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REPORT OF THE

NATIONAL TASK FORCE ON HEALTH INFORMATION
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PREFACE
PREFACE

This Preface affords me the opportunity for an expression of some personal impressions.

Disclaimers and Acknowledgements

I undertook the assignment of Chairman of a National Task Force on Health Information, on urgent request from several persons I respected, because I perceived the task to be a major challenge with significant public interest.

My preconceptions (and current views) are well-represented by the following quotes:

"The Public Health is the foundation upon which rests the happiness of the people and the welfare of the nation." (attributed to Benjamin Disraeli); and

"The road leading to health for all by the year 2000 passes through information." (from a World Health Organization report).

I have no background in health and have no intent of establishing a "foreground". As retired Chief Statistician of Canada, my ambition in this assignment is to produce results, with integrity, which will be productive. Though the Task Force was sponsored by government, it was fully understood by all that its work would be independent and entirely in the public domain.

I approached the assignment (in June 1990) with an open mind (some might say an empty mind) insofar as health matters are concerned. I counted on the availability of persons with professional knowledge and experience to provide worthwhile substance, and I was not disappointed. I have been continually impressed by the admirable calibre and character of the many people in the field of health that I had the opportunity to work with and consult. My perception of the complexity of the task kept increasing with involvement, but so also did my gratification with the responsiveness of contributors to the Task Force mission.

Overall Assessment

I was aware from the outset that Canadian health information was not in good shape. My current assessment is that it is in a deplorable state. My image of health information is somewhat like an unmapped forest with undefined boundaries. Multitudinous health constituencies have important information needs associated with their responsibilities (they need a map pertinent to their position in "the forest"). Typically, those information needs -- for policy, management, research, health care provision, health promotion, dynamic population health status, technology/treatment assessment, cost-benefit evaluation, outcomes monitoring, personnel planning and training, budgeting, resource allocation -- are unmet or inadequately met, with important exceptions. And this situation is co-existent with a vast array of data collected and accumulated by many constituencies, public agencies and care-givers.

In general, virtually no health constituency (jurisdiction, institution, industry, profession, advocacy group, research centre, population category) is in a position unilaterally to satisfy its information needs.
(again with important exceptions); and mechanisms for co-ordination and co-operation are insufficiently effective or do not exist. Moreover, substantive and bureaucratic complexities are such that one "cannot see the forest for the trees".

These assessments are not particularly new. As documented elsewhere in this report, many of the findings and recommendations from the work of the Task Force are disturbingly repetitive of those from the 1964 Royal Commission on Health Services. As well, over the decades, a variety of federal-provincial committees have been launched by the Conference of Deputy Ministers of Health to improve health information development -- the National Health Information Council (NHIC) being the most recent incarnation. The new structural feature of NHIC is that it formally includes Statistics Canada, adding some hope that the decades-old efforts by the statistical agency to improve health statistics may be aided by more effective co-operation among and with federal and provincial health ministries.

The mandate and mission of NHIC are excellent (Reference 9.1). However, my very early impression that NHIC was constituted far too narrowly to meet that mandate was steadily reinforced in consultations -- curiously, both by those who had the same impression and by those who were not sensitive to the issue.

But the early enthusiasm that NHIC might be a "breakthrough" is itself a strong indication of the fundamental importance of establishing effective methods of co-ordination. And in the field of health, it is surely immediately apparent that for the evolution of effective health information systems, co-ordination and co-operation of government health ministries is necessary, but obviously far from sufficient.

The Strategic Issues Are Structural

Health information systems are, and will be, complex and difficult to design and implement. Their development can only come in an evolutionary mode, with incremental changes as opportunities or pressures can be exploited for progress. Evidently, continuing planning consultations are necessary to canvas information requirements, to recognize methodological desiderata, and to establish the distribution of priorities among constituencies. However, in my considered judgement, the threshold strategic issues are structural -- namely mechanisms to achieve co-ordination on decisions, and co-operation/collaboration in implementation and operation. In the field of health information, the co-ordination/co-operation which is essential for productive incrementalism can only be based on consensus through authoritative compromise among equal persons who represent all health constituencies.

Operational Aspects

Given a forum or mechanism for co-ordination on health information development "policy" through authoritative compromise, the derivative question concerns operational factors. Statistics Canada and its Canadian Centre for Health Information (CCHI) is a key operating player. However, as discussed elsewhere in the report, essential functions cannot be adequately discharged by CCHI (or any government organization). Thus, non-government operating capacity is required -- for standards and guideline negotiations, for information services on customer demand, for management of a consensus planning process, to provide a clearinghouse/brokerage function for access to data bases, to provide a focal point for the marketing of health information, to help structure and co-ordinate data-based health services analyses and health science research. Such functions will require truly partnership collaboration with CCHI, whose effectiveness and efficiency would be enhanced by that partnership.
The foregoing logic leads me, compellingly, to the (simple in principle) structural recommendations that:

(a) A Health Information Co-ordinating Council (HICC) should be established (via grassroots consultation and nomination) which is acceptably representative of all health constituencies -- government (health ministries and other) and non-government (for profit and not-for-profit).

(b) A non-government Institute for Health Information (IHI) should be set up to be a full collaborating partner with CCHI.

(c) To ensure and facilitate co-operation of IHI and CCHI, both organizations should be subject to direction from HICC, IHI on a de jure basis, CCHI on a de facto basis (as Statistics Canada has accepted for NHIC); IHI should report to no body other than HICC.

(d) HICC should encourage co-operation among all institutions with pertinence to health information development.

Observing that the existing non-government organizations, the MIS Group and HMRI, are separately engaged in some important aspects of what would need to be achieved more generally by IHI/CCHI, it is an immediately attractive notion that those two organizations be merged to form the nucleus for IHI, with an expanded mandate which would subsume their functions.

While I have no doubt that each of HMRI, the MIS Group and CCHI are performing useful work, it is evident that:

(a) their current production does not satisfy the range of health information needed;

(b) their joint performance has potential for improvement from co-ordination/collaboration;

(c) while there may be short run advantages from the directional relationships of HMRI and MIS Group to hospitals, one cannot proliferate similar organizations to meet the information needs of nursing homes, pharmacists, various advocacy groups, etc.

**NGOs and the Private Sector**

The abbreviated designation "NGO" (non-governmental organization) is a common one in the health field. What I find confusing is the distinction which some seem to make between NGOs and the private sector. I could not determine the dividing line! The importance of this seemingly unimportant semantic confusion is that some senior government officials challenge the appropriateness of the private sector being involved in concerted health information development while being prepared to accept participation from NGOs.

Are not-for-profit nursing homes NGOs, while for-profit nursing homes are private sector? Are pharmacists NGOs, while pharmaceutical associations are private sector (or vice versa)? Are insurance companies which provide health and disability and accident insurance (a role parallel to government health insurance) NGOs or private sector? Is the CMA an NGO while private practice physicians are private sector? Is MedicAlert an NGO? Since the private sector provides so many goods and services central to health care, and is concerned with occupational and environmental safety, absenteeism, health care insurance, etc., surely it is appropriate and in the public interest to assure that the private sector is well equipped with health information, and intimately involved in health information systems development.
Openness

From the outset, the Task Force was committed to openness in participation, in sharing documentation, in all deliberations. I value greatly a letter of May 5, 1991 from a senior government official who wrote: "One aspect of the Task Force's work which I admire greatly is its openness, which I believe will result in a much better product than if you had proceeded along more traditional bureaucratic lines." I strongly recommend that judgement as having central importance in work to improve health information systems.

Priorities

Specifying priorities is always important, and dominantly so in the complex field of health information. However, in health information the first question which arises is whose priorities? Every health constituency has important information needs. Each advocacy group (smoking, cancer, multiple sclerosis, kidney, etc.), each professional association (CMA, CNA, CPHA, etc.)¹, each institution (college, hospital, research centre, etc.), each community and so on, has an important human mission. Specifying priorities cannot be done as an exercise in logic or cost-benefit analysis -- whose cost, whose benefit? Like many important areas of human endeavour, health information priorities will emerge as a function of opportunities and compromise consensus. For such priorities to be practically productive, the consensus needs to be based on broad and authoritative participation.

Analysis, Linkage, Privacy

Vast amounts of health data are recorded. Reliable information is in much shorter supply. Task Force consultations indicate a strong consensus that much-extended analytical work is needed. Still, the view by some that improved analysis may alleviate the need for extensive health data systems development seems far too optimistic. Deficiencies in current data systems -- non-consistent concepts and definitions, absence of longitudinal information, no linkage of medical care encounters, lack of comparable unit costing data, lack of data quality control, etc. -- severely limit the capacity for analysis.

The relation of a manufacturing process to raw materials is analogous to that of analysis to data. Excellent raw materials may yield a poor product if the process is bad and an excellent process may lead to a poor product if the raw materials are bad. With unreliable data, excellent analysis may lead to no information, or worse, to misinformation.

As discussed elsewhere in the report, capacities to link data are crucial to effective analysis. But data linkage poses important public interest questions regarding privacy. Once again, one can perceive the need and value of an authoritative body -- acceptably representative of all health constituencies -- establishing policies and ensuring co-operation regarding common data standards, linkage requirements, and advising on the acceptable balance between privacy and health advancement.

¹ CMA (Canadian Medical Association), CNA (Canadian Nurses Association), CPHA (Canadian Public Health Association)
Population Health Status

There is increasing attention by health professionals to the "risk factors" for good health and well-being. The bulk of health information, such as it is, is oriented to illness, illness care and risk factors for disease. Issues such as lifestyle, job satisfaction, socio-economic status, community and family support systems, childhood development circumstances, are perceived by many as underdeveloped areas relative to traditional medical/hospital treatment insofar as health sustenance is concerned.

Statistics Canada operates expensive and extensive monthly surveys of employment and unemployment, of prices and inflation, to mention just two regular economic "status" surveys. These are important. However, no comprehensive, systematic periodic statistical data are collected to indicate population health status and trends! Since identified health care costs account for nearly 10 percent of the Gross Domestic Product, even on narrow economic grounds this lack of dynamic data on the health status of Canadians to monitor and inform health policy is curious. If shifts in the health paradigms, which health professionals feel is overdue, are to find public and political support, then periodic statistical indicators of population health must be produced and promulgated. (The analogy with the importance of public awareness of economic and financial matters is immediate.)

Tensions and Competition

The health "information gap" has been widely recognized for a long time. My conjecture is that the persistence of this gap is indeed closely connected with the central importance of the topic of health. Precisely because health is so complex and so dominantly important in human affairs, there are inevitable multitudinous tensions, disagreements and competitiveness among health constituencies. Conflicts of interest and judgements cover many arenas: institutional versus community health care; importance of lifestyle versus medical treatment; issues of professional autonomy; professional status and prestige; resource allocation among localities, among technologies, among care institutions, among disease treatments; compensation levels; profits; etc.

There is a real and continuing basis for this competitiveness -- and some of it is productive to the public interest. Reliable and objective data development is neutral in promising general net benefits to all constituencies (and to the public), but support for health information systems development will be forthcoming only if all health constituencies feel they are influential participants and beneficiaries of the process.

Governance

Tensions among constituencies derive in part from disagreements that are subject to removable uncertainties. Examples are many: the effectiveness or desirability of surgical procedures (e.g. a coronary by-pass); the wisdom or appropriateness of medications; the cost-benefit of expensive imaging technologies; the potential gains from health care devolution; the health significance of environmental "hazards"; the importance of lifestyle; the balance or importance to population health between medical treatment and socio-economic policies. Reliable health information can contribute to reducing unproductive tensions, to virtually everyone's benefit.
Accordingly, governance arrangements in support of health information development must accommodate these tensions based on a "bottom up" process. There is a need for leadership to develop acceptable governance and operational capacity, but the "nominations" for representation need to come from the "grass roots" -- somewhat analogous to the untidiness of democratic politics.

A consortium of health ministries would seem the most likely source of leadership, perhaps the only one, for an effort to initiate a broad-based partnership of equals to establish governance toward co-ordinated health information development. For such leadership, health ministries must be prepared to relinquish control. The governance process will be effective only if no sector is perceived to dominate.

"Long Twilight Struggle"

Impediments to health information development are many and major. But the importance of information to human health improvement and to resource management is strong motivation to persist in the "long twilight struggle". This is not an area for "quick fix", like a one-shot survey or a "magic bullet"! Health policy and science are awesomely complex, and complicated further by the virtual impossibility of controlled experiments. Health science has not yet developed broad theoretical structures which subsume large areas for prediction or prescription. Health knowledge and policy are heavily dependent on piecemeal data, anecdotes, plausible impressions and unsubstantiated beliefs. The potential for successful evolutionary improvement in health information is surely enormous.

In my judgement, an important threshold step to unlocking that potential is leadership toward establishing broad-based governance, by a representative body of equals, acceptable to all health constituencies, to oversee, direct and co-ordinate the evolution of improved health information systems from Canada.

Martin B. Wilk
Chairman
FOREWORD
FOREWORD

The work of the Task Force was addressed to developing consensus viewpoints regarding health information based on consultations with, and contributions from, a broad spectrum of health constituencies. To that end, the following report reflects the full array of some 21 project teams reports, briefs and letters from various stakeholders, plus significant extracts from recorded consultations and various public documents.

The documentation associated with the work of the Task Force and this report is extensive. While the inclusion of all that documentation in the report distribution would be highly desirable, it was judged impractical. However, the references undergirding this report are listed in Section 9.0, with a convenient tear-out sheet for requesting selected items. Typically those references will be available in English.

Initial plans to condense the variety of input information into an integrated Task Force report had to be substantially adjusted for a variety of compelling reasons. Thus, to a larger extent than might be optimal, most project teams reports must speak for themselves.

Most of the investigation of "implementation" issues was by oral interaction. And, as it happened, that area was the only one where "non-consensus" might be potentially significant. In reporting the findings regarding implementation, a sincere effort has been made to reflect in summary the range of positions and uncertainties encountered. The discussion of various positions provided in the section on implementation is intended to stimulate thought on alternatives. The material there reflects judgement of the Task Force chairman developed in the course of extensive consultations with various Task Force members and representatives of many health constituencies.

The May 31, 1991 presentation (Reference 9.8) to the Conference of Deputy Ministers of Health and the Chief Statistician was a preliminary condensation of selected Task Force findings and recommendations. There is some question as to whether the implementation recommendations of that document would be regarded as having "consensus" support. I believe, however, that they did reflect the recommendations by the majority of (the very many) with whom I reviewed objectives and alternatives concerning implementation. But, some of my consultees may have modified their evaluations, as is both their right and reasonable.

The merits of the Task Force work derive from the widespread contributions of many persons and organizations. Naturally, some contributed more intensively than others, but commendations are in order for all of the some 600 identified individuals who played a role in this public interest endeavour, as well as others who contributed anonymously. Particular mention should be made of the National Health Information Council and the Conference of Deputy Ministers of Health who, with the Chief Statistician of Canada, sponsored and supported the Task Force investigations.

I want to express my personal thanks to the many persons who informed and guided me in this challenging assignment. I appreciate also the time and courtesy afforded to me by the many senior persons with whom I had the privilege of consulting. The field of health is so broad and indefinitely defined that it is impossible even in principle to assert "full" consultation. And given the limited time horizon of the Task Force, only selected areas could be probed, often only generally. But the Task Force mission had sufficient intensive public interest importance that it proved possible to tap the accumulated knowledge, experience and judgement of many accomplished persons. I hope that the present document does justice to their contributions and proves productive.

Martin B. Wilk
Chairman
1.0 INTRODUCTION

This report has many facets. It is a vehicle for organizing findings and recommendations from the 21 project teams reports, each of which is intrinsically part of this Task Force report. It is a stimulus to condense the various impressions and judgements which emerged from oral exchanges and consultations. It provides an opportunity to summarize Task Force activities and achievements. It provides a vehicle for delineating concerns regarding health and health information and, perhaps, provoking further creative consideration of those concerns. It may serve to promote or stimulate networks or interactions among health constituencies in different disciplines or with different responsibilities.

1.1 Purpose

The summary purpose of this report is to make broadly available information on the findings and recommendations associated with the work of the National Task Force on Health Information.

1.2 Mission

The mission of the Task Force was to make strategic planning recommendations toward the development of effective health information systems for Canada. The Task Force was sponsored and supported by the National Health Information Council (Reference 9.2) and the Conference of Deputy Ministers of Health and the Chief Statistician of Canada (Reference 9.7).

1.3 Task Force Processes

The Task Force was constituted by any and all persons who were interested in participating and contributing. There was not a closed, pre-selected cadre, though some persons did provide a core organizational role.

All activities and consultations of the Task Force were in the public domain. All meetings were open.

The strategy of the Task Force was based on widespread consultations and soliciting contributions of current knowledge, experience and judgement from interested and informed persons and health constituencies. Early efforts were made to extend participation through invitations to health-related stakeholders and constituencies, and to arrange for country-wide consultations.

The Task Force sent letters to 56 stakeholder organizations and received briefs or other responses from 23. Consultations were held by Task Force representatives in each province and territory, as arranged by the relevant NHIC member, with the Deputy Minister of Health’s support.

An all-day public workshop was held in February 1991, in concert with Statistics Canada’s Health Statistics Advisory Committee. Attended by some 120 persons, preliminary reports on the Task Force work were presented. A Task Force newsletter, Tidbits, was sent out bi-monthly to some 580 recipients. Several project teams organized all-day workshops - on Lifestyles, Community Care, Confidentiality, Marketing.

Task Force representatives met with each of the provincial and federal Health Deputies (one by phone), the Chief Statistician, the Chairperson and the Executives of the National Health Information Council (NHIC) and with the full NHIC on several occasions. They also met with
senior persons of other government departments and organizations such as Canadian Medical Association (CMA), Canadian Hospital Association (CHA), Canadian Nurses Association (CNA), Canadian Public Health Association (CPHA), Canadian Council on Health Facilities Accreditation (CCHFA), Canadian Institute for Advanced Research (CIAR), the Management Information Services (MIS) Group, Hospital Medical Records Institute (HMRI), Ontario Premiers’ Council on Health, Ontario’s Department of Labour, etc.

After an initial period of "brainstorming" sessions to overview current status and identify areas for particular investigation, the Task Force established project teams (typically with nation-wide membership) to pursue particular areas of concern. Thence, the following topics are covered by Project Team Reports which constitute the backbone of Task Force work (and are intrinsically part of the present report):

- Indicators of Health Status
- Health Policy Information Requirements
- Identification of Key Actors and Stakeholders and Their Information Needs
- Requirements for Marketing Health Information
- Implications of Privacy and Confidentiality Concerns
- Information Needs Relating to Lifestyle
- Information Needed to Support Community Interactions and Interventions
- Comparability of Health Services Information
- Information for the Economic Analysis of Health
- Information Needed to Support Health Human Resource Management
- Health Care Quality Assurance and Outcomes
- Information in Support of Epidemiology
- Information on Health Determinants
- Health Information Analysis: Potentials and Impediments
- Development of a Structural Model of Concepts of Health Information (Template)
- Mapping Existing Information Programs onto the Template, Identification of Data Gaps and Provincial Systems Directions
- Data Acquisition Alternatives
- Interface Examination, MIS/HMRI
- Interface Examination, MIS/Statistics Canada
- Interface Examination, HMRI/Statistics Canada
- Interface Examination, Statistics Canada/
  Health and Welfare Canada
- Interfaces Among Institutions doing Health Services Analysis
1.4 **Health Issues**

Concern with improving information systems is generally symptomatic of significant perceived problems, provocations or opportunities in the substantive area. These factors are applicable in the current health arena.

(a) Many challenges have emerged to the traditional paradigm which relates health tightly to medical/hospital treatment of disease. Increasingly, health is being perceived as more than the absence of disease, with increased emphasis on lifestyle influences, including socio-economic and environmental factors. Attention is being directed not only to the risk factors for identified diseases but also to the "risk factors for chronic good health".

(b) Direct expenditures on health care consume a major fraction of Canada’s GDP (Gross Domestic Product) and have been increasing more rapidly than population, the overall economy or (probably) improvement in the health status or longevity of Canadians. With fiscal deficits in virtually every jurisdiction, concern with health budgets has become every government’s obsession. Questions are raised on the basic affordability of Canadian health care practices. Attention is being focused on whether increased productivity or other savings are possible.

(c) Canadian demographic trends indicate increasing aging of the population with implications regarding the costliness of care provision for the elderly and the planning for the corresponding proper profile of health care resources (acute care, chronic care, home care, community care).

(d) There is widespread recognition of the uncertainties of longer term outcomes or effectiveness of medical treatments and technologies. Hospital and medical "discharges" are not systematically followed by patient monitoring.

(e) Serious questions are being raised regarding health policies and management practices. Some of these questions concern the wisdom of proposals for devolution from hospitals to nursing homes to home care to community care; from centralized management of health care facilities to community-based arrangements; from medical care specialists to paramedical care practitioners; etc. Other questions concern matters of efficacy (what works in principal); effectiveness (what works in practice); efficiency (what is cost beneficial in scarce resource allocation); human resource development (numbers, training and distribution); medical technology distribution (including hospital location and size).

(f) A troubling underlying concern to many health constituencies is the non-concurrence of public perceptions and expectations with those of health professionals. Examples include: lifestyle significance (smoking, alcohol); capacity of the health care system; limitations of resource allocation; consequences of medication; relative frequency and well-being impact of various health impairments in the population; importance of socio-economic and environmental influences; etc.
1.5 **Health Information Issues**

The perceived need for improved health information is not a recent development, though the current focus on some of the above-mentioned health issues has perhaps amplified the continuing information needs.

Indeed, as detailed in the sequel, the present Task Force findings on deficiencies of, and requirements for, health information development seem very much like rearticulated echoes of those of the 1964 Royal Commission on Health Services.

In view of the unanimous agreement that population health advancement is a matter of pre-eminent public interest, and the general consensus that health information systems improvement would be beneficial to the public interest, it may be of value to consider issues which may have impeded progress.

(a) Health matters are usually intensely private and legislative and professional standards require protection of that privacy. Thus, access to basic health care data is difficult, in principal; and in practice, standards for recording appropriate data are spotty or non-existent. Direct survey questions on health status or experiences may also be restricted so as not to "invade privacy".

(b) Health matters are enormously complex. Even specialists differ on diagnosis, disease classification, severity assessments, appropriate treatment, or assessment of outcomes.

(c) Health matters are not easily examined via controlled experiments. Observational data are typically costly, requiring complex analytical adjustments for interpretation.

(d) Health is a dynamic characteristic and its assessment needs observation over time. Longitudinal (follow-up) data are notoriously difficult to develop.

(e) Management/financial data for health care administration and budgeting are hard to standardize and implement given the complexity of hospitals, nursing homes, medical practices, etc. coupled with the traditions of professional autonomy and independence of health professionals.

(f) Data quality and reliability are always difficult to assure, perhaps additionally so in an environment where immediate attention to the health requirements of a specific human being in need is bound to overweigh attention to data records.

(g) Because of the bewildering complexity of factors that may be significant to health -- treatment, management, budgeting, technology assessment, policy -- no one designed data set will generally suffice for effective analysis. Thus, there is the need -- and the promise -- of using linkage methods to supplement information requirements. Such linkage might involve association of successive encounters of a given individual; or the extension of one data base by linkage to other data bases (e.g. health care data augmented by socio-economic survey data), or the linkage of individuals with common symptoms. Techniques and computer-based capacities for data linkage are well developed and practical. It is undoubtedly essential to use such capacities if health information systems are to evolve productively.
However, there is a very serious downside risk in data linkage namely, invasion of privacy and breach of confidentiality. And even when full safeguards are in place, there is the risk of public perception of invasion of privacy with subsequent resistance to provision of data, in practice or via policy.

(h) Health information, perhaps more than any other information category, is a "public good". In contrast to most other scientific disciplines, the full value of health science findings will not accrue to the public interest unless the implications are appreciated and practised by the population at large.

For this reason, and because of the essentiality of public support and co-operation in order to gather health information, health information development needs to be in the public domain, and effectively marketed to the public.

An essential ingredient for the applied value of health information, as is true in general for all scientific, statistical and media-reported data, is that it not only be objective and reliable but that it have the credibility to be perceived as having been developed with professional integrity.

(i) Strong motivations or agreed upon needs are not quite sufficient for achievement. In the case of Canadian health information, other attributes are also positive. Those include: state of the art informatics and communications technology; government funding of health care systems; the initiative of the Deputy Ministers of Health to establish the National Health Information Council in co-operation with Statistics Canada; the fact that Canada has a centralized statistical system of premier calibre; the existence of the world-class Canadian-based Population Health Research Program sponsored by the Canadian Institute for Advanced Research; and the experience of the Task Force in obtaining participation and encouragement from virtually all health constituencies.

1.6 Task Force Achievements

Task Force initiatives had an effect somewhat like introducing a crystal into a "super-saturated" solution, namely triggering a fairly massive precipitation. Some of the achievements of the Task Force include:

(a) Despite major tensions among health constituencies on matters of policy, practice and emphasis, the widespread approval and support of Task Force efforts demonstrate that concerted co-operation is practically possible in the avenue of health information;

(b) Task Force encounters support the judgement that health information is widely accepted in principle as a "neutral" area of unchallenged public interest relevance (but with varying reservations in practice);

(c) Task Force consultations strongly support the judgement that a national co-operative effort to improve health information systems is vitally important to cope with the policy dilemma of fiscally unsupportable escalating health care costs confronting public expectations of health services;
(d) Task Force process and projects helped to create or advance communication networks among persons and institutions, often of differing disciplines or responsibilities. Indeed, many felt that that aspect alone of Task Force efforts was of significant lasting value;

(e) Task Force work led to the development of a conceptual structural model (the Template) to delineate coherently the enormous scope of health information;

(f) Project teams developed documentation and recommendations for a wide variety of identified needs for various purposes and constituencies;

(g) Project teams provided assessments and recommendations regarding important techniques, methodologies and collateral issues, such as privacy and confidentiality;

(h) Widespread consultations and assessment of alternatives by Task Force representatives led to articulation of scenarios for implementation of directives and operating mechanisms for the evolution of improved health information systems.

1.7 Despite the fact that the Canadian public is generally satisfied with Canada’s health care system, which compares favourably with that of other countries, the predominant view of researchers, health care providers, policy analysts and managers is that significant improvements can be achieved, both in the health of Canadians and in resources management, if health information could be made more reliable, comparable, extensive and available.
2.0 CURRENT STATUS

The overall assessment of the current status of health information systems in Canada is implicit in the project team reports as in other informed public documents. In general, the consensus perception is that the current status is grossly inadequate and quite deplorable in many areas -- quality assurance, assessment of treatment outcomes, technology assessments, associating costs with procedures, management of resources, utilization rates, cost-benefit evaluations, human resources development, community health care, dynamics of population health status, comparisons of procedure rates, impact of environmental influences, disease incidence, lifestyle implementation, etc.

Naturally, different health constituencies identify differing information deficiencies and priorities responsive to their interests. The diversity of these is such that perhaps a best summary portrayal of current status is to provide a collage of direct quotes from project teams’ reports and from other qualified sources. This collection of extracts is provided later in this section.

2.1 The 1964 Royal Commission on Health Services

A perusal of those summary assessments will be indicative of the breadth of current perceptions of health information needs and deficiencies. However, it is important to appreciate that these current assessments are disturbingly reminiscent of judgements made 27 years ago in the report of the 1964 Royal Commission on Health Services, which expresses general and specific concerns. Some extracts from the 1964 report follow:

"Despite the volume of health statistics collected, we have found serious shortcomings... moreover... the analysis of health statistics... has lagged substantially behind the collection of data."

"... it was not possible in many cases to obtain data that would permit an evaluation of the effects of health programmes..."

"But as we were concerned with the health problems of the Canadian people as a whole, our main need was for national statistics and for data showing significant variations among provinces and regions. These were difficult and sometimes impossible to obtain."

"...national hospital statistics... series were 3 or 4 years old... (when) published."

"Despite the general concern over the growing cost of hospitalization... we have no adequate information indicating whether there is over-use or perhaps under-use of hospital facilities."

"Only very limited statistics are available on... medical group practice, home care and rehabilitation services."

"...little effort has been made to define and quantify the positive state of health rather than the negative state manifested by illness."
"No (adequate) effort has yet been made to cope... with emerging health problems such as chronic disease... mental disorders, accidents, physical and mental handicaps... dental disorders and others."

"Data have not always been obtained with a view to making effective use of modern recording and data-processing equipment."

2.2 Discussion of a Paradox

The persistence of negative perceptions in the face of near-unanimous consensus on unfilled public interest health information needs is a challenge for explanation. Following are a few conjectures:

(a) Progress has indeed been made in the years since 1964, perhaps significant progress, but the perceptions of magnitude of information need is such that the progress may appear as a small hill in relation to a towering mountain.

(b) Health policy and practice are so important in public perception that they are in a constant state of crisis and excitation. Paradoxically, the very importance of health matters may tend to inhibit the deliberate, concerted, persistent developments necessary to lay a foundation for effective health information systems development.

(c) While health information needs appear to be endemic among health constituencies, their areas of concern may not interact sufficiently to stimulate the spontaneous creation of the co-operation and co-ordination mechanisms which are fundamental for progress in this complex area.

(d) Tensions and competitions are many among health constituencies -- for status, control, resources, priorities, rewards, profits, etc. These recurrent almost-adversarial relationships are such that creation of the essential co-operating/co-ordinating arrangements to harvest the joint benefit of effective health information systems requires surmounting major thresholds of suspicion or distrust or misunderstandings or conflicts of interest.

(e) Health constituencies tend to be fiercely protective of their independence and autonomy. It was a breakthrough even for the provincial and federal health ministries to create the National Health Information Council in co-operation with Statistics Canada. Significantly, no non-government constituencies were part of the initiative.

- Provincial professional associations have varying degrees of association with their national counterparts.

- Two non-government organizations doing valuable health information work, the MIS Group and HMRI, tended to have minimal mutual interaction. And neither group had a Statistics Canada representative on its board of directors until a few months ago.

- Statistics Canada and Health and Welfare Canada have not yet been able to establish mutually agreeable principles and practices on responsibilities for health information development. (e.g. Health and Welfare Canada maintains a Physician Register, Statistics Canada maintains a Nurses Register.)
Some government officials are leery of the good faith of the health industry private sector.

Most non-government health constituencies are emphatically resentful of the intrusiveness and domination of governments.

Privacy concerns may be an important inhibiting factor.

2.3 What weighted combination of these or other factors (such as the chronic refrain of budget problems or debate on how to share costs) may be responsible for the almost inexcusable lack of satisfactory progress is a matter for careful judgement. Historical experiences strongly suggest that meaningful progress in health information development will require surmounting substantial thresholds if the status quo is to be significantly improved.

2.4 Current Status Assessments

The intent of the following random sequence of extracts is to provide perspective impressions of current assessments of the state of health information by a wide spectrum of constituencies.

"If we could make only one change to the present data collection, it would have to be the establishment of individual unique identifiers from cradle to grave."

"The ICD was designed (to classify) cause of death... it can be frustrating to use... to... measure other than mortality. (Extracts from the Report of the Project Team on Information Needs for Health Care Quality Assurance and Outcomes.)

"... (with) the right information, we might be able to distinguish among the various possible causes of this variability (of surgical procedures rates) -- natural random variation, data errors (etc.)... or is it a quirk of the number of specialist physicians in each community, and whether they were trained in the U.K. rather than the U.S. (Extract from the Project Team Report on the Template.)

"The lack of standard data definitions, minimum data sets, standard edit rules, as well as quality control and security procedures is completely unacceptable." (Extract from the Project Team on Comparability.)

"Standardization of data collection across the country is absolutely paramount to making rational decisions as to areas of need in health care resources or, indeed, areas of access."

"... we had little faith that we were counting the same things in the different hospitals. (Extracts from Canadian Cardiovascular Society Brief)

"Data elements must be standardized across institutions, organizations, and jurisdictions to permit adequate monitoring and tracking of the information required for judgements
about progress or quality." (Extract from Cancer 2000: Draft Discussion Paper: May 1991)

"... the typical physician lacks any idea of how his/her practice compares to others, and would love to know. Knowledge of the effectiveness of various therapies ... is key to making rational decisions." (Extract from the Report of the Project Team on Information Needs for Health Care Quality Assurance and Outcomes.)

"That much of our discussion about outcomes can only so far be based on incomplete data, points to the need for improved follow-up services and data collection."

"... we have a responsibility to ensure that we track outcomes and modify practice as a result of what we have learned." (Extracts from Speech by Dr. Patricia Baird, Chairperson, Royal Commission on New Reproductive Technologies, Whistler, B.C., May 24, 1991.)

"There are four things you need to know to run your facilities:
1) Do you know the kind of interventions occurring in your facilities?
2) Do you know how appropriate these interventions are?
3) Do you know the quality of these interventions?
4) Do you have any idea about the function of life after these interventions?"

"The most elementary measure of the outcome of disease is the case-fatality rate... with the exception of cancer (in some provinces) and end-stage renal failure, no population based measures of disease outcome exist." (Extract from the Report on Information in Support of Epidemiology.)

"the evaluation phase at all policy levels seems amenable to a good deal of objective information content - have we or have we not produced more health - but at no level has an especially strong tradition of outcome evaluation yet developed." (Extracts from the Project Team on Health Policy Information Requirements.)

"... most providers receive almost no feedback of hospital discharge data."

"There is very little data currently collected in Canada that can be used to assess quality of care in ambulatory settings."

"... if unique identifiers with accurate diagnostic and procedure information were on the physician billing data, and this could be linked to pharmacy data... and lab testing, one would have the beginnings of a system for assessing effectiveness and quality of care."

"Administrative data sets need to be considered more fully in terms of their value in assessing efficacy of therapy, effectiveness of therapy, and quality of care."
"(need) to develop... health care outcome indicators that control for... severity..."

"... while a large amount of information is currently available on heart by-pass procedures by age, sex and residence, very little, if any, information is collected on illness severity, or multiple hospital visits/discharges as a result of this procedure."  (Extracts from the Report of the Project Team on Information Needs for Health Care Quality Assurance and Outcomes.)

"The current (health information) system is based on health care and illness treatment -- not upon health promotion or health."  (Extract from Report of Project Team on Lifestyles.)

"Severity measures are needed for any comparison of outcomes. Before we can collect such data, there must be some consensus on measures."  (Extract from the Report of the Project Team on Information Needs for Health Care Quality Assurance and Outcomes.)

"While the MIS Guidelines have been developed they have not been fully accepted and implemented despite the fact that the project has been underway for over 10 years." (Extract from the Comparability Project Team Report)

"Individual provincial health surveys are too costly. It would be better to buy into special samples of the Canada Health Survey."  (Comment received during Provincial/Territorial Visits - Winnipeg, Manitoba)

"(A) National Statistical Agency (has a) primary focus... to produce data for the "public good"... funded from the public purse, with recovery of costs only for... services that go beyond what is made freely available through public dissemination networks... A (non-government) Health Records Institute (would have a) primary focus (on) provision of information services on a cost recovery basis... the basic contract... is a financial one based on services provided. Although the orientations... are different, there is... much potential for overlap... the question of how best to ensure coordination of... the two agencies is paramount..."  (Quoted from the Report of the HMRI/CCHI Interface Study.)

"It is notorious that new interventions are introduced and... disseminated, in the absence of... evidence (on effectiveness, still less cost effectiveness)."  (Extract from "Producing Health, Consuming Health Care" by Evans and Stoddart.)

"... three basic principles should be adopted when discussing the information (needs) for health economics: it should be robust in terms of accuracy; .... the fewer organizations having to provide the information the better; and it should emphasize more information rather than more data. "  (Extract from the Working Group on Health Economics.)

"Real data sets... lack detailed clinical... information on... condition... at... hospital admission and discharge..."  (Extract from the Report of the Project Team on
"A clearinghouse for information about the existence and nature of projects involving health data production, development and analysis (and grants awarded for such projects) should be established and maintained."  (Extract from the Project Team Report on Health Information Analysis: Potentials and Impediments.)

"...By far the largest part of health care costs are incurred in the area of human resources... Health human resources expenditures are never below 60% and may, sometimes, be as high as 80% of total health care costs"  (Extract of the Report on Information Requirements in Health Human Resources.)

"The Committee... identified the need for information on experience with devolution in other jurisdictions... for example:
- what are the most effective means...?
- how does devolution affect cost-effectiveness...?
- what problems does devolution address...?
- ...has devolution... (involved) local people in decision(s)?
- ...has devolution made services more responsive...?
- ...what are... conditions... and contra indications... for devolution?"

"The management of health human resources, in its broadest sense, entails various monitoring, planning and policy research functions that rely on the availability of relevant, accurate and consistent information."  (Extract from Report on Information Requirement in Health Human Resources.)

"(We need) data to reduce rates of over-testing, unnecessary surgery and poor prescribing."  (Extract from the Report of the Project Team on Information Needs for Health Care Quality Assurance and Outcomes.)

"Failure to provide adequate support for health data analysis can be a penny-wise and pound-foolish decision if it prevents the analysis of under-utilized data whose production and maintenance were and are extremely costly, and when analysis would result in better allocation of the tens of billions of dollars per year spent on health care."

"There is a worldwide shortage of highly trained, highly skilled data analysts, in particular, of analysts of health data."  (Extract from the Project Team Report on Health Information Analysis: Potentials and Impediments.)

"It is important to standardize data for better national analysis and interprovincial comparison of human resources based on occupational supply, measure of workload capacity and service requirements."  (Extract from Dr. Jean Dupont's Paper on Health Human Resource Management.)
"If the policy makers, provincial and federal governments and the home support sector itself are going to be in a position to respond to increasing demands for health and social services in the home, we must be able to refer to a bank of national data." (Extract from HomeSupport Brief)

"The purpose of all health human resources activity is to identify and achieve the optimal number, mix and distribution of personnel, at a cost society is able to afford... Specific human resources planning initiatives have often been hampered by inadequate data and questionable methodologies..." (Extract from the Report on Information Requirements in Health Human Resources.)

"Health information systems (for community-based services) are needed, ... developed in a bottom-up manner."

"(There is a) lack of appropriate and efficient mechanisms for locating and accessing health information and the lack of resources and skills among community groups."

"...if you cannot get (at) the information, regardless of the reason, it, in effect, does not exist."

"...whilst there (is) considerable diversity in community health information needs, there (are) also a number of similarities. (Common) issues which ran through them were accountability, accessibility, appropriateness, cost, unavailability of data/information, accuracy and timeliness." (Extracts from the Project Team Report on Information Needed to Support Community Interactions and Interventions.)

"... the health care industry is simply one part of the information base contributing to the health status of the population. ..." (Extract from Optima Humanus Inc. Brief.)

"The provinces and territories need to be able to evaluate how their approaches to the health of their populations compare with others." (Comment received during Provincial/Territorial Visits - Regina, Saskatchewan)

"... the presence of illness and utilization of the health care system is not the best indicator of the health status of individuals and communities..." (Extract from the Project Team on Health Status Indicators.)

"In terms of population type information, objective measures of population status, health related behaviours and disease burden will continue to have ongoing relevance to policy makers at all levels." (Extract from the Project Team Report on Health Policy Information Requirements.)

"A major area of current health care policy concern is small area variations in surgical procedures rates. Using the limited data available, we find very large variations... There is certainly smoke, but not enough information to determine where the fires are." (Extract from the Template Tour, Section 6.)

National Task Force on Health Information
"There was a strong consensus among the (project) team members... that there is a need for the marketing of health information... that the value of health information to society can only be fully realized if that information is absorbed and acted upon by the population at large." (Extract from Report of Project Team on Marketing.)

"A vast range of concerns in the health area are continually competing for attention... cancer, heart disease, AIDS and multiple sclerosis... concerns about types of health interventions such as hospital care versus home care, or curative versus preventative approaches... risk factors such as PCBs, electromagnetic radiation, smoking, or dietary fat intake. Still others raise questions about... psycho-social phenomena like work place stress... No information is provided on (the) relative importance of (these concerns)... environmental damage from a tire fire is measured in numbers of tires, and allusions to effects on local ground water... As a result of (such) partial and inconsistent information... the public is concerned and confused." (Extract from Memo by M.C. Wolfson for CIAR Population Health Research Program.)

"... Ontario has identified a lack of information... (on exposure) to environmental risks..." (Extract from the Report of the Project Team on Health Status Indicators.)

"Cancer information systems and public information lines must be accessible to all Canadians. They should offer up-to-date information on: health promotion; prevention; unorthodox, innovative, and conventional therapies; psycho-social support services; and cancer control activities in general." (Extract from Cancer 2000: Draft Discussion Paper, May 1991)

"... the most outstanding feature of the field of workplace reproductive hazards is the lack of good information... we don't know how or if most workplace exposures are linked... to reproductive problems... Instead we have speculation..." (Extract from Speech by Patricia Baird on "Workplace Health and Society", March 1991, Hamilton)

"There should be compulsory registration of every diagnosis of cancer wherever that diagnosis occurs." (Extract from Cancer 2000: Draft Discussion Paper, May 1991)

"An example of successful data sharing is the National Cancer Incidence Reporting System. Information from each province about each new primary case diagnosed in Canada is reported to a central cancer registry. The provinces also pool their vital statistics (data on births, deaths and marriages) at Statistics Canada. Such registries have immense analytical potential. This potential increases with the timeliness, accuracy and completeness of data reporting, and with the comparability of data from different locations." (Extract from the Project Team Report on Health Information Analysis: Potentials and Impediments.)

"... there is a dearth of information on disease incidence at the national level and this should be a major concern."

"No consistent time series can be assembled for other tremendously important risk factors
such as blood lipids, blood pressure (treated and untreated), alcohol consumption and diet." *(Extracts from the Report on Information in Support of Epidemiology.)*

"The absence of data items (variables) in multivariate data prevents... measuring... interrelationships... because there is no information about the smoking habits of cancer patients, ... provincial cancer registries... cannot be used to study the relationship between smoking and cancer." *(Extract from the Project Team Report on Health Information Analysis: Potentials and Impediments.)*

"One of the most consistent messages... is that Canadians are no longer willing to allow the "experts" or "authorities" to make decisions on their health and well-being for them." *(Speech by Dr. Patricia Baird, Chairperson, Royal Commission on New Reproductive Technologies, Whistler, B.C., May 24, 1991.)*

"with few exceptions, the marketing of health information has usually been considered an after-the-fact activity -- to consider questions as to potential clients or audience, what they need to know, and what format or medium would be most effective." *(Extract from Report of the Project Team on Requirements for Marketing Health Information.)*

"... more information is required on disability, mental health and the impact of occupational and environmental hazards on health." *(Extract from the Report of the Project Team on Health Status Indicators.)*

"While there is now more than enough research and information to understand the magnitude of the dangers, the risks, and the consequences of tobacco use, there is a desperate need for much more and much better information on how to develop and implement effective interventions to solve the problem, especially in the area of public policy. An additional factor is the need for improved dissemination of, and access to, whatever information currently exists or becomes available." *(Extract from Canadian Council on Smoking and Health Brief.)*

"In the current operations of (HMRI and CCHI) there are... areas of activity in which both are involved... However, there is... complementarity... That is not to say there are no opportunities for greater collaboration between the two organizations...specifically:

- modification/expansion of HMRI data base;
- enhancement of HMRI diagnostic and procedural edits;
- Canadian implementation of ICD-10...;
- coding education...;
- provision of ad hoc... data bases;
- provision of hospital specific... reports." *(Quoted from the Report of the HMRI/CCHI Interface Study.)*

"The fact remains that information needs cannot be prioritized let alone articulated with any precision in the absence of insights into what the most appropriate measures and
"A main focus of provincial health indicators appears to remain on the measurement of illness or the prevalence of a particular disease."

"... a need to measure the autonomy of Canada's aging senior population and a need to develop indicators on their mental health..."

"... most provincial reviews identify a need for additional health status indicators on the presence of disability and mental well-being..."

"... the impact of environmental variables on health."

"... progress to develop, and regularly provide measures beyond the traditional indicators of health has been limited."

"... while there appears to be a recognition of a need for "health status" and "the determinants of health" indicators there has been very little progress with respect to the specification and elaboration of these types of indicators."

(Extracts from the Report of the Project Team on Health Status Indicators.)

"There is a growing gap between our understanding of the determinants of health, and the primary focus of health policy on the provision of health care." (Extract from "Producing Health, Consuming Health Care" by Evans and Stoddart.)

"... one principle issue which COACH would emphasize... would be to establish health information as a global resource and to promote secure access by and for all..." (Extract from Canadian Organization for Advancement of Computers in Health (COACH) Brief.)

"... there is widespread agreement that our present systems are largely inadequate in supplying comparable information. In some cases this is due to the non-existence of national comparative reporting systems, while in other areas it is due to inconsistent data definitions, improper analysis, lack of standards and guidelines, poor data quality management and lack of incentives."

"Reporting of expenditures and counting of resources has consumed most of the information system resources, and even in these areas, comparability is a problem."

"HMRI prepares comparative reports but only for its own clients -- it is not a national system."

"... (even the best attempt(s) at national comparative reporting (have a) concern... about... timing, with many hospitals and provinces failing to report on a timely basis..."

"... comparability of information is made more difficult because there are several different organizations involved in setting standards, collecting and storing data, analyzing and..."
disseminating results."
(Extracts from the Comparability Project Team Report.)

"Health information analysts are constantly frustrated and impeded by lack of comparability of data from different sources or from different time periods." (Extract from the Project Team Report on Health Information Analysis: Potentials and Impediments.)

"...data systems across the country must be integrated...(to) allow comparisons and support the knowledge that can be gained by understanding what other areas are doing..." (Extract from British Columbia Children’s Hospital Brief.)

"There is no motivation to push comparability along in Canada and this is critical." (Extract from Children’s Hospital of Eastern Ontario (CHEO) Brief.)

"... longitudinal information... is needed to provide insights into emerging health policy issues and into the public’s capacity to accept possible new health policy initiatives." (Extract from the Project Team on Health Policy Information Requirements.)

"A major barrier to equality for blind and visually impaired persons is lack of appropriate and timely information ..." (Extract from a Canadian National Institute for the Blind Brief.)

"There are many different users of (health) information each with different purposes...our present system has resulted in vast amounts of data being collected mainly for purposes of clinical practice and basic administration. These data are largely unusable for the purposes of research, policy analysis and policy making, and are very limited in their ability to support enquiry into the critical questions now being asked. Most notably, (our current information system) fails to collect data for...the factors in the new paradigm..."

"The recognized weaknesses of our present information systems are:

- lack of a clear definition of a service encounter;
- lack of national standards for coding elements of the service encounter;
- lack of consistent identifiers across programs;
- lack of a minimum data set;
- data quality is often poor...;
- data sets... are frequently incomplete" etc.
(Quoted from various Project Teams’ Reports pertinent to Information and Data Needs.)

"The range of important factors in human health is wide and the underlying causal pathways highly complex ... conventional scientific methods such as randomized controlled trials ... are technically infeasible, if not unethical ... as the central method for generating and testing hypotheses ... observational approaches... are the best method."
"Current observational studies... still are dominated by macro- or meso-data ... rather than on full micro-data. Such analyses suffer from the fundamental methodological risