health
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in canada

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Acknowledgements

About the Organizations

The following three organizations collaborated in the national consultation sessions to identify health information needs in Canada:

- Advisory Council on Health Info-structure (Health Canada);
- Canadian Institute for Health Information; and
- Statistics Canada.

All three organizations have mandates relating to health information.

Advisory Council on Health Info-structure

"Our mission is to help the people of Canada maintain and improve their health."

Health Canada

The Advisory Council on Health Info-structure was established in August, 1997 to contribute to the development of a national strategy for an integrated Canadian health info-structure by providing recommendations and strategic advice to the Federal Minister of Health. The Council is expected to present its final report to the Minister in early 1999. It is envisioned that the work of the Advisory Council will contribute to the development of a strategy that will enable the people of Canada to make informed decisions about health. The 25 members of the Advisory Council come from a diverse base of representatives from organizations across Canada, including both the private and public sectors, and a cross section of stakeholders with complementary interests.

Canadian Institute for Health Information

The Canadian Institute for Health Information (CIHI) was established in 1994 with a mandate "to serve as the national mechanism to coordinate the development and maintenance of a comprehensive and integrated health information system for Canada" and "to provide and coordinate the provision of accurate and timely information required for the establishment of sound health policy, the effective management of the Canadian health system and generating public awareness about factors affecting good health".

Statistics Canada

The Health Statistics Division of Statistics Canada is authorized under the Statistics Act to collect, compile, analyse, abstract and publish statistics related to the health and well-being of Canadians. The Division's primary objective is to provide statistical information and analyses about the health of the population, determinants of health and the scope and utilization of Canada's health care sector.

Executive Summary

The current context of health and health care in Canada is characterized by change and transition associated with health system reform. Health information and integrated health information systems will continue to play a key role in supporting the health objectives of Canadians as individuals, and as a society.

Three organizations participated in this national consultation, the Advisory Council on Health Info-structure (Health Canada), CIHI and Statistics Canada; all have mandates relating to health information.

This consultation on health information needs involved approximately 500 participants representing six key health system groups from all provinces and territories, including consumers. In addition, representatives of national NGOs as well as Health Canada participated in special sessions.

Notwithstanding the differences in regional emphasis, experience and state of transition, a common vision emerged of a national health information system.

This vision is driven both by the exigencies of reform and public affordability, and by the opportunity to strategically use information to improve population and individual health and to better manage the system. Central to this vision is a client focus which is characterized by a keen sense of personal accountability for one's own health choices and decision making.

However, primary care, ambulatory care, and privacy stand out as the substantive priority issues for health information development. A new ethos of performance permeates the entire debate and results in priorities for data to support evidence-based decision making and comparability of outcomes at all levels.

No one jurisdiction can master the entire puzzle, nor would it be efficient. Relevance and value are associated with the roles of convening, facilitating and mobilizing the experience and know-ledge of jurisdictions in favour of a bottom up, centrally coordinated national system.

Finally, jurisdictions see health information as essential and urgent for the sustainability of the national health system. In this connection, their priorities for application are:

- Building capacity at the provincial, regional and community level for information use and evidence-based decision making.
- Distributing information on health to consumers.
- Decreasing cycle times, be it in terms of policy development, analysis and reporting.
- Improving quality of health system performance based on comparability of outcomes at all governance and population levels.
- Increasing system efficiency and affordability.

These priorities serve as the benchmarks for the National Agencies in terms of relevance, value and utility of services and products.

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Purpose of the Report

The purpose of this report is to present a summary of the results of the consultation sessions on health information needs. The report is organized in five parts.

- Part One provides the background to this project, its purpose and scope. It also describes the consultation process, persons involved and overall approach.
- Part Two presents a summary of key issues within, and surrounding, the health system and the future outlook.
- Part Three describes the information needs with respect to these issues, in support of decision-making and for analysis of performance.
- Part Four outlines strategies national agencies can implement in order to be more responsive in meeting these needs, now and into the future.
- Part Five provides a summary overview of the issues and needs.

Comments presented throughout the report are drawn from the views of consultation participants.

Introduction
Background

The current context of health and health care in Canada is characterized by change and transition associated with health system reform. Although the context differs among jurisdictions, the major objectives are similar, and include:

- increased emphasis on health promotion and disease prevention;
- decentralization of accountability and decision-making;
- shift from hospital to community-based services;
- integration of agencies, programs and services; and
- increased efficiency and effectiveness in service delivery.

Health information and integrated health information systems will continue to play a key role in supporting the health objectives of Canadians as individuals, and as a society. As a result, a number of provinces and territories have launched major initiatives towards the development of new health information systems in support of reform initiatives and the health of their constituents.

The three organizations involved in this national consultation, the Advisory Council on Health Info-structure (Health Canada), CIHI and Statistics Canada, all have mandates relating to health information.

The Consultation Process

Across the country, health administrators, governors, researchers, service providers, representatives from the consumer/general public, Health Canada, and national non governmental organizations (NGOs), and government officials met to discuss health information issues. The consultations painted a consistent picture of change and transition, and the strategic role that information could play to support this transition and better health and health care for Canadians.

The consultations were coordinated with a senior ministry official from each province and territory. Representatives of key stakeholder groups were invited to participate to ensure that all major groups had an opportunity to articulate their issues, describe their related information needs, and their preferences for products and services relating to these needs. While a balance of stakeholder representatives was the goal for all sessions, this was not always achieved. Consumers, for example, were sometimes under-represented.

The overall objectives of the consultation were to:

- identify major current and emerging health issues;
- identify associated health information needs;
- identify priorities for health information in Canada; and
- gain insight as to how the partner organizations can be more responsive.

The following is the summary report of the Health Information Needs Consultation Sessions held across Canada between February 16 and April 15, 1998. This report follows the session process, first with a review of the issues as identified by the participants, then a review of the discussions with respect to their information needs, and finally it concludes with a review of priorities for responsiveness. All highlights are drawn directly from the comments and discussions of the participants.

Issues—Present and Future

In plenary format, participants discussed current major health related priorities and issues in their jurisdictions, or in the case of consumers, of public importance to their communities. Participants were also asked for their views on future key issues or priorities, either within or impacting on the health system. For example, what will emerge in three to five years?

The issues identified tended to cluster into two thematic groups. One theme, health system reform, includes issues associated with the pace, scope and duration of change and the challenges of adaptation and response. The second theme, population impact, includes issues which, while different in nature, all have influence on the shape of the health system, the demands placed on it, and its capacity for response. This group includes such issues as geographic dispersion of populations, demographics, globalization and technology.

Participants believe in their health system and want it to be the best system possible. Canada is a very diverse country due to its geography and multi-cultural, varied population: this in many ways defines who we are. These factors are also important drivers when we try to define our health system, and the system we want to have in the future.

Participants all saw the need for change and firmly believe that the status quo is not an option. However, different jurisdictions find themselves at various points along the path of restructuring and at different stages of readiness, and different levels of acceptance. In addition, it was also apparent that different jurisdictions have different areas of concern related to their specific cultural, economic, environmental, or other situations.

"The status quo is not an option."

This report reflects the common concerns and issues that were expressed across the provinces and territories and by the various stakeholders involved in the consultations, rather than focusing on specific jurisdictional/stakeholder concerns. A separate report for each consultation session has been prepared and contains a synopsis of the issues and discussion. These session reports are available on the CIHI web site.

Issues within the Health and Health Care System

All jurisdictions throughout Canada are in a process of change and transition associated with health system restructuring and healthcare reform. The closure of facilities, the reduction of budgets and loss of professionals, raise fundamental questions about the direction and sustainability of health care as it has been known and give rise to a number of important concerns which pre-occupy both decision-makers and the public. These include:

- lack of vision, understanding and commitment;
- the shift to home care;
- sustainability of the health system;
- elements of an emerging vision of health care;
- consumer expectations and the role of the public;
- accountability and governance;
- public/private;
- privacy/confidentiality;
- alternative and traditional medicines; and
- human resources—availability, skills.

Lack of Vision, Understanding and Commitment

Participants in several jurisdictions spoke to the need for a vision which would clarify the integrated approach to health and health care which is expected to emerge—a vision which would help people shift their focus from what they are leaving behind to what they are moving towards. In the absence of such a vision, there is a broad-based perception that reform is simply the child of reductionist provincial economies. People do not understand the reform process; they are concerned that the speed, duration and extent of change is exceeding the capacity to adapt and respond. As a result, energies are being diverted by the "crisis du jour" associated with emergency waiting times and the like. Based on anecdotal evidence and the popular media, the public is fearful that the system "won't be there when I need it".

Policy makers are concerned over the lack of alignment between a framework based on promotion, prevention and population health while service providers are focused, perhaps necessarily, on acute care, illness and treatment. In the absence of a vision, there is resistance to change,

stagnation in some jurisdictions, and a belief in a return to the prior status quo in others. But by and large, a certain pragmatism emerged within the sessions. Participants held the view, "let's get on with it" we may have to shape the vision as we go, but we cannot stand still. In this connection a number of jurisdictions spoke to the need for multi-stakeholder processes, partnerships and other cooperative mechanisms to tackle issues which exceed the capacity of any one sector to resolve.

The Shift to Home Care

No issue embodies more the meaning of "reform" than the shift from facilities-based treatment to home care. Some of the issues cited include:

- inadequate financial and human resources to support this transition;
- emerging need for appropriately skilled human resources to support this shift; e.g., home care nurses with post-op training;
- existing information systems are limited to traditional service delivery facilities and sites (e.g., hospitals) and do not extend to home care—hence it is not possible to assess needs, access or outcomes;

"Assumptions are made about home care being better than other service sites."

- the role of the private sector in home care raises questions of data collection, use, access and adequacy of service;
- the need to ensure safe, competent care in the home care environment;
- the ability to collect data on needs in order for decision-makers to know how best to allocate resources at community and home care levels; and
- the transference of costs to the primary caregiver, usually women in the home, and the implications for lost earnings and personal needs for care and respite.

Sustainability of the Health System

Sustainability is the issue that pulls together the concerns of various stakeholders (government, service providers, and consumers). It may be a paradox that concern over the sustainability of a publicly funded health care system has been both the cause and result of reform. Either way, policy makers, health professionals and consumers see the same prescription for sustainability. It rests on successfully addressing three issues: access, balance and consistency.

1. **Access**
   At the heart of the sustainability issue is a concern about access to services, particularly for public confidence. Hand-in-hand is the issue of affordability. The question becomes: how do you create a system that ensures access, defines suitable expectations, and is affordable in terms of public expenditure and personal costs?

2. **Balance Needs and Services**
   The second question under sustainability is how to strike the balance of supply to demand within an overall context of public and personal affordability. Some jurisdictions referred to the issue as "Getting the system right". Others described it as maximizing the cost/quality/service functions—others described a service/location need with a service/cost/access equation. However it was labelled, the common concern was how to allocate resources and services to optimize access and affordability and quality of outcomes.

"Sustainability of the safety net includes everything in the spectrum from acute care to financial assistance."

The question of balancing needs and services goes to the heart of the health reform debate and carries the most significant implications for information needs. For example, it requires a very sophisticated capacity to understand the demand side of the equation. It means detailed analysis of needs and usage patterns, ranging from populations down to individuals at different geographic levels (province to community) with sensitivity to culture, gender, age and different socio-economic levels.

The supply side has similar implications for information. Evidence-based information is required at all decision levels from policy to programs through to treatments and care methodologies. In addition, comparative cost information on services at various sites is required. Taken together, policy and decision-makers, service providers and consumers can shape a system which visibly and transparently makes best use of resources, optimizes access and ensures affordability.

3. Consistency

The third issue addresses consistency of services and outcomes. Again, the use of evidence-based decision-making is essential to build confidence on the part of both service providers and the public—confidence that the practices at policy, management and service delivery levels are best practices and consistent practices. This leads to consistency in quality of health care, if not always in terms of location and access.

Elements of an Emerging Vision of Health Care

Consultation discussions yielded the view that health system transition is not solely a function of reform, but also a function of emerging vision, which is broader than the traditional bio-medical model including determinants of health and population health. This vision has been taking shape throughout the decade and was perhaps best articulated through the work and reports of the National Forum on Health. The key features of this new vision, as described by participants is that it is:

- knowledge/evidence based;
- results oriented; and
- people centred.

The essential features include the following:

- Focus on population health with relevant comparison between jurisdictions to assess performance and to identify best practices.
- A shift in emphasis from care to prevention and promotion.
- Focus on population data—based on vertical integration of data from clinical practice to surveys—in order to create a rich data base. This will, in turn, ensure access from various levels for purposes of analysis of usage patterns and needs along geographic, social economic, cultural, gender and age lines.
- Focus on results, at every decision level, together with cost data to determine best value for public and personal expense. This together with inter-jurisdictional linkages to mobilize knowledge on best practices and, simply put, "what works".
- A broader definition of health and health care spanning the full continuum of care including primary care, community service, home care, ambulatory care, private extended care, alternative and traditional Aboriginal therapies, and so on, with linkages between service providers along the continuum.
- A broader capture of health and health care needs data at the community level to include the homeless, mental health clients and other marginalized members of the community.
- Linkages to other determinants of health especially education, socio-economic levels and housing to determine evidence of what makes a difference, especially for children in high risk environments.
- Underpinning this vision is an emerging culture of evidence-based decision making across all decision-makers, together with a capacity for information management and application.
- Participants saw primary care and determinants of health as the principal foci in terms of the approach. The first step is to build a good information system across the continuum of care, identifying efficiencies and best practices, leading to an evidence-based system for policy through to delivery. The second step is to link this through to the determinants of health, for example links to information on education, housing, etc.
- Finally, the emerging vision sees the patient/client as the focus of the system with information to track the person across the continuum. This represents a significant shift from the service provider/site-based system now in place.

Consumer Expectations and the Role of the Public

The expectations of the public was a consistent message throughout much of this debate. Consumer representatives typically raised the point that public confidence in a publicly funded health and health care system is a function of performance. The key performance criteria are:

- access—in terms of location and waiting time;
- cost and affordability of products and services;
- quality of services;
- support for personal knowledge and decision-making based on credible, accessible information;
- clear accountability by service providers for services and outcomes; and
- shift from doctor-centred to client-centred service model.

"Consumer expectations exceed the ability to provide."

An important element of consumer expectations concerns the shift in accountability for whom is responsible for one's health. Consumers are increasingly accepting or reclaiming this role and now have expectations for information and information access which, they admit, exceed the capacity of the system.

Accountability and Governance

The new models of governance in use across jurisdictions (regional authorities) have important implications for the roles and responsibilities of all decision-makers in the system. Participants spoke of the many aspects of decision-making policy, programming, budget allocations, identification of best methods of service provision, etc. and indicated that the roles and responsibilities of the various actors must be clear and efficiently integrated.

This issue has unique characteristics in the Northwest Territories as it moves towards division, as well as the Yukon due to the many Aboriginal self-government jurisdictions coupled with expansive administrative regions.

Public/Private

While the health care system has always had a mix of both private and public delivery systems, the future scene is unclear. Participants noted that there is a lack of understanding of current directions and their implications for the system in terms of access, services and costs. What balance between the public and private delivery systems will our societal values accept in the future?

Privacy/Confidentiality

While not restricted to health, the traditional doctor-patient confidentiality is seen as a defining characteristic of the medical service. The vision of a system inter-connected across service providers, with linkages across the continuum of care, links to determinants of health, and the building of bottom-up data bases create real concerns for privacy, confidentiality and more generally, the place of the individual in the system. Managing the balance between data utility applied to better health care and protecting private interests stands as the key restraining factor at the ethical level.

"Need a balance between rights of the public to know and patient's right to privacy."

Alternative and Traditional Medicines

As accountability for health shifts to consumers it opens the door to a more pluralistic notion of choice of therapies and the inclusion of these therapies in a publicly funded system. This is a particularly important issue in regions with large immigrant populations which practise non-Western medical traditions, as well as in northern regions where self-government includes responsibility for health.

"Alternative health practices need to be integrated."

Human Resources—Availability, Skills

Recruitment, retention and training of health professionals is an issue across Canada but particularly in the Northwest Territories, Yukon, Prince Edward Island and Newfoundland. It presents a very real constraint to service and access and is a

major pre-occupation in these jurisdictions. Looking ahead to the future, the situation becomes more urgent as demographics drives out many professionals due to retirement to be replaced by a smaller base of highly skilled professionals. This in turn raises issues over pay and benefit flexibility to recruit and retain human resources. There is risk of isolation due to competition between jurisdictions rather than development of a coherent human resources strategy.

Also important is the changing skill mix required in the future. The home care shift requires community care professionals with skills to follow acute care treatment. Health prevention/promotion requires training in community health. And, computer literacy will be essential to build the information-culture necessary to support and fully implement evidence-based decision-making.

External Issues Influencing the Health System

The second cluster of issues includes those which are outside the health care system but which have or will have significant impact on it. These include:

- demographics;
- geographic dispersion;
- globalization; and
- technology.

Demographics

Demographics came up at every session as a key driver of change. An aging population or relocation of seniors to retirement regions has implications for chronic, ambula-tory and pharmacare. In some jurisdictions, youth unemployment has led many to leave their communities for other centres, often placing them at risk, or on the edge of risk (i.e., homelessness), and consequently they are not visible to the health system. Increased birth rates in Aboriginal and immigrant communities has implica-tions for pre- and post-natal care as well as links to determinants of health (e.g., income levels, employment levels, housing conditions).

"Changing demographics— pressures on system— implications for resources, long term care..."

Geographic Dispersion

In most provinces, the NWT and Yukon, the geographic distribution of inhabitants represents a significant issue in terms of planning the optimal location of services, and in determining the best balance of access to cost. Again, this issue has implications for data, for analysis of needs and usage, as well as challenges to data collection.

There is an important link to technology as telehealth/telemedicine are seen as levers to improve equality of access. Similarly, those in remote regions do not identify with service or governance models bred in large urban areas. They want to compare population health indicators with such centres but see other like-communities as sources of best practices. A suggestion in the NWT was to develop a network of "North of 55°" communities to share best practice data and experience.

Globalization

Globalization raises two issues. The first is the context of world convergence toward a common health care model and the implications for Canada. The second is in terms of global travel and the potential for exotic diseases to migrate very quickly. The implications for international surveillance and early warning systems are significant.

Technology

Finally, technology is seen as the all-encompassing component on which other aspects depend for the future successful operation of the health and health information systems. Key areas of concern include the absence of hardware, software, inter-operability among systems, access to data, consistency, and use literacy at the community/service provider level. As a result, there is a core capacity-building requirement associated with the technology issue.

"We need to move from paper to electronic forms for effective and efficient sharing."

Future Issues

Consultation participants also discussed those issues which they saw emerging in the three to five year time frame. Without repeating the previous discussion, the highlights were:

- research and technology;
- communication technologies;
- public expectations;
- private/public;
- policy; and
- early childhood risks.

Research and Technology

Significant advances, such as identifying all 100,000 human genes, threaten to spill into new generation bio-engineered products, in turn giving rise to consumer expectation, growth in service costs and ethical and legal challenges.

Communication Technologies

Participants saw the emergence of a network of electronic and information technologies which will connect users to an incredible service infrastructure—the risk is that a two-tier information system will emerge, one for those with the capability to use and understand technology, and one for the techno-illiterates who could be left outside this cyber-health system.

Public Expectations

Expectations will shift to information services, and information itself will have an impact on their health. At the same time, more vocal extremes will focus the debate on single interest agendas. It will be harder to find common ground for community-based solutions.

Private/Public

The private sector may play a more important role, although the shape and mix is unclear.

Policy

Policy will need to address what is included in medicare—given alternative therapies, traditional medicine, the nature of illness and injury of an aging population, socio-economic determinants of health, and on-going budget constraints.

"Am I going to get what I need, when I need it?"

Early childhood risks

There is a need for increased focus on early childhood risks.

Issues identified include both those resulting from reform as well as those seen as opportunities to improve both population health and personal health and well-being. The successful completion of the transition will require strategic use of information technologies; the building of info-capacity at the user level; the creation of a results-oriented, evidence-based decision culture; the transition to a client-centred service and information model; and the implementation of new information architecture which enables access to data, applied analysis, connectivity while addressing rights of privacy.

Information Needs and Priorities

Participants discussed their information needs relative to four factors:

- types of information required in line with the issues raised earlier;
- information needs associated with decision-making;
- information needs with respect to performance measurement, and from a consumer perspective, information required to assess their own health and the performance of the health system; and
- finally, participants were asked how they saw their information needs changing in the future.

Current Information Needs

What emerged from the discussion was a highly integrated view of information needs. Segmentation along the lines of issues, decision-making and performance tended to blur as key requirements both for the system and its capabilities invariably moved throughout these discussions.

The key needs arising from this discussion were as follows:

- the need for an integrated health information system;
- regional and community information;
- cost data;

- evaluation information on alternative interventions and technologies;
- performance information including comparative data and benchmark indicators;
- outcomes data;
- validated information;
- linkage of information;
- framework and guidelines for privacy and confidentiality;
- private sector services/costs;
- information on human resources;
- data quality;
- managerial information;
- health indicators and trend information; and
- consumer expectations.

The Need for an Integrated Health Information System

This discussion again raised a precise and articulate vision of an information system which is based on standardized information collection, analysis, data sets, etc. The terms "connected", "linked", and "integrated" were most often used to describe this information system, which has as its aim the promotion of health and the sustainability of the health system by enabling decision-makers to maximize and balance the access/cost/quality function with affordability.

"Need to develop better integrated and more community-based data."

The key features of this information model include:

- Common standards across the continuum, such as disease and intervention classification codes.
- Health outcomes-oriented.
- Evidence-based.
- People-centred—real time information.
- It connects service providers and patient episodes across the horizontal continuum of assessment, intervention care and placement. This has important implications for interoperability of data across the system (i.e., data exchange).

- It aggregates data vertically, combining bottom-up clinical data with survey and other data, to create a comprehensive body of data for multiple use at community, regional and provincial levels.
- It provides links across to determinants of health.
- It is user-oriented, empowering users with access to data, inquiry capability, and supports local customized analysis and interpretation.

The following broad requirements were raised repeatedly in connection with an integrated health information model:

- The need for quality and comparability across jurisdictions, emphasizing the importance of data integrity based on common definitions, consistent standards, accurate coding and timeliness of collection. Related to this is the need to develop minimum data sets with standard definitions, and a core set of health indicators. To focus on better data, information and analysis are required, rather than simply more data.
- Timeliness of information, especially survey information.
- Capacity building at the user level. There are implications for:
  - technology: hardware and software applications standards; and
  - skills development in data analysis, interpretation, and application to decision-making.

Regional and Community Information

The capacity to integrate data at different levels (province, town, community) in terms of demands, usage, demographic profile, socio-economic status, disease incidence, treatment profiles, etc.

Cost Data

Financial and cost data related to:

- policies and programs;
- interventions and outcomes;
- facilities and services operations;

"Are we getting value for money?"

- volunteer/home care workers; and
- across the episode of a patient's care including: assessment, referral, intervention, and outcome.

Evaluation Information on Alternative Interventions and Technologies
Information that encompasses alternative interventions and technologies need to be included in a format that permits their evaluation against other options.

Performance Information Including Comparative Data and Benchmark Indicators
A broad range of common standards and indicators are required for cross-jurisdictional comparison on policies, services, structures, access, efficacy, equity, health status, health expectancy, prevention, quality of outcomes, customer satisfaction, professional satisfaction and morale as well as more general population health. Types of performance information include efficiency; effectiveness; acceptability; safety; and provider competence. This performance information is required across the continuum.

The role of comparative data is to enable decision-makers to understand where they are in the spectrum of experience; to assess performance (relative to cost and outcomes); to measure opportunities for improvement; and to ensure continuous adoption of "best practices". Along with the need for comparative data is the need for analysis and interpretation as well as skills development for these purposes.

Outcomes Data
Outcomes data on different service delivery models and specific interventions as well as macro outcomes data, for example the impact of restructuring on population health, the cost/benefits of shift to home care, etc.

Validated Information
Validated information for the general public for use in personal health assessment, informing oneself on choices of treatment, and for general information on health issues.

Linkage of Information
- Linkage of information on population health to determinants of health. This will require development of core standards, and indicators for data flow.

- Linking of service utilization and population health information at the community/regional level to enable micro data analysis of needs, usage patterns and health issues for purposes, planning and optimization of access and service delivery.

Framework and Guidelines for Privacy and Confidentiality
A framework must be in place which allows service providers, researchers, and decision-makers adequate access for their particular role while preserving the fundamental principles of privacy. The risks to privacy of an integrated information system are significant and make this issue urgent especially as a number of provinces are proceeding with privacy legislation for health information.

Private Sector Services/Costs
As the private sector plays a larger role, data coverage will need to be extended to ensure capture of services, quality, and costs. This need is particularly important as private sector growth is linked to health system restructuring—home care.

Information on Human Resources
Information on human resources, including availability and skills range, is a critical component in service planning at the community level.

Data Quality
Providing training tools for coding by service providers in order to ensure better quality data. As data is captured more at the front-line than at the clinical level, this becomes more important.

Managerial Information
Managerial information including: integrated data on resource allocation, workload volume, overtime, outcomes, risk management, service quality, costs and customer satisfaction.

Health Indicators and Trend Information
Broadly defined:

- morbidity;
- mortality;
- development of new, goal-oriented population health indicator, including wellness as opposed to illness indicators;
- individual level health indicators;
- lifestyle and risk indicators;

"Need to identify what constitutes good health and good outcomes."

- development of broader health indicators such as literacy levels in communities or regions; and
- trend information tracked over time including demographics and societal values.

Consumer Expectations
Including:

- easily accessible, plain language, credible information to complement what service providers offer;
- ratings on hospitals, possibly "report cards" on the health system, facilities and services;
- age, culture, gender specific information; and
- multi-lingual information to serve needs of immigrant/high-risk populations.

Future Information Needs

Participants were asked to provide their perspectives on their information needs in the future. Overall, participants reinforced the need to address standards, commonality and comparability in health information as well as the need to ensure privacy and confidentiality.

- Both health professionals and consumers expect to see greater use made of the Internet to exchange data, access information and provide telehealth services in remote communities. Technology is a gateway to improve equitability of access due to cost, mobility and distance factors.
- "Smart cards" or a variation are expected to emerge as technological tools to capture cross-continuum health information—however, participants see risks in terms of privacy, lost cards and emergencies.
- Ethical and legal issues will arise in tandem with further advancements in genetics research and applied bio-engineering.
- Aging population will drive expenses in many chronic disease areas. Examples include:
  – arthritis and joint replacement
  – cardiovascular and expanded heart centres
  – vision–transplant and assistance costs
- Information on environmental risks and health impacts, especially breast, prostrate and other cancers.

- Information on alternative therapies, especially as consumers increasingly shop around for information.
- Increasing self-management by consumers requiring tools such as personal health report cards.

Summary of Information Needs

The participants' statement of information needs formed a consistent and coherent vision of an evidence-based, results-oriented, client-centred system, driven by common standards consistently applied, with key linkages between all actors and to data repositories. The thrust of information is to optimize access, quality of service and affordability to allow meaningful comparison across jurisdictions and to support important reform-driven shifts, and patient accountability for knowledge, choice, and health status.

Responsiveness of National Agencies

The final component of the consultation sessions focussed on participant discussion on three questions related to the responsiveness of National Agencies to the information needs and expectations of their clients:

- What priorities should National Agencies focus on to be most relevant, useful and timely in their information services and products?
- How could CIHI/Statistics Canada/Health Canada improve their services to you in terms of:
  – accessibility
  – timeliness—geographic considerations
  – response to requests
  – providing custom services
  – cost structures
- How could your jurisdiction strengthen its level of involvement in projects conducted by CIHI/Statistics Canada/Health Canada?

Priority Focus for Relevance, Usefulness and Timeliness

Overall, participants want a national clearing-house for timely, accurate, customized data that is readily accessible and affordable, particularly to smaller population provinces and regions. More specifically, jurisdictions want national agencies to focus on the following priority areas.

Development of Standards

Participants clearly expect national agencies to play the lead/coordinating role for the development of such priority standards as:

- Common definitions and core health indicators.
- Priority development of standards across the continuum with particular emphasis on community health standards, data elements, etc., to close the gaps: home care, ambulatory care, etc.
- Benchmarks for policy, management and service delivery.
- Broad based frameworks and data sets for determinants of health. There is a need for a collaborative effort at the national level between CIHI, Statistics Canada and Health Canada with other agencies such as the Canadian Council on Health Services Accreditation, Human Resources Development Canada and Environment Canada to identify the key questions or determinants of health, define the information outputs, and define the data elements and methodologies for collection.

"Establish, define and set standards nationally."

- Standardized formats for data collection, analysis and dissemination and audit compliance to ensure comparability, timeliness, relevance, and best practices.
- Develop and disseminate "best practices" as operating standards.
- Develop and disseminate standard templates for indicators that emerge from a re-definition of health and health outcomes.
- Develop standard templates for data quality review.
- Develop national principles and standards and protocols to address privacy/confidentiality requirements.
- Develop standards, definitions and minimum data sets which allow for comparability of client-based information.

Informed Access to Products and Services of National Agencies

On the premise that jurisdictions and consumers cannot access what they are unaware of, several groups recommended more visible marketing and dissemination of products and services. They suggested three priorities:

- A tripartite catalogue of reports, data, products and services.
- Eliminate dual or parallel tracks of access or dissemination–create one integrated track (links between agencies).
- Make services visible and available to consumers.

Services to Enable and Build Capacity

The combination of health restructuring and the shift to evidence-based decision making has created new decision-making levels which are challenged beyond their technical capacities and personal skills. National Agencies could play an instrumental role by recognizing that with transition comes a need for training and infrastructure building, and that these initiatives are costly. Assistance should be considered for regional, community and service-level professionals with regard to:

- hardware configuration recommendations;
- data collection access, analysis, interpretation and use;
- provision of decision tools, support and training.

Support and Advisory Services

Support was requested to shape questions for research or analysis, to customize analyses, to assist in interpretation and application of results.

Leadership in Goal-setting

Several jurisdictions argued that the development of health and health care goals would provide focus to the system: decisions, information needs and data requirements. They see the National Agencies as best placed to take the lead role.

Recommendations to Improve Service Attributes

Participants are looking to National Agencies to play a pro-active role in helping to build an evidence-based, information-oriented culture across the health system. In addition to products and services, jurisdictions value the building of ongoing relationships which will support local initiatives, assist in development of provincial capacity and strengthen utilization of information at all decision levels.

More specific recommendations included:

Marketing and Dissemination
Participants want National Agencies to continuously promote services, products, and use of information at the jurisdiction level. In this latter connection they see a role in facilitating the education of governments.

They also placed heavy emphasis on dissemination of information products, including preliminary survey data.

Dissemination/Access Channels
Participants proposed greater use of electronic channels such as the Internet and e-mail, as well as multi-media storage (CD-ROMs) which allow for data manipulation and analysis.

Data Scope
Participants want larger survey sample sizes to allow for meaningful micro-unit analysis while protecting privacy.

Communication and Consultation
Participants want to be involved on an ongoing basis—especially at the front-end of project design.

Recommendations for Collaboration

Participants discussed how they might increase or improve their level of collaboration with National Agencies. This question resonated with jurisdictions across Canada as well as with the national NGOs and Health Canada representatives. Open communication channels, clarity of roles and early involvement at the outset of information initiatives were key themes. The common thread to these discussions was that jurisdictions understand best their needs. In

many instances, provinces and territories have launched initiatives to meet their own needs. Consequently, collaborative initiatives were proposed to facilitate the efficiency of the system as a whole, lever provincial and territorial investments and mobilize the knowledge gained to a wider community of interest. A "facilitator", and "convenor" are functions seen to be of value. The more specific recommendations of participants included the following highlights with respect to:

- roles;
- relationships;
- collaboration;
- specific initiatives; and
- local capacity.

With Respect to Roles
- Reduce duplication and improve coordination between National Agencies and provincial jurisdictions.
- Clarify the rules of the game regarding data initiatives, e.g., standard project methodology which will ensure maximum benefit of initiatives for multiple jurisdictions.
- In the same vein, facilitate the sharing and collecting of data in a consistent manner, across provinces and territories.

"National Agencies should complement each other."

With Respect to Relationships
- Provinces and territories want ongoing dialogue with National Agencies not just communication on a project-by-project basis.
- Provinces, territories and other stakeholders want to work in partnership to define "sustainability" in terms of policy change and to determine the information requirements to monitor and assess sustainability.

With Respect to Collaboration
- Stakeholders are looking for more involvement in decision making on data collection. Jurisdictions see a responsibility for themselves in defining needs—in part to discipline the process so that unnecessary data is not collected, and in part because their vantage point qualifies them to provide valuable input.

"Continue and broaden proactive approach in identifying opportunities for participation."

- Stakeholders want to assist in the development of standard data elements as well as standards for collection, analysis, interpretation and management of health information. Specifically, where they have experience in priority areas, such as home care, they want to be involved and used as resources.
- Stakeholders see National Agencies, specifically CIHI, as being well positioned to convene jurisdictions to build consensus on priority needs for development.
- Improved communication begins with better communication of needs—the importance of communication with service providers was stressed in order to identify emerging needs.
- Overall, jurisdictions called for more communication on plans and initiatives, to provide the opportunity for input and to keep stakeholders abreast of what is happening. In short, jurisdictions want to take an active role in key issues, such as ambulatory care, privacy, classification systems (ICD-10), etc. They also proposed new emphasis on feedback from users as another way to gauge the degree to which current services relate to needs.

With Respect to Specific Initiatives

Participants suggested a number of specific means to improve collaboration on initiatives:

- They propose that a priority initiative for the three National Agencies is to collaborate on the development of a set of health indicators.
- They propose privacy is an urgent issue, one which requires leadership, collaboration and consensus building to shape a framework which is compatible with a modern vision of information management.
- Several jurisdictions called for some central repository to catalogue what information is currently available, where it is and how to access it.
- One jurisdiction proposed that Statistics Canada consider adding household health to its census survey.
- Participants suggested that local health professionals, who have community experience and involvement in collecting qualitative data, be involved in order to identify distortion in data.
- They suggested using professional organizations to provide input on emerging data needs and definitions.

With Respect to Local Capacity

Jurisdictions across Canada argued that restructuring and reform has shifted the level and complexity of decision making requiring greater information management capacity at all levels but especially at the community/service level. They want to be assured of adequate resources to support projects before they begin. They are looking for commitment by federal and provincial governments in terms of technology, skills, and development resources, as well as front-line resource for data capture and collection.

"Increase involvement of community health service providers in development of more community-based information."

Summary of Discussion of Means to Improve Collaboration

The central themes arising from this discussion focused on the importance of consulting users and front-line professionals on needs; the desire of jurisdictions to be involved at the beginning of new initiatives on standards development; the importance of sharing the experience and initiatives of jurisdictions; focus collaboration on priorities such as home care; and share the load and harness the initiatives and energies of provinces/territories to build a coherent, national health information framework.

Summary

This consultation on health information needs involved approximately 500 participants representing six key health system groups, including consumers. In addition, representatives of national NGOs as well as Health Canada participated in special sessions.

Notwithstanding the differences in regional emphasis, experience and state of transition, a common vision emerged of a national health information system.

This vision is driven both by the exigencies of reform and public affordability, and by the opportunity to strategically use information to improve population and individual health and to better manage the system. Central to this vision

is a client focus which is characterized by a keen sense of personal accountability for one's own health choices and decision making.

However, primary care, ambulatory care, and privacy stand out as the substantive priority issues for health information development. A new ethos of performance permeates the entire debate and results in priorities for data to support evidence-based decision making and comparability of outcomes at all levels.

No one jurisdiction can master the entire puzzle, nor would it be efficient. Relevance and value are associated with the roles of convening, facilitating and mobilizing the experience and knowledge of jurisdictions in favour of a bottom up, centrally coordinated national system.

Finally, jurisdictions see health information as essential and urgent for the sustainability of the national health system. In this connection, their priorities for application are:

- Building capacity at the provincial, regional and community level for information use and evidence-based decision making.
- Distributing information on health to consumers.
- Decreasing cycle times, be it in terms of policy development, analysis and reporting.
- Improving quality of health system performance based on comparability of outcomes at all governance and population levels.
- Increasing system efficiency and affordability.

These priorities serve as the benchmarks for the National Agencies in terms of relevance, value and utility of services and products.

Appendix

Appendix

Listed below are the questions that were used to guide the consultation at the provincial and territorial sessions. The questions are associated with each of the four session objectives. The consultation questions were slightly modified for the Health Canada and Non-governmental Organization Sessions.

Objective 1—Identify the major current and emerging health issues

Questions—Health Professionals

1. What are the major health-related priorities and issues in your jurisdiction at this time?
    *   people
    *   environment
    *   the health system
    *   processes

2. What do you foresee as the major priorities and issues in the future three to five years?

Questions—Representatives of Consumers/General Public

1. As a member of the public, what are the major health-related priorities and issues of public importance to your community?

2. How do you see your health priorities evolving over the next three to five years?

Objective 2—Identify associated health information needs

a) **Issues**
    1. What types of information do you need to be informed on key issues eg.
        *   health of the population
        *   keeping individuals and populations healthy
        *   management of health system
        *   personal health

    2. What sources do you rely on?

b) **Decision making**
    3. What are the principal information priorities for your role or function?
        *   State priorities.
        *   How do you access priority information?
        *   Are there gaps or duplication in sources?
        *   Is the format adequate? E.g., date, analysis, interpretation
        *   If not, what are your priorities for analysis, aggregation, integration?

c) **Performance Measurement**
    Question—Health Professionals

    4. What indicators are essential for monitoring the performance of the parts of the health system under, or in your jurisdiction?
        *   Are these indicators available?
        *   How do you compare your performance to other jurisdictions?
        *   How could information on national comparative reporting be improved?

4. What information would help Canadians to assess the performance of the health and health care system?

5. What information would help Canadians to understand their personal health status?

Objective 3—Identify priorities for health information in Canada

1. Looking to the future, how do you see your information priorities changing?
   • New information requirements
   • Sources—media products
   • Uses/applications

Objective 4—Gain insight as to how the partner organizations can be more responsive

1. What priorities should national information agencies focus on to be most relevant, useful and timely in their information services and products?

2. How could CIHI/Statscan/Health Canada improve their services to you in terms of:
   • accessibility;
   • timeliness—geographic considerations;
   • response to requests;
   • providing custom services; and
   • cost structures linked to level of information and timeliness?

3. How could your jurisdiction strengthen its level of involvement in projects conducted by CIHI/Statscan/Health Canada?