefficiency and public anxiety. It is based on the perception that physicians and all health care providers need a means to keep abreast of the global explosion in health knowledge. Its foundation is a respect for provincial jurisdiction in health care delivery and a recognition that provincial and territorial health information systems represent the building blocks for a national health infostructure.

In light of these realities, the national health infostructure should:

1. **Empower the public by:**
 - (a) **providing reliable health information useful to Canadians as health consumers and citizens**
 - (b) **ensuring equitable access to health information**
 - (c) **offering opportunities for community accountability, participation and input.**
2. **Strengthen and integrate health care services by:**
 - (a) **improving quality, accessibility and efficiency within provincial and territorial boundaries**
 - (b) **enabling interprovincial health care applications and better portability**
3. **Create the information resources for accountability and continuous feedback on factors affecting the health of Canadians to:**
 - (a) **provide new understandings of health determinants and the long-term impacts of health care interventions**
 - (b) **improve management and cost-effectiveness within the health sector**
 - (c) **contribute to the sustainability of our publicly funded health care system by supporting better health policy formulation and analysis**

These strategic goals and objectives need not all be advanced at once for benefits to flow. Advances toward one will assist in achievement of another. A more involved, informed public will support the formulation of better health policy. Effective use of new information resources for management, health policy development and research will empower the public and strengthen health care services. This synergy will help realize our vision.

1. Empowering the Public

The national health infostructure should empower members of the public to make informed choices about their own health and about health policy. For this strategic goal to be achievable, three conditions must be met:

First, the national health infostructure must provide Canadians with credible information that will be trusted and useful to them as health consumers and as citizens. Consumer health information is essential to primary health care and integral to a publicly funded health care system. The source of the information should be clear, as should the distinction between credible information and advertising. Responsible report cards on health programs and services should be available. This will allow people to make informed decisions about their own health and health care. For citizens to have input on health policy, they

must have access to solid data and analysis as used by health policy makers. The content of consumer and policy information should be relevant, timely, credible and usable by the average Canadian.

Second, the national health infostructure should ensure equitable access to health information and opportunities for influencing the development of health policy. It is paramount that there be equitable access throughout Canadian society to the health infostructure. Policies to encourage access should take into account factors such as geographic location, cognitive ability, language, cultural origin, educational background, income, social differences, technophobia, and traditional and digital literacy, not to mention the stress many patients and caregivers face in simply seeking information and support. Policies to encourage access must focus not just on delivery technologies but on the format, level of difficulty, language and ethnocultural assumptions that will determine the usefulness and acceptability of information for different groups.

Third, the national health infostructure should offer opportunities for community accountability, participation and input. Surveys indicate that Canadians want to be involved in policy decisions shaping the future of the health care system. We are all consumers, and the infostructure, by providing solid data and analysis on

health policy, will facilitate our involvement. For example, the Internet can animate communities, independent of distance and at very low cost – that is, allow people to exchange information electronically, formulate common positions and take collective action on health issues, whether at the local, provincial and territorial, national or international level. In this way, the public should be able to provide effective input to policy makers and hold them accountable for their decisions.

2. Strengthening and Integrating Health Care Services

In addition to strengthening health care by encouraging a more informed and involved public, the national health infostructure *directly* contributes to enhancements in health care services. Its essential building blocks, the provincial and territorial infostructures, will have a sweeping impact, laying the basis for integration and coordination of health care services. Further improvements will occur as the infostructure takes on a national dimension.

First, the national health infostructure should improve the quality, accessibility and efficiency of health care services within provincial and territorial boundaries. Information and communications systems in the health infostructure should link the diverse services in today's complex health

system into an integrated whole and ensure that they operate in a fully coordinated fashion. Only in this way can the geographically separated sites of merged hospitals or the new institutes, community-based facilities and homecare providers ensure that their varied programs and services work efficiently together in the interests of patients.

New communications technologies should allow the health care system to deliver better-quality services electronically to hitherto underserved rural and remote areas and help local providers to deliver better care. Telehealth should enable remote areas to benefit from expertise and skill in urban centres, resulting in significant improvements in the quality and accessibility of health care services across Canada. Special applications such as tele-homecare should extend health care into the home, responding to the growing demand for community-based care as the population ages.

Significant efficiency gains should result from care providers having ready but confidential access to electronic health records, which by showing test and case histories should sharply reduce redundant lab tests and procedures. Clinical decision-support systems, continually updated with the best available evidence from health researchers, should markedly improve the quality of decisions made by physicians and health care providers. The health infostructure should also deliver to health care providers, independent of

location, new training and upgrading tools, permitting them to maintain competence – now a full-time job in an era of rapidly changing medical and health knowledge.

Second, the national health infostructure should enable interprovincial health care applications and services. More specifically it should allow health professionals to look for training and upgrading tools beyond the boundaries of a single province or territory or even Canada, in search of the best in the world. Interprovincial exchanges of health information through the infostructure should eventually improve portability of health care services. For example, travellers to other provinces should be able to authorize instant but confidential access to their electronic health records in case of illness or accident. The infostructure should also in due time facilitate provincial collaboration in providing telehealth services, allowing aggregation of demand and savings on telecommunications costs. However, in Council's view, interprovincial access to personal health information is not an urgent priority at this time.

3. Creating the Information Resources for Accountability and Continuous Feedback

The national health infostructure should enable creation of strategic information resources, addressing everything from costs of health services and medical interventions to their impacts on health, or the influence of non-medical determinants of health. These new information resources should be the foundation for a new accountability throughout the health sector. By providing continuous feedback on the health impacts of medical interventions, health programs and services, this information should provide the basis for continuous improvement in the quality of health care. Such new information resources – some linked, some unlinked and surrounded by safeguards in order to protect personal health information – should be designed with a clear customer focus to serve, in addition to the public and health care providers, health researchers, health managers and health policy makers.

First, a national health infostructure should encourage new understandings of health determinants and the long-term impacts of health care interventions. We have substantial gaps in our understanding of the factors affecting individuals' health over the medium to long term. For example, what is the longer-term effectiveness of sometimes competing procedures or interventions –

such as, say, coronary bypass surgery and balloon angioplasty? What are the special health risks of different occupations? What are the long-term effects of many environmental hazards? To what degree, if at all, do people with low incomes or educational levels benefit from “equal access” provisions in the *Canada Health Act*? These and other determinants of Canadians’ health (including, but not limited to, performance of the health care system) can be studied only through large samples of persons whose socio-economic and health histories are followed over an extended period. Stringent safeguards for privacy are central to such an undertaking.

Second, the national health infostructure should improve management and cost-effectiveness within the health sector. At present, Canada lacks breakdowns of the costs of specific health interventions, comparable across provinces and different kinds of health care providers. Nor do we have a clear sense of the costs or effectiveness of services outside hospitals and doctors’ offices – in clinics, long-term care facilities, laboratories and homecare. The health infostructure should allow managers, without their having access to personally identifiable health information, to achieve a much more detailed and comprehensive picture of costs and to ensure better coordination and even integration of services across the spectrum of care. The infostructure

should create unprecedented opportunity for health managers to track not just expenditures and claims, but the kinds of health care decisions leading to unnecessary costs – such as redundant laboratory tests or costly interventions when a less expensive but equally effective alternative exists.

Third, the national health infostructure should contribute to the sustainability of our publicly funded health care system by facilitating better health policy formulation and analysis. Health policy makers now lack sufficient access to solid empirical information on the costs of different policy scenarios or their potential impacts on the health of large populations. A national health infostructure should enable the creation and analysis of knowledge on costs and health impacts of existing policies, as well as the projected implications of alternate policy approaches. This empirical feedback on policy should allow more effective decisions and should be available to the public as a basis for accountability.

THE NEED FOR NATIONAL COOPERATION

Canada's expenditures on information technology in the health field are expected to rise from less than \$1 billion a year in 1996 to more than \$1.5 billion by the year 2000⁴. European countries, Japan and the United States are also investing heavily in information and communications technology applications for the health sector. The competitive nature of the U.S. health sector may well make it more difficult to achieve a national health infostructure. According to the prestigious American Diebold Institute for Public Policy Studies, single-payer, publicly funded health care systems, such as those in Canada, may have a strategic advantage in implementing national health infostructures⁵.

It is important to remember that Canada has not one, but 12, interlinked single-payer, publicly funded health insurance systems. They are not in competition with each other, but many ambitious efforts (described in Annex B) to develop province-wide health

information systems – the necessary building blocks for any national infostructure – have occurred without sufficient consideration of how these will ultimately fit together into a national system more than the sum of its parts. A national strategy is needed to shape these developments, but one fully reflecting provincial and territorial needs and concerns. It must also support the requirements of First Nations and Inuit communities to whom the federal government is devolving ever greater responsibility for health care delivery.

The federal government, in addition to responsibilities for health promotion and disease prevention, has a role in facilitating cooperation among the provinces and territories on matters of national importance. Disparities between provinces and territories in the resources they can dedicate to building a health infostructure reinforce the importance of this federal role. Aboriginal communities face even greater resource constraints within a context of pressing health needs.

Council believes strongly the federal government must show leadership by encouraging mutual cooperation and collaboration among provincial and territorial governments, Aboriginal communities, and all stakeholders in developing and implementing our national health infostructure. Otherwise, an important opportunity will be lost to empower Canadians on health matters, to strengthen and integrate Canada's health

⁴ A.C. Nielsen and IDC Canada. Cited in Patrick Brethour, "Hospital cures computer ailment," *The Globe and Mail*, July 29, 1998.

⁵ The Diebold Institute for Public Policy Studies, Inc., *Health Care Infostructures*, Westport: Praeger, 1995, pp. 35, 43.

care services, and to improve substantially management, policy making and research in the health sector.

Fortunately, the first significant steps have already been taken. Federal, provincial and territorial Chief Information Officers for health ministries are already meeting on a regular basis to discuss cooperative

approaches to health infostructure issues. As well, the Canadian Institute for Health Information (CIHI), an independent, non-profit organization, has brought together more than 350 leading health and health information technology experts from the public and private sectors across Canada to develop cooperation and standards for the national health infostructure.

3. CHALLENGES TO PROGRESS

The challenges to be overcome in developing a health infostructure vary considerably, depending upon whether one's goal is to empower the public, strengthen and integrate health care services, or create information resources for accountability and continuous feedback on factors affecting the health of Canadians.

CHALLENGES TO EMPOWERING THE PUBLIC

Three conditions must be met before the health infostructure can empower people to make effective decisions about their own health and health policy. The right kinds of consumer information must be developed. People must have access to it. Meaningful opportunities must exist to provide input to health policy and to hold the health system accountable.

Information for the Health Consumer

Canadians' attitudes toward their health system have shifted profoundly. Consumers now want to take control of their own health, not leave it in the hands of trusted professionals. Many want to understand the treatment options they face and choose the alternative they believe fits their needs.

Information for the health consumer could thus include where to go for

treatment or diagnosis in a particular locality, data on drug side effects and interactions, assessments of treatment options, report cards on health programs and services – in short, whatever might help laypersons facing decisions about their own health. The quality of such information will be higher to the degree that research can be done to create the strategic information resources for continuous feedback on factors affecting health care and the health of Canadians.

Health Canada's Canadian Health Network represents a significant step forward. It provides people with a single window – including a multilayered Web site – on timely and credible consumer health information. The goal is to create an integrated health information service managed and sustained by many partners, including provinces and territories.

In developing consumer health information, it is important to recognize that the people needing it are diverse, with differing cultures and languages, levels of educational attainment, health concerns, disability levels and cognitive abilities. Many will be patients and caregivers experiencing stress and fear. To say information and its delivery must be user friendly is only to scratch the surface. The information must be developed with the needs of these diverse groupings in mind.

In many cases, simple public access to a range of consumer health information databases, however perfectly indexed, will be insufficient. Non-profit organizations with genuine expertise and responsiveness to particular needs are a major source of health information to many. Others may need some means of personal contact with knowledgeable, sensitive people who can provide reassurance and answers to questions. In Canada, Quebec's *Info-Santé* represents an ideal example of such a service. It is now moving onto the Internet and discussions are under way to make similar services available in other provinces.

Should consumer health information also focus on the effectiveness of particular health programs and services? Such "report cards" would have to be scrupulously fair and, for example, not penalize providers with a different case mix. Such information would be essential for peer review and improvements in the quality of professional care.

Another issue is the public's ability to recognize the credibility of available health information. The health infostructure should provide a means to distinguish credible information from that based on misinformation or a desire to promote a product. Who should make these distinctions? Government?

Non-governmental organizations? The private sector? Should certain kinds of information be forbidden altogether on, say, the Internet – the likely vehicle for reaching the public with health information? Given the global nature of the Internet, such regulation would be unenforceable.

Should government or some other third party validate the information made available to the public? Or would it be more feasible to focus on pointing to "credible" sources of information? In February 1998, the National Conference on Health Info-Structure in Edmonton saw a need for national leadership by Health Canada in proactively providing guidance to consumers on quality, recommended sites for health information.

Health information is not static and there are few final answers. What is "credible" today may not be appropriate tomorrow. Even so-called scientific information evolves or can be shaped by values and biases.

The issue of validating the "credibility" of consumer health information or sources of information can have important ethical and legal implications. Who is responsible if someone acts on bad advice? How should these moral and liability issues be resolved? Laws already exist for published health information that might be relevant in such cases.

The opportunity to inform and empower health consumers through the national health infostructure is so great that the resolution of these issues is urgent. However, these are also not the kinds of issues government can solve alone. Public interest groups and key stakeholders should take part in the search for solutions.

The Access Challenge

The national health infostructure should ensure equitable access to health information. Rapid advances in communications technology over the last 30 years, combined with the rising power and flexibility of computers, promise a rising capacity to transcend traditional barriers of distance and geography, and provide all Canadians with better health information and opportunities to participate in health policy formulation and implementation. The Internet is rapidly entering Canadian homes and provides a unique tool for information exchange and the animation of communities of interest across the country.

Such technological progress does not eliminate the need for deliberate policies to ensure that the public has affordable and equitable access to health information and opportunities for participation in health policy debates.

Such policies must recognize that the access issue involves much more than

technology. Although the speed, reach and cost of a particular technology will always be important, the mode in which information is presented, the language used, the ethnocultural insensitivity and assumptions underlying it can all present unscalable barriers to use by many Canadians. Equity demands the removal of such barriers.

Access policies will also have to acknowledge the importance of user friendliness in technology and the public's need for instruction in its use. For reasons of equity, such policies must take into account the different needs of women and the particular challenges facing people with disabilities or too low an income to have Internet access. Others lack basic literacy or speak a language other than English or French. The Internet itself also has much less French-language information on health and other subjects.

In removing technological obstacles to access, much has already been accomplished as a result of the federal government's connectedness agenda. The SchoolNet and Community Access Programs (CAP) represent a recognition by federal, provincial and territorial governments, communities and their private sector partners that access is a serious policy concern. These programs are now connecting all of Canada's schools and libraries to the Internet. In the year 2001, CAP will have created 10,000 public access sites in rural/remote

communities and urban neighbourhoods. First Nations SchoolNet is bringing the Internet to First Nations schools on reserves. These local sites already serve as places where community members can receive health information.

However, it is vital to recognize that not every Canadian will be able to go to a public access site or use the Internet to seek out health information or electronic communities on health policy. Multiple modes of accessing health information – including the Internet, but also phones, fax and perhaps direct contact with sensitive, knowledgeable staff – will be critical to ensuring the health infostructure actually does empower the public. The Canadian Health Network already provides such multiple modes of access.

To reach rural and remote communities and help extend the health infostructure across the country, the securing of communications satellite capacity for health applications may be necessary. Since a satellite footprint covers the entire country, it may be possible to aggregate demand for such satellite channels across Canada's entire health system, thereby reducing costs for participating health institutions.

The Input and Accountability Challenge

In a climate of fiscal restraint and media stories about crises in Medicare, Canadians have begun to demand greater involvement in health policy decision making and the information that will allow them to hold the health care system accountable.

The Internet is now animating communities of interest, independent of distance and at very low cost – by allowing people to exchange information electronically, develop common positions and take collective action on issues, whether at the local, provincial/territorial, national or international level. This process allows the public to provide effective input to policy makers and hold them accountable. Exploiting the infostructure to generate policy research data and improve their availability should also help ensure more informed public input on health policy.

However, the groups representing the public are voluntary organizations wholly dependent on volunteers' time, energy and financial resources. In the present economy, such groups may require funding if they are to be effective in involving the public in health policy debates.

The public is also far from homogeneous. The needs and priorities of Aboriginal communities, for example, differ significantly from those of other Canadians. People with disabilities, seniors, women – to mention only a few – will each have a unique view on the shaping of health policy, a national health infostructure and the information it carries.

In Council's view, it is necessary to establish ongoing mechanisms to carry out policy research and to formulate health policy options. Participants in the Edmonton conference saw a similar need.

As a result of a recommendation by the National Forum on Health, an independent National Population Health Institute (now the Canadian Population Health Initiative) is already coming into existence to do research and analysis as a basis for reports to the public on national health status and the performance of the health system.

Council is exploring options for a mechanism to undertake evidence-based policy formulation and ensure continuing input from and collaboration with the general public. One possibility would be annual conferences on health policy, with wide participation by groups representing the public and key stakeholders. Another would be to

establish a national, collaborative body to undertake policy formulation, facilitate public consultation and manage other activities to support better, more accessible health information.

We welcome your comments on the form such mechanisms for policy research and evidence-based policy formulation might take.

CHALLENGES TO STRENGTHENING AND INTEGRATING HEALTH CARE SERVICES

The national health infostructure promises to lay the basis for integration and coordination across the entire spectrum of health care services in the patient's interests. Achieving this objective will significantly improve the quality, accessibility and efficiency of health care. Applications such as telehealth, tele-homecare, electronic health records, national and international disease surveillance systems, decision support systems, and training and upgrading tools can make a similar contribution. The challenges to be faced in realizing this promise differ, depending upon whether one is attempting to move forward within a single province or territory or to enable interprovincial applications.

Challenges at the Provincial and Territorial Level

Developing health information systems, telehealth, telemedicine, tele-homecare, electronic health records, various kinds of decision support, and training or upgrading tools for health care professionals within a single province or territory faces a number of challenges. These relate to funding, the adoption of these applications by health care professionals, organizational and ethical issues, privacy and standards. The privacy concerns and standards issues will be discussed in the next chapter⁶.

Implementation of these new systems will be expensive, although they will result in savings through increased efficiency and effectiveness. These gains will be particularly impressive from the health information systems used to help coordinate and integrate health care services so that patients can move seamlessly between services. Telehealth will mean reduced spending to transport people from rural and remote areas for diagnosis or treatment. Several telehealth projects have already received positive evaluations in Canada.

Insofar as electronic health records, decision support systems or electronic training and upgrading tools are concerned, it is important to note that very few physicians and health care

professionals now use them. Some are suspicious of the technology. Most will require training in how to use it. In addition, the greater the range of health care professionals involved in selection and design of such systems, the more likely they will be useful and user friendly and that people will actually use them. A similar rule applies to telehealth, telemedicine, tele-homecare and any health information system.

It is important to recognize that living, breathing human networks allow infostructures or communications networks to succeed. The introduction of these infostructure applications – especially health information systems to support the integration of services – will likely lead to a shift in the balance of responsibilities among health care professionals and between them, patients and the general public. A similar realignment may occur among health institutions such as hospitals, community health institutions and long-term care facilities, as well as between them and the home. These changes will be welcomed by some and resisted by others. Goodwill across institutional and professional boundaries will be vital to ensuring that these new systems make their contribution to the strengthening of health care services. While many of these issues will be successfully tackled by professional bodies and institutions, addressing some may require an ongoing process.

Challenges to Interprovincial

⁶ See pages 27 to 39.

Applications

Interjurisdictional exchanges of personal health information under conditions of confidentiality can improve the portability of health care services and facilitate interprovincial cooperation in the provision of telehealth services to rural and remote areas. The standards to support such exchanges and the privacy and security safeguards which should be in place are discussed in the next chapter⁷.

Other challenges will arise from differences among jurisdictions in legislation, regulations and professional requirements – to mention only a few examples – governing delivery of health care. A strategy for telehealth will have to address these issues, particularly the need for cross-border licensing of professionals. As well, when services are provided across jurisdictional boundaries, how will service providers be reimbursed? If something goes wrong, who will be accountable? The solution seems to lie in a harmonization of provisions in these areas, a trend already apparent in some jurisdictions.

Language may pose a practical obstacle to telehealth across provincial and territorial borders and sometimes

within a particular province. For example, a French-language patient from Quebec or New Brunswick might encounter difficulties if the English-language practitioner providing treatment did not have access to a person or service with a strong capacity to translate a French-language health record into English.

New communications technologies are becoming available as possible platforms for advanced telehealth applications, such as those requiring high-resolution images. For instance, CA*net 3, a very high bandwidth optical network operated by CANARIE (the Canadian Network for the Advancement of Research, Industry and Education) which is intended to support broadband applications development with a special focus on new health applications.

CHALLENGES TO CREATING INFORMATION RESOURCES

A national health infostructure will allow the creation of many different kinds of strategic information resources for accountability and continuous feedback on factors affecting the health of Canadians. The first challenge to meet in creating such resources is that of determining who needs what information. The second is to build such strategic resources.

⁷ The most challenging of these relate to privacy protection and standards. These are discussed below on pages 27 to 33 and 33 to 39, respectively.

Determining Information Needs

What kinds of health information needs do health managers, policy makers, researchers, providers of care, consumers and the general public have? The National Forum on Health has looked at this question, as has the Canadian Health Network and several provinces.

Council, the Canadian Institute for Health Information (CIHI) and Statistics Canada reported in *Health Information Needs in Canada* on a national consultation held early this year involving 500 participants representing six key health system groups in all provinces and territories, including consumers. People from national non-governmental organizations and Health Canada took part in special sessions.⁸ As priorities, participants identified:

- ◆ “the need for an integrated health information system”
- ◆ “regional and community information”
- ◆ “cost data”
- ◆ “evaluation information on alternative interventions and technologies”

⁸ See *Health Information Needs in Canada* (Ottawa: Canadian Institute for Health Information, 1998).

- ◆ “performance information, including comparative data and benchmark indicators”
- ◆ “health indicators and trend information”
- ◆ “consumer expectations”

The consultation represented an important step in determining health information needs. We are pleased to learn that CIHI, Statistics Canada and Health Canada are jointly developing a specific follow-up plan for presentation to federal, provincial and territorial Deputy Ministers of Health and to this Advisory Council.

Further work to define health information needs more precisely should also be carried out. To this end, we invite you to tell us what your health information needs are.

Building Strategic Information Resources

The raw data for the research to produce strategic information resources constitute longitudinal, patient-specific information held in provincial and territorial health administration systems. The data should be organized around persons rather than incidents, as is not always the case now.

Only longitudinal data – that is, data tracked over a number of years – can reveal the long-term effects of interventions, other health determinants,

environmental hazards, and so on, on people's health. However, access by health researchers to such information would be subject to strict privacy and security safeguards which are discussed more fully in the next chapter.⁹

For a national picture to emerge on outcomes or costs of a particular intervention or the impact of a particular health determinant, a common core of information will have to be collected and interpreted on interventions reported in provincial health administration systems. In developing such systems, provinces and territories will need to use compatible coding standards, including the same nomenclature for both diagnoses and interventions.

For sound research results, the raw data – for instance, on outcomes from a type of intervention or a change in the configuration of health care services – have to be correlated with other available information. This might include, for example, data on death registrations or perhaps the results of a survey in which people assessed their own health.

Finally, once all personal identifiers have

been expunged, these data will have to be analysed and shaped for use by health policy makers, managers, care providers and researchers. It is in this anonymized form that most of the work will be carried out on the data to make it useful within the health-care system and to the public. The availability of these anonymized data for analysis is a crucial precondition for the creation of strategic information resources.

Thus, in order to develop these strategic information resources, it would seem Canada will have to develop a strong national capability for creating person-based (as opposed to incident-based) Medicare files as a necessary basis for analysis of the health impacts of medical interventions and other health determinants. To fill out the picture, we may have to develop and integrate with Medicare files other outcome measures, such as death registrations and periodic survey data on people's assessment of their own health. Finally, if anyone is to benefit, the information so created must be properly exploited through research and analysis carried out by a wide range of qualified researchers in the context of stringent safeguards for privacy.

⁹ More specifically, see pages 27 to 33.

4. STRATEGIC ISSUES

The development and implementation of a national health infostructure raises a number of strategic issues. The largest of these is privacy, which is a concern of every Canadian and remains at the heart of the Council's ongoing work. Another is the need to determine what standards will be needed to make a health infostructure work effectively. A third involves ensuring that a health infostructure serves Canada's Aboriginal peoples. Collaboration between public and private sectors in infostructure development will be necessary, but it too raises concerns. Finally, there exists a need to invest in the infostructure.

In a few areas, including privacy protection, Council believes the need for action is so urgent that it has made interim recommendations. However, we have not exhausted either these or other subjects and accordingly invite your input.

PRIVACY – AN OVER-ARCHING CONCERN

In survey after survey, Canadians have expressed concern about losing their privacy in the new electronic environment and, more specifically, their control over personal information. Of such information, few categories are more sensitive than personal health information. Council in its own consultations found much anxiety about

this issue among stakeholders in the health sector and representatives of the general public.

Privacy is often defined as the right to be free from intrusion or interruption and is linked with other fundamental human rights such as freedom and personal autonomy. In relation to information, privacy involves the right of individuals to determine when, how and to what extent they share information about themselves with others. Privacy also can be a concern for groups such as Aboriginal and immigrant communities worrying that research on their members is released to the media without notice and used to stigmatize them.

Safeguarding privacy includes protecting information about oneself – that is, any information that can be linked to an identifiable individual or group. Protection of personal information requires adherence to fair information practices in managing such information.

Confidentiality refers to the obligations on one person to preserve the secrecy of another's personal information. Security refers to the procedures and systems used to restrict access and maintain the integrity of that information.

Privacy, while a fundamental value and right, is not generally regarded as an absolute right in law and in Canadian society. For example, in criminal cases or

in matters affecting public health, there are justifiable circumstances in which privacy must be weighed against other public goods. Such balancing should never involve considering the sacrifice of personal privacy on a broad scale, even to achieve some presumably overwhelming public benefit. Rather, the consideration *might* relate to a *degree* of privacy intrusion with specific restrictions and safeguards, *if* the resulting public benefit is likely to be truly pervasive.

Privacy and the Three Functions of a Health Infostructure

We recognize that, just as different functions of the health infostructure involve use of different kinds of information by different people for different purposes, so too do the practical implications of privacy protection vary depending on function. In alignment with our strategic framework, the three functions of the infostructure are to empower the public, strengthen and integrate health care services, and create the information resources for accountability and continuous feedback on factors affecting the health of Canadians.

In serving the first function, that of empowering the public, the infostructure should permit release to the public of consumer health information and policy data, but not personal health information. In other

words, the information disseminated to the public raises no privacy issue itself. Such an issue might arise if, for example, the operator of a health information Web site – say, an AIDS information site – started identifying the people who visited it electronically and distributing or selling this information to others. As well, if privacy means control of information about oneself, then it follows that individuals should have access to their own health records. Council intends to examine such questions in depth in its final report.

In the case of the second function, that of strengthening and integrating health care services, its performance involves distribution of a patient's personal health information – often electronic health records – among physicians and health care providers involved in caring for that patient. Clearly, privacy is at issue here, as it always has been. Now as in the past and even the electronic future, patients consent to a release of their personal health information to those providing care, with the explicit understanding that its confidentiality will be preserved and respected. While there may have been exceptions, this trust is for the most part not abused in the paper-based world, although hard copies of personal health information and medical records may be circulated among health care providers as the patient's needs dictate. Within a health infostructure, this information will move electronically, raising concerns about inappropriate access. In fact, as shall be seen below, within the context of

effective privacy and data protection legislation and regulation, electronic security systems and good security practices promise to make personal health information safer in this electronic world than in the traditional paper-based world where these rights, obligations and procedures have not always been explicit or well enforced. *Technology can also be used to certify the identity of a person giving consent to the release of personal health information, as well as authenticating the validity of that consent. In Council's view, such measures should be mandatory.* Indeed, this same technology may be used to provide individuals with better control over their own health information, as well as to ensure that different health care providers receive only the portion of the health record relevant to their specialization and responsibility.

Privacy concerns are most evident in relation to the third function of a health infostructure, that of creating information resources for accountability and continuous feedback on factors affecting the health of Canadians. The ultimate source of such data is longitudinal patient-based information in provincial health administration systems. In many cases, it will be impractical to secure consent from patients for particular research projects, essentially because the nature of the project will not be known at the time of data collection. However, it might be

desirable at that time to give notice about possible research use of the data, either in anonymous form or following review by an independent ethical panel.

While we recognize privacy is a relative and not an absolute value, we believe we must start with the very strong bias that personal health information (that is, control over one's personal information) should be protected from secondary use. We further believe that the burden of proof should be on anyone proposing use of such information without consent to demonstrate that: (a) a tangible public good of significant benefit will result, (b) consent is impossible to secure, (c) anonymous data will not serve the same purpose, and (d) no harm can occur to any person directly as a result of this use of his or her personal information.

We do not accept that there must be a blanket prohibition, on the basis of privacy, against research intended to create the information resources to support accountability and continuous feedback on factors affecting the health of Canadians. Rather, we believe such questions should be considered on a case-by-case basis in accordance with sound legislation, thoughtful judgement and common sense.

Thus, we are inclined to believe that a transparent and explicit process should be put in place to weigh on a case-by-case basis and according to recognized criteria, whether or not the public good

resulting from a proposed research project is of sufficient importance and value to justify the proposed use of personal health information without consent. If justifiable, then the researchers should be placed under binding obligations – for example, requirements for confidentiality and the destruction of personal identifiers after a specific period of time, to mention only a few – to ensure that no harm befalls any person as a result of this use of his or her personal information. We as a Council would appreciate your views on this position.

The benefits derived from such research results, once all personal identifiers have been expunged, would include:

- ◆ the general public is able to hold the health system accountable and make more informed choices about its health;
- ◆ health care providers are supported in making clinical decisions and maintaining competence;
- ◆ health managers have improved management tools and can contain costs; and
- ◆ health policy makers can sustain and improve the health system because they have access to continuous feedback on the factors affecting the health of Canadians.

The anonymous data used to create information resources for these purposes would be linked to identifiers, but not those corresponding to any real individual. In Council's view, it will not be enough to assume all identifiers of real people have been expunged before data is made available. *A formal, transparent and explicit process should be put in place to review whether unidentified data are truly anonymous and free from any information that might lead to identification of an individual.*

Security Systems and Procedures

In terms of security systems and procedures to protect personal health information, the electronic world of the health infostructure may well prove safer than the paper-based world of the past.

Encryption involves the coding of data for privacy protection or security considerations so that only authorized persons can have access to it through the use of codes or card entry. Encryption is also used in telecommunications to ensure that only the person to whom a message is sent can read it.

Security practices have now advanced to where one can prevent access entirely to electronic information systems or allow different people different levels of access to the same information at different times. The explicitness, versatility and automatic nature of such security systems have obvious applications in a

health infostructure, where different health care providers may require different levels of access to the same personal information and a researcher may require only very limited access to a number of patient files. Such precise discrimination can be programmed into an electronic security system.

Health Canada is a full participant in the federal government's efforts to develop a public key infrastructure for its operations by early 1999. The new system will contain an encryption component to address privacy and access control, and allow digital signatures.

Plans are now being made to employ new privacy-enhancing technology (PET) using encryption techniques in large networks. These technologies, developed in the late 1980s and early 1990s, would be capable of generating several pseudo ID numbers for the same individual. An individual would not have one integrated health file, but several different data sets with different ID numbers scattered randomly across a

database. Certain data sets, completely unlinked to the real individual, could be made available for purposes of health management, public health or research.

However useful privacy enhancement, encryption and electronic security systems may theoretically be in protecting personal health information, they will not do their job if the people responsible for preserving the confidentiality of the information do not follow fair information practices. These in turn must be supported by responsible security procedures and practices, including the need to audit all accesses to personal health information. Council cannot overemphasize the need for all organizations with access to personal health information to implement such practices and procedures.

But security systems and procedures, however effective, will not be sufficient without privacy protection legislation that specifically addresses personal health information.

Legislation and a Harmonized Approach

Every Canadian jurisdiction should have a strong and effective legislative framework for privacy that specifically addresses personal health information. We also recognize that provincial and territorial governments, because of their responsibility for delivery of health care to most Canadians, have the primary responsibility for protecting personal health information within their jurisdictions. At present, significant variations exist in provincial and territorial laws, regulations and guidelines for privacy and the protection of personal health information in the public sector. Three provinces have recently introduced or passed new legislation intended to protect personal health information. Concern for compatible approaches is not always apparent in these endeavours.

In Council's view, a real danger exists that Canada could end up with many different approaches to privacy. Diversity could render difficult, if not impossible, improvements in the portability of services or the creation of information resources needed for accountability and continuous feedback on factors affecting the health of Canadians. In some cases, any exchange of information might be prohibited by law – unless the recipient jurisdiction is able to show that its regime provides protection as effective as that of a potential sender of information. In

Council's view, refusal to share information in such circumstances would be entirely defensible, though it is to be hoped that the circumstances justifying such a refusal can be avoided in Canada.

For this reason, Council cannot emphasize too strongly the importance and urgency of federal, provincial and territorial governments working together to harmonize their approaches to the protection of personal health information. However, since some provinces and territories have advanced further than others, this harmonization should not occur around the lowest common denominator for protection. We believe that all Canadian jurisdictions should have strong, effective and enforceable legislation specifically designed to protect personal health information.

Recommendation 1

All federal, provincial and territorial governments in Canada should ensure legislation is in place addressing privacy protection and specifically aimed at protecting personal health information through explicit and transparent mechanisms.

In our final report, we shall be looking at the approaches and provisions that would have to be incorporated into such legislative frameworks. These would also form part of any accord among federal,

provincial and territorial governments to harmonize their approaches to privacy and protection of personal health information. Movement toward such an accord is vital if interprovincial applications of the technology are to be achieved.

Recommendation 2

The Minister of Health should take the lead in encouraging an accord among provincial, territorial and federal governments to harmonize, taking into account best practices internationally, the approaches in their respective jurisdictions to privacy and the protection of personal health information around the need to:

- (a) certify, in the case of consent for the release of personal health information, the conditions of consent and the identity of the person giving the consent, in addition to authenticating the consent itself;**
- (b) review, in the case of anonymous data, whether the data are indeed anonymous (“non-nominative”) and cannot be linked back to any individual; and**

- (c) have ethical review panels established to weigh, in the case of uses of personal health information for research purposes where securing consent is impractical, the value of privacy against the significance of the public good that might be achieved by the research.**

Council recognizes the strategic importance and complexity of the privacy issue and the need to engage the public in its resolution. *We believe extensive consultations should be held in the context of this effort by federal, provincial and territorial governments to harmonize their approaches to privacy and protection of personal health information.*

STANDARDS

Standards are documented agreements containing technical specifications or other criteria to be used consistently as rules, guidelines or definitions of characteristics to ensure that materials, products, processes and services are fit for their purpose. The compatibility of standards within and across provincial and territorial boundaries will be critical to many of the functions performed by a national health infostructure.

In creating strategic information resources, for example, compatible

standards for data will be critical to ensuring the collection of useful data. As seen above, standards for minimum data sets are needed so that provincial and territorial health administration systems collect a common core of data as a basis for research on outcomes and health determinants. Similarly, compatible coding standards – say, for the nomenclature used to describe diagnoses and interventions – are vital to the integrity of such data; without them, users of the system will be unsure whether the record contains – to use a prosaic analogy – apples or oranges¹⁰. A range of technical standards and information exchange protocols will be needed to allow health managers, policy makers, researchers and care providers to communicate with databases and with each other.

Technical standards will be equally important to ensuring that the infostructure contributes to the strengthening and integration of health care services. For effective use of an electronic health record in medical consultations, for example, each physician's hardware and software will have to be compatible so each can read the record. In addition, "one of the biggest barriers to widespread

acceptance (of telemedicine) is the nonconformance of existing standards in clinical networks. Clinical networking can be defined by the integration of telemedicine, patient records and personal access communications systems (PACS)/radiology information systems." Telemedicine "must avoid being implemented as an island solution. It must be integrated with clinical networks¹¹."

At the same time, it is important to emphasize that standards in the health care area will not just be for hardware. Data and clinical standards will be critical to optimizing the usefulness of the electronic health record and ensuring that entries are not misunderstood. In telehealth, clinical standards – that is, what is appropriate from a purely clinical viewpoint – will be vital to determining, for example, what kinds of procedures should be used, given a certain level of technological capability.

Need for a National Standards Capability

Standards emerge in many ways. Sometimes, governments make standards mandatory when the public interest is at stake – for example, when health or safety or personal privacy is at issue.

¹⁰ Since coding standards would also be used in electronic health records as a basis for health care, the consequences of misunderstanding could be serious. Clarity and compatibility are crucial.

¹¹ Jeff M. Vachon, "Connectivity standards are emerging for telemedicine systems," *Canadian Healthcare Technology* (July 1998), p. 18.

Market forces can create a *de facto* standard when some product – such as, for example, *Microsoft Windows*TM – achieves dominance. Other standards arise through consensus building by standards development organizations or other kinds of associations. The process can be slow, labour intensive and time consuming.

The importance of standards in health information and telematics has been acknowledged repeatedly at the international level. The International Standards Organization (ISO) established this year a technical committee to look at standards in this area. Many developed countries, including the United States, have created formal standards development organizations¹² focussing specifically on health informatics and telematics and with a mandate to participate in ISO deliberations.

In Canada, governments, professional associations, hospitals and community health organizations have been building health information systems of various kinds within their respective jurisdictions for some time. Until recently, ensuring that these systems are at least minimally compatible has

received insufficient attention. Despite significant progress, Canada has a long way to go in developing compatible standards. For this reason, Council believes there is a real need in Canada for a strong, national capability to manage cooperatively the development and adoption of compatible standards in the areas of health information and telematics.

Recommendation 3

Canada should develop a strong, national capability for cooperatively managing the development and adoption of compatible standards in the areas of health information and telematics, with strong links to international standards deliberations.

Personal Identifier Systems

It is through the prism of privacy concerns that Council views the efforts of a number of jurisdictions in Canada to introduce or improve systems of unique personal identifiers. Such standard identifiers may be used for a number of reasons. In health care, duplicate identifiers for the same individual, or many individuals with the same identifier, can lead to misidentification of health records, rendering them useless and perhaps hazardous to health and life. It is for this reason, as well as financial and administrative ones, that all provincial

¹² Standards development organizations are organizations mandated by a country to develop national standards and participate in international standard setting on its behalf.

and territorial health insurance systems should use unique personal health identifiers for their residents.

Governments also use a number of other unique personal identifier systems, some of the best known being the federal Social Insurance Number and the number on drivers' licences. For reasons of efficiency, jurisdictions have often contemplated and sometimes partly implemented personal identifier systems to cover people's interactions with government across a number of different domains. Council at this time opposes such multipurpose identifier systems, especially if they include the health domain. The linking of data across domains facilitated by such systems has the potential to create serious invasions of privacy and breaches of confidentiality.

Indeed, we believe efforts to improve or combine personal identifier systems even in the health domain alone should proceed only at such time as privacy legislation specifically addressing

personal health information can be passed and effective electronic security systems and security procedures can be implemented in health institutions. As noted earlier, security systems and procedures can provide effective protection for personal health information by ensuring that people only have the level of access sanctioned by legislation and appropriate to their roles and responsibilities. The new privacy-enhancing technologies show particular promise in this respect. Yet only compatibility among the electronic infrastructures for security across provincial and territorial boundaries will ensure the efficient sharing of information in a manner that respects privacy concerns. To ensure that these concerns are fully respected, it is Council's view that provincial, territorial and federal privacy commissioners should be carefully consulted during each stage in the development of an integrated approach.

Recommendation 4

Provincial and territorial governments should advance or combine their personal identifier systems in the health area only at such time as they have:

- (a) put in place a legislative framework for privacy protection specifically designed to address personal health information;**
- (b) implemented privacy-enhancing technologies in their own jurisdictions; and**
- (c) ensured the compatibility of their electronic security infrastructures for health information in consultation with their respective privacy commissioners.**

Joint Priority Setting for Interoperability

Once these measures to safeguard privacy have been taken, it will be time to put in place compatible standards that will ensure interoperability – that is, the capacity of different systems to accept, process and forward each other's messages. It should be emphasized that interoperability does not mean everyone with access to one network has access

to all networks and the information on them. Privacy legislation, privacy-enhancing technologies and security procedures will erect barriers around personal health information that only persons authorized by explicit criteria can cross.

Governments must take primary responsibility for achieving the level of interoperability needed to strengthen and integrate health care services. Provincial and territorial governments are responsible for delivery and administration of health care services in their respective jurisdictions. The federal government plays a national role through the *Canada Health Act* and through its duties as a national facilitator with specific responsibilities for health promotion, disease prevention and health protection. We believe the federal Minister of Health, in fulfilment of this federal role and in the context of appropriate privacy safeguards, should affirm the importance of interoperability to the effectiveness of a national health infrastructure in strengthening and integrating health care services. He should take the lead in gaining the support of provincial and territorial ministers for the achievement of interoperability.

Recommendation 5

The federal Minister of Health should:

- (a) affirm the critical importance of interoperability, in the context of appropriate privacy safeguards, to the contribution of a national health infostructure to strengthening and integrating health care services; and**
- (b) take the lead in gaining the support of provincial and territorial ministers for achievement of the level of interoperability required for this purpose.**

Chief Information Officers and their equivalents in provincial and territorial health ministries are in a position to help ensure that this level of interoperability is attained. Council applauds the establishment of a federal, provincial and territorial Health Chief Information Officers' Forum and the role of Health Canada officials in facilitating it. Among the key issues they identified at their first meeting for future discussion were technical standards and interoperability. Council strongly supports these developments and suggests these meetings be organized on a more formal basis.

One challenge confronting the Chief Information Officers, the CIHI Partnership on Health Informatics and Telematics or anyone working on standards for health information and telematics is the enormous range of standards that have relevance. For the work of these groups to be manageable, it will be necessary to collaborate across Canada in the development of a plan to achieve compatible standards across provincial and territorial jurisdictions. Such strategic guidance and direction should recognize that many national priorities may be achievable only in the long term, while others – such as perhaps the integration of services across the spectrum of available care – should be addressed on a more urgent basis.

Recommendation 6

Health Canada should encourage national collaboration in the formation of a plan for the development of technical and data standards that would permit the eventual evolution of a national health infostructure, keeping in mind that:

- (a) many national priorities may be longer-term elements of the plan; and**

- (b) other national priorities, such as the integration of services across the spectrum of care, should have a shorter time horizon.**

THE ROLE OF ABORIGINAL COMMUNITIES

In Council's view, the national health infostructure should be as helpful to Aboriginal communities as to any other Canadians. It should empower Aboriginal communities on health matters, strengthen and integrate their health care services and create the information resources to support accountability and provide continuous feedback on factors affecting Aboriginal health. We recognize that the ways in which a health infostructure contributes to these objectives and the issues it raises may well be very different for Aboriginal communities.

For example, socio-economic and other factors have tended to put the health of Canada's Aboriginal peoples at far greater risk than that of the general population. At present, the life expectancy of some First Nations communities is 12 years below the Canadian norm. An Aboriginal health infostructure would respond to a legitimate need to highlight Aboriginal health issues and concerns.

Any strategy to implement a health infostructure must respect the special relationship the federal government has always had with Canada's Aboriginal peoples. Such a strategy should also clearly take into account the differences between Aboriginal and other Canadian communities – for instance, by acknowledging the role and effectiveness of traditional medicine in Aboriginal communities.

There are profound differences among Aboriginal communities. First Nations and Inuit communities operate within very different treaty and legislative frameworks, while there is no framework to assist Métis and Non-Status Indians. Many First Nations and Inuit communities are located in remote areas where geography can pose a serious obstacle to delivery of health care services and health information. Many Métis and Non-Status Indians live in the inner city where the obstacles are very different.

The Aboriginal experience with researchers – including health researchers – has led to suspicion and distrust. Frequently, communities do not receive the results until they appear in the media, often in stigmatizing form. As a result, Aboriginal privacy concerns do not merely revolve around individuals, but around the community's desire to ensure that it is not portrayed in a manner prejudicial to its interests. There is a

sense that only participation in research planning and control and ownership of the results can prevent such outcomes.

Despite such concerns, the feeling is growing among Aboriginal communities that knowledge is power and the health infostructure, shaped to meet their needs, could provide important tools for self-determination and for identifying how to get on with the job of providing the best of health programs and services for their members. This sentiment is in keeping with the move toward increasing self-government on the part of First Nations and Inuit communities – and, more specifically, toward taking greater control of health care delivery to their members. Already, 80 percent of First Nations communities are moving toward management of their own health care. This change is the result of joint federal and First Nations’ negotiations to devolve upon those communities the responsibility for health care once assumed by the federal government.

Council is undertaking two studies with the Assembly of First Nations. The first deals with the full range of social, political and operational issues – some of them mentioned above – that provide the necessary context for any strategy to put in place an Aboriginal health infostructure. A key emphasis here will be the need for extensive consultation with Aboriginal stakeholders during design and implementation of the health infostructure. The second focusses

specifically on an Aboriginal health infostructure and will suggest strategic opportunities to Council as a basis for recommending health infostructure solutions that could lead to improved health for Canada’s Aboriginal peoples.

NEED FOR COLLABORATION

A trend is now apparent toward greater involvement by private industry in the provision of health infrastructure – particularly in the development and implementation of information and communications technology and its applications. In a variety of different ways, the federal government and all provincial governments are collaborating with industry in this area. For example, IBM Canada is a participant with the Government of Alberta in Alberta *Wellnet*. In the present environment, it would seem that industry is more likely than the public sector to have the technological expertise to develop and implement the complex information and communications systems required for many purposes in the public sector, including a health infostructure. Council believes there may be a need for more research to grasp fully the implications of this trend.

However, given the differences between public and private sectors, it seems appropriate that guidelines should be put in place to govern such collaborations. For example, they should contribute to a public good in the health area and be

fully consonant with public administration and governance of the health system, as well as the values underlying it. They should not lead, either directly or through some process of functional creep over time, to any diminution in public administration and governance of the health system or the influence of the social values now informing it. Privacy legislation in the area of health should also be fully respected.

A STRATEGIC INFRASTRUCTURE INVESTMENT

At present, the Canadian health care industry lags considerably behind other sectors of the economy and the U.S. health care sector in investment in information systems.

Because the major benefits to be derived from these systems tend to materialize over time, finding investment in the short term is always a challenge for the provincial and territorial systems which will be the essential building blocks for a national health infostructure. Various stakeholders have told us it is impossible to develop a new way of delivering health care services and information by pulling funds out of existing, declining capital and operating health budgets. In our view, this argument makes sense. However, without provincial and territorial health information systems to build on, there will be no Canadian

health infostructure.

Clearly, investment in the Canadian health infostructure or its provincial and territorial foundations is not an investment like any other. The infostructure is a strategic, national infrastructure, and its funding should be regarded as a strategic, national infrastructure investment decision. Developing a Canadian health infostructure is analogous to building a national railroad or highway, but this time for the knowledge society and digital world of the 21st century. While many were dubious about investments in the railroad in the 1870s or in an electric power grid at the turn of the century, few would disagree about the transformative impact of those strategic infrastructure investments now. Here are some examples of health care organizations that view health infostructure funding as strategic infrastructure investments:

- ◆ The *Government of Saskatchewan* is now building a Saskatchewan Health Information Network (SHIN) linking health services across the province, using integrated electronic records and drawing on a range of health databases. In a recent study, Ernst & Young identified a number of strategic benefits. With access to more timely and accurate health information, decision-making capabilities will be improved, resulting in better diagnosis and

care. Efficiencies will arise from reduced duplication of laboratory testing and radiology procedures. Improved tracking of medications will lead to more cost-effective drug prescription. Less time spent in records management will give nurses more time for hands-on care and other patient-related activities. SHIN will lead to improved service for rural residents and less need to travel to receive services. Rural physicians, less isolated because of better access to information, will be able to participate more fully in skills development and knowledge exchange with other health care providers. The greatest benefits will be improved care and increased productivity because of better coordination and integration of health care services to Saskatchewan residents. *Ernst & Young concluded that SHIN, when fully implemented, would benefit the health system to the tune of \$58 to \$114 million a year through higher-quality health service delivery, better use of health care provider time and dollar savings.*

- ◆ The Washington-based Health Care Advisory Board (HCAB) recently examined the experience of *Foundation Health* in moving to a more consumer-oriented information systems approach. *Foundation Health* is a large health plan created by the mergers of no

fewer than 23 previous health plans. The HCAB described the *Foundation* systems effort as “a marriage of demand management and disease management as well as 4th generation medical management.” The *Foundation Health* approach includes a digital front door – a 24-hour support line linked to 47 “timely destinations.” These are grouped into four packages or clusters – self-care, primary care, specialist care and emergency care. An electronic patient record accessible by the on-call nurse fully backs this 24-hour support line. Also on-line are protocols, provider directories and scheduling capability. Services offered include referrals for all medical conditions, centralized scheduling, speciality and urgent care pre-authorization, as well as outbound wellness and follow-up calls.

- ◆ *The Toronto Hospital (TTH)* is a leader in information technology. Its Taking Charge strategy (1995-97) required capital investment of \$20 million, raising information technology (IT) spending to 3.2% of its total budget. According to the hospital, the result was an impressive gain in productivity: “The efficiency of hospital operations at TTH has improved dramatically during the time that Taking Charge was implemented. Cost per weighted

case has dropped by more than 15% since the plan was first approved to a level below the costs predicted by the Ontario government funding formula for hospitals.... Also, despite higher expenditures on information technology initiatives, total overhead costs (which include IT costs) have decreased as a percentage of the total hospital budget over the past two years. Although a cause and effect relationship can not be conclusively demonstrated, IT expenditures prescribed by Taking Charge have been associated with increases in productivity and a decrease in overhead costs.”

These examples show some of the strategic benefits realized through investments in health infostructure. Council believes that additional funding must be provided for a national health infostructure to reap these and many other benefits for all Canadians.

It is difficult to set precise targets for levels of funding. Because of differing definitions for information technology between and within jurisdictions, it is hard to develop solid comparative figures on how much is being spent on information and communications technology in the health sector, either

within Canada or abroad. Such gaps in information are, of course, exactly what a health infostructure might be expected to fill.

Participants at the National Conference on Health Info-Structure in February 1998 stated that only new investment could achieve anything significant. In the Council’s view, Canadian governments must invest enough additional money to:

- ◆ integrate clinical services around electronic patient records;
- ◆ reap the benefits of economies related to automation of functions such as laboratories, prescription, etc.;
- ◆ empower the public by allowing it to participate meaningfully in decisions about its own health and health policy, as well as to hold the health system accountable for quality and performance;
- ◆ invest in the generation of research concerning the major factors affecting the health of Canadians; and
- ◆ develop a strong capacity for setting standards for health information.

If a national health infostructure sufficient to these tasks can be put in place, we would expect to see a significant improvement in the quality of health care and in the health of all Canadians.

Such infostructure investment should target those whose health is more at risk. More should be invested, for example, in infostructure projects in First Nations communities where health risks are higher than the Canadian average.

According to a 1995 report by the McKinsey consultancy, a health infostructure could reduce U.S. health care costs by 25 percent or \$270 billion a year. While we expect considerable cost savings in Canada, too, they will likely not be achieved by downsizing, as in the banking industry. Canada's health sector has already "downsized" during a decade of fiscal constraint. In Council's view, a health infostructure will allow its labour force to work more efficiently and effectively providing quality care to Canadians.

5. THE NEED FOR PUBLIC DEBATE

For a large majority of Canadians, our publicly administered health care system is so fundamental that it is a defining feature of our nationality. We as a Council believe the national health infostructure can strengthen that system enormously, making it more accountable to Canadians and more capable of serving them effectively and efficiently – in short, in the way they have come to expect.

Telehealth and tele-homecare, for example, should strengthen significantly the quality and accessibility of health care in Canada – in rural and remote areas and in the home and community. Health information systems may well represent our best chance to integrate fully and effectively the myriads of health care services characterizing today's complex health system. This infostructure will also give people the information they need to make more informed decisions about their own health and those of others. One result will be better decisions by health professionals, administrators and policy makers. Another will be a new capacity on the part of patients and individual Canadians to take control of their own health and hold the entire health sector to higher standards of accountability.

Challenges exist to the emergence of a national health infostructure, and it does raise important, even strategic, issues. The need for movement is so urgent in some of these areas – particularly privacy and standards – that we have recommended immediate action. However, neither our recommendations nor our preliminary thinking have exhausted these issues, nor given us a complete understanding of the challenges that must be overcome to build the national health infostructure.

We do not have all the answers to these serious and far-ranging questions. We suspect no one does. We do know, however, that the building of a national health infostructure will demand an unprecedented cooperative effort by the federal government, provincial and territorial governments, Aboriginal communities, health care professionals, administrators and policy makers, health institutions in all their variety, the private sector and the general public in all its diversity. We know everyone will have to be involved in the creation of a national health infostructure for the 21st century.

This report is your invitation to join the debate. What is your take on the issues raised here? Where do you believe the solutions lie?

You can send your comments on this report to the Advisory Council by mail at:

Advisory Council on Health Info-structure Interim Report
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By electronic mail to: ohih-bis@www.hc-sc.gc.ca

We look forward to receiving your views.

Please submit your comments to us by November 6, 1998.

GLOSSARY

- Broadband services:** A range of communications services that require and use larger bandwidth than traditional voice messaging. A broadband communication system can simultaneously accommodate television, voice, data and many other services.
- Coding standards:** Standards for identifying individuals and organizations. Natural language (terming) standards. Classification standards. *See standards.*
- Encryption:** The coding of data for privacy protection or security considerations.
- Health infostructure:** The application of communications and information technology in the health sector to allow the people of Canada (the general public, patients and caregivers, as well as health care providers, health managers, health policy makers and health researchers) to communicate with each other and make informed decisions about their own health, the health of others, and Canada's health system.
- Information exchange protocols:** Standards that typically define message formats for the electronic exchange of information. Some information exchange protocols also define codes for specific fields in the messages. *See standards.*
- Information privacy:** A subset of privacy, it speaks to the right of individuals to determine when, how and to what extent they will share personal information about themselves with others. Protecting information privacy involves protecting personal information and following fair information practices. *See privacy.*

Internet:

A vast international network of networks that enables computers of all kinds to share services and communicate directly. It is, in fact, the largest and fastest growing international computer network, and links individuals, and academic and commercial organizations.

Interoperability:

The capacity of different information or communications systems to accept, process and forward each other's information. It has also been defined as (a) the ability of knowledge-based systems to function together in a symbiotic manner and (b) the capacity of different system components and platforms to work together smoothly and predictably.

Management information standards:

A range of standards that relates to the management of information. It includes information modelling standards and guidelines on privacy, confidentiality and security. Information management standards have also been developed for the processing of health data into information that is useful for outcomes monitoring, resource management, program evaluation and other purposes. These include, but are not limited to, minimum data sets, indicators and grouping methodologies. *See standards.*

Personal information:

Any information about an identifiable individual that is recorded in any form, including electronically or on paper. Some examples would be information about a person's religion, age, financial transactions, medical history, address or blood type. *See privacy.*

Privacy:	Most often defined as the right to be left alone, free from intrusion or interruption, privacy is an umbrella term, encompassing elements such as physical privacy, communications privacy and information privacy. Privacy is linked to other fundamental human rights such as freedom and personal autonomy.
Public Key Infrastructure (PKI):	A network of connected third-party certification authorities allowing the movement of data and information between organizations that have their own security architecture or system.
Standards:	Documented agreements containing technical specifications or other precise criteria to be used consistently as rules, guidelines or definitions of characteristics to ensure that materials, products, processes and services are fit for their purpose.
Technical standards:	Standards describing the specific attributes of technology. This may include specifications for physical interfaces. <i>See standards.</i>
Telehealth:	Use of information and communications technologies in the delivery of health information, services and expertise over short and long distances.
Tele-homecare:	The use of electronic communication networks for two-way transfer of information and data required for medical diagnosis, treatment, consultation and/or health maintenance between a patient's residence and a health care facility.

MEMBERS OF THE ADVISORY COUNCIL ON HEALTH INFO-STRUCTURE

Richard Alvarez is the President and Chief Executive Officer of the Canadian Institute for Health Information (CIHI). Mr. Alvarez has had a distinguished career in the Canadian health sector, both at the national and provincial levels. He has served as Chairman of the National Health Information Council (NHIC), as the Chairman of the Interim Board of the CIHI and has been a Trustee of Alberta Blue Cross. Prior to joining the Institute, Mr. Alvarez was an Assistant Deputy Minister with Alberta Health.

Danièle Bertrand, alternate for John MacDonald, is one of the leading executives in the Canadian telecommunications industry. She is President of the Innovation Centre, which was established by Stentor in 1996. As President, she is responsible for identifying and promoting new businesses in the field of telecommunications. She works with leaders in innovative technologies and with the nine telcos that comprise the Stentor Alliance. It is a position that draws on her creative business, diplomatic, and technology abilities. Before her appointment as President, Ms. Bertrand was Managing Director, Corporate Development, at Stentor Resource Centre Inc. Her

responsibilities as Managing Director included strategic and financial planning, market research, and the evaluation of business opportunities.

Andrew Bjerring has been President and Chief Executive Officer of the Canadian Network for the Advancement of Research, Industry and Education (CANARIE) since October 1993. His involvement as a founding member and Secretary of the Board of Directors with CANARIE dates back to its beginning in 1990. Prior to his appointment at CANARIE, Dr. Bjerring spent nine years as Director of Information Technology Services, and six years as Assistant Vice President (Academic Planning and Budgeting) at the University of Western Ontario.

Madeline Boscoe is Executive Coordinator of the Canadian Women's Health Network (CWHN). The CWHN's key goal is information exchange and networking for consumers, community groups, researchers and providers, through mechanisms such as an on-line clearinghouse. In this capacity, the CWHN is an active participant in the Centres of Excellence in Women's Health Research program. She has lengthy experience in the areas of health

promotion, community development and policy analysis, most recently with the Women's Health Clinic, a community health centre in Winnipeg.

George Browman is the Scientific Program Leader of HEALNet (Health Evidence Application and Linkage Network) and Professor and Chair of the Department of Clinical Epidemiology and Biostatistics at McMaster University. He also leads the Ontario Cancer Treatment Practice Guidelines Initiative and in September 1997 he became Director, Program in Evidence-based Care for Cancer Care Ontario. He is still active as a medical oncologist and health sciences researcher. Dr. Browman maintains a clinical oncology practice at the Hamilton Regional Cancer Centre.

Monique Charbonneau is the President and Chief Executive Officer of the "Centre francophone de recherche en informatisation des organisations" (CEFRIO). Her career has included management positions over a 10-year period with the federal government in Ottawa, Montreal and Quebec in the field of documentation and information. After working with the Office de la langue français, madame Charbonneau held a variety of positions in research and information technologies with the Quebec Ministry of Communications prior to joining CEFRIO. She is a member of the Comité consultatif du Québec sur l'autoroute de l'information

and a member of a number of administrative councils.

Ivan P. Fellegi was appointed Chief Statistician of Canada in 1985. He is also Vice Chairman of the Board of the Canadian Institute for Health Information. Dr. Fellegi has published extensively on statistical methods regarding the social and economic applications of statistics and on the successful management of statistical agencies.

Debbie L. Good is a Chartered Accountant and presently an Investment Advisor with Nesbitt Burns, Charlottetown, P.E.I. Ms. Good was a member of the National Forum on Health, serving on the Determinants of Health Working Group. She was also Chair of the P.E.I. Health Policy Council, a former Commissioner of the Hospital and Health Services Commission, an a former member of the Board of the Queen Elizabeth Hospital Foundation.

Doug Hull is currently Director General, Information Highway Applications Branch, Industry Canada. In this capacity, he is responsible for implementing key elements of the Canada national access strategy, including the effort to link all schools, libraries and rural communities to the Internet by 1998-99. He also has responsibilities related to fostering the conversion of public services for

electronic service delivery and for

stimulating the emergence of world-class telelearning and telehealth sectors in Canada.

Mary Ellen Jeans became the Executive Director of the Canadian Nurses Association (CNA) in February 1996. Dr. Jeans has practised as a staff nurse, researcher, educator and administrator. Prior to her appointment to the CNA, she was Director General, Extramural Research Programs Directorate, Health Canada where she was responsible for the National Health Research and Development Program.

The Honourable Wilbert J. Keon is Director General of the University of Ottawa Heart Institute and also a Member of the Senate of Canada. Dr. Keon has sustained a leadership role in the surgical, academic and scientific community throughout his career. Dr. Keon has led the development of the Heart Institute which has become one of the world's leading academic and health care centres.

André Lacroix is an endocrinologist at Hôtel-Dieu pavillion of Université de Montréal Teaching Hospital (CHUM) in Montreal, and a Professor of Medicine and Director of the Endocrinology Training Program at Université de Montréal. He is also Co-director of the Telemedicine Unit of the CHUM Research Centre and President of the "Comité central du réseau inter-régional

de télémédecine au Québec.”
Dr. Lacroix is the Canadian representative on a G-7 group of experts in telemedicine systems where he is the coordinator of Subproject 4 in telemedicine of the G-7 Global Health Care Applications Project.

John MacDonald is the President and Chief Operating Officer, Bell Canada. Prior to joining Bell in November 1994, he was President and Chief Executive Officer of the New Brunswick Telephone Company (NBTEL), which he joined in 1977. Mr. MacDonald was a member of the Information Highway Advisory Council.

Cameron Mustard is an Associate Professor in the Department of Community Health Sciences, Faculty of Medicine, University of Manitoba, with active interests in health services research in the areas of mental health, pediatric care, obstetrics and in chronic disease epidemiology with a focus on socio-economic disparities in health status and the utilization of health services. Dr. Mustard is a member of the Manitoba Centre for Health Policy and Evaluation and has recently been appointed to a five-year term as an Associate of the Population Health Program of the Canadian Institute for Advanced Research.

David Naylor is a Senior Scientist at the Medical Research Council of Canada. He was the founding Chief

Executive Officer of the Institute for Clinical Evaluative Sciences, and was the first director of the Clinical Epidemiology Unit and Research Program of the Sunnybrook Health Science Centre where he is also a staff physician, a professor in the Department of Medicine at the University of Toronto and a member of the School of Graduate Studies. Dr. Naylor holds several cross-appointments in the University's Faculty of Medicine, as well as the graduate Faculty of Nursing and the Institute of Medical Science.

Tom W. Noseworthy, co-chair, is Professor and Chair of Public Health Sciences, Faculty of Medicine and Oral Health Sciences, University of Alberta. He is an internist and critical care physician. He served as a member of the Prime Minister's National Forum on Health, in which he was a member of the Evidence-based Decision Making and Striking the Balance Working Groups, and Chair of the Steering Committee. Dr. Noseworthy's past appointments include President and Chief Executive Officer and Vice-president - Medical Services of the Royal Alexandra Hospitals, Edmonton. He currently chairs the Senior Reference Committee of Alberta *Wellnet*, the province's health information system.

Alan B. Nymark, co-chair, is Associate Deputy Minister of Health Canada. Prior to this appointment, he was Assistant Deputy Minister of

Industry and Science Policy at Industry Canada. Mr. Nymark joined the public service in 1972 and has held various senior-level positions, for example, with the Privy Council Office, Department of Finance, and as Assistant Chief Negotiator on the Canada/US Free Trade Agreement and subsequently the North American Free Trade Agreement. Mr. Nymark has worked in the private sector as a special advisor to the Royal Bank of Canada and with the International Monetary Fund in Washington, D.C.

Robert Perreault is the Chief of Preventive Medicine (HMR), Public Health Directorate, Montreal Centre. He is also a Professor, Faculty of Medicine at the University of Montreal and an Assistant Professor, Faculty of Medicine at McGill University. In addition, Dr. Perreault is Co-director of the Research Centre on Health Promotion in Montreal.

Jeff Reading obtained PhD (1994) and Master of Science (1990) degrees from the Department of Community Health at the University of Toronto. At present, Dr. Reading splits his time between an academic appointment as Assistant Professor at the Department of Community Health Sciences, University of Manitoba, and as a private health research consultant based in Victoria, British Columbia. Dr. Reading's research interests include the general

area of Aboriginal health with specific research projects concerning the non-traditional use of tobacco by Aboriginal peoples, First Nations heart health, diabetes, Aboriginal Head Start early childhood education and community-based health promotion for Aboriginal children. Dr. Reading is a Mohawk from southern Ontario and lives with his family in Victoria, British Columbia.

Carl Robbins received his medical education from Dalhousie University. His interest in the delivery of health care services to rural and isolated environments spans three decades and has included involvement in Memorial University's early telemedicine research and development projects. He maintains this interest in his current capacity as Vice-Dean, Professional Development, and Chair of Telemedicine in the University's medical school.

Dorothy Spence is the co-founder, President and Chief Executive Officer of TecKnowledge Health Care Systems Inc., a Canadian telemedicine company. Ms. Spence's background is in biomedical engineering consulting, sales and business management in the health care industry.

H. William Thomson, Vice President and Branch Manager of Sierra Systems Consultants Inc. - Victoria office, is responsible for the firm's British Columbia's health industry consulting.

He is actively involved in management positions within health care organizations, high-level feasibility studies and strategic systems planning. Since 1984, Mr. Thomson's health care experience has included various management positions and health initiatives throughout North America.

Mamoru (Mo) Watanabe, Professor Emeritus of Medicine, is former Dean of the Faculty of Medicine at the University of Calgary. Dr. Watanabe is a researcher and medical educator, Chair of the Board of CANARIE, member of the National Cancer Institute of Canada's Committee on Planning and Priorities, Alberta Health's Senior Reference Committee and Chair of

Frank Winter is Director of Libraries for the University of Saskatchewan Libraries. Prior to moving to the University of Saskatchewan in 1980, Mr. Winter held positions with the University of Windsor Law Library and the University of Windsor Library.

Alberta Telehealth Coordinating Committee. He was an advisor to the Medical Research Council on health research and a former member of Industry Canada's Information Highway Advisory Council and the National Forum on Health.

John A. Williams is President and Chief Executive Officer of *SmartHealth*, a jointly owned subsidiary of EDS Canada and Royal Bank. He is also Vice-President of Health Care Industry - Canada for Royal Bank. *SmartHealth* has been contracted by the Province of Manitoba to design, develop and implement a province-wide health information network.

ANNEX B

PROGRESS TOWARD A HEALTH INFOSTRUCTURE

Canadians are already building a health infostructure piece by piece. Most of this activity is occurring at the provincial and territorial level, where most of the responsibility for actually delivering health care resides. The federal government in its areas of jurisdiction has also undertaken initiatives aimed at putting in place some of the key elements of a national infostructure. While all of this activity is laudable and encouraging, it does not add up to a coherent strategic approach to building a national health infostructure. Without such an approach, the full benefits of the infostructure will not be realized.

PROVINCIAL AND TERRITORIAL INITIATIVES

The use of communications technology in health care began with the advent of the telephone in late 19th and early 20th centuries, which practitioners used to communicate with patients or caregivers when a house call was difficult or impossible. In the 1970s, computers began to pervade the health care system – most often in the processing of financial, administrative and claims data in larger health care institutions or provincial and territorial ministries of health. Even in this period, various pilot projects tested the feasibility of using the

technology to deliver health care services and health education to remote and rural areas. In the 1990s, the number of such trials exploded. Almost every Canadian province is now actively investing in province-wide health information systems that will collect and analyse information on treatment outcomes and population health to provide a sounder basis for all health-related decision making.

Virtually every province and territory now supports telehealth projects of one sort or another. They are in fact so numerous and so varied that they defy summary. They use a wide range of technologies – including everything from fibre optics to satellite links to videoconferencing – and involve teleradiology, telecardiology, teledermatology, tele-psychiatry, telemaintenance, health education and perhaps in the future telesurgery. The object of many of these projects is to provide improved levels of health care service to traditionally underserved rural and remote areas, where patients often have to be transported at considerable inconvenience and cost to major urban areas for diagnosis, let alone treatment. Partly in response to the aging of the Canadian population, a number of projects also involve tele-homecare, using the technology to bring

health care services into the home.

Most provinces are also building province-wide health information systems:

- ◆ The **Island Health Information System** on Prince Edward Island will provide stakeholders with service support, links among care providers and information for patient care, planning, evaluation and research.
 - ◆ Québec's **Info-Santé** is intended to offer access to an organized set of patient information and link consumers, health care providers, pharmacies, laboratories, hospitals and government as a means of improving the population's health and well-being, the quality of services, and the efficiency and use of health and social services. Once privacy and ethical concerns are addressed, a new "smart" health insurance card will allow the exchange of billing and administrative information and eventually access to a patient's medical record.
 - ◆ The goal of Ontario's **Smart System** is to support and improve the quality of health care delivery, planning and administration by integrating computers and information via a telecommunications network.
- Ultimately, it will provide access to an organized set of patient information and link key stakeholders, including consumers.
- ◆ The **Manitoba Health Information Network** is intended to develop a network to exchange information in a secure and confidential manner among authorized health professionals as a means of improving Manitobans' health. Its vision involves encouraging development and use of outcome measurements as a determinant of health policy, increasing the focus on prevention and community-based services and monitoring services for effectiveness and efficiency.
 - ◆ The **Saskatchewan Health Information Network** aims at facilitating the creation and sharing of a comprehensive electronic health record for each person in the province, protected by security mechanisms and strictly controlled for confidentiality. Access by health care providers to complete, accurate and vital information is intended to result in better decisions and more effective overall health care.

- ◆ The goal of **Alberta Wellnet** is to enable better decisions, using integrated system-wide health information, to improve the health of Albertans and the management of the health system.

These represent only some of the more dramatic initiatives by provincial and territorial governments. They also constitute the building blocks for a national health infostructure.

FEDERAL INITIATIVES

The Government of Canada took seriously the 1997 recommendations of the National Forum of Health to move toward establishing a national health infostructure to gather, develop and distribute better evidence for health-related decisions by the general public and stakeholders in the health sector. In the 1997 Budget, the federal government set aside \$50 million for initiatives in this field, and action has already begun in areas falling within federal jurisdiction.

Health Canada is now working with a variety of partners across the country to develop a key element of a national health infostructure, the **Canadian Health Network** (formerly the National Population Health Clearinghouse), to provide both the general public and health stakeholders with a gateway to

the most credible, timely and accessible health information existing in the public domain. While Health Canada is taking a leadership role in establishing the clearinghouse initially, the ultimate goal is to have an integrated health information service, external to government, that is jointly managed and sustained by many partners.

The **First Nations Health Information System** will build on a unique community-based, comprehensive, computerized application developed through a partnership between First Nations and Health Canada's Medical Services Branch. It consists of 13 integrated sub-systems that track information and support case management on a variety of health topics. The system will facilitate delivery, management, planning and evaluation of health programs in over 500 First Nations communities across Canada.

Work is also under way on a **National Health Surveillance System** which will eventually be a collaborative network of people and organizations, each providing standard health surveillance data (on incidents of disease, laboratory test results, etc.) electronically as health events are recorded. This will allow the timely monitoring of the health of a region, a province, the nation as a whole or the world through exchanges of information with other countries. The

system will also provide decision support applications to help analyse data. In collaboration with the Canadian Health Network, the system will disseminate this information to health professionals and the general public.

The **Health Transition Fund**, announced in the 1997 Budget, provides \$150 million over three years to help the provinces and territories undertake projects – such as new approaches to home care, drug coverage, primary care reform and integrated service delivery – to test ways in which the health system can be improved. Telehealth and health information systems are important components of home care, primary care reform and integrated service delivery. The Fund also supports some national initiatives, including the National Conference on Health Info-Structure which took place in February 1998.

In March 1998, Health Minister Allan Rock announced the establishment of a **Health Infostructure Support Program** to promote projects that will

stimulate use of advanced information technologies and applications in the health field. The program is open to non-profit, non-government organizations in Canada. It will provide partial support for trial demonstrations or pilot projects that aim at proving, evaluating or raising the level of awareness of advanced network-based services in areas such as public health, health risk surveillance, First Nations health, population health information, pharmacare, homecare and telehealth.

In 1992, the Minister of Health mandated the creation of the **Canadian Institute for Health Information**, an independent, not-for-profit organization which collects, processes and maintains a comprehensive and growing number of health databases and registries covering health human resources, health services and health expenditures; develops national standards for financial, statistical and clinical data, as well as standards for health informatics technology; and provides value-added analysis from its information holdings.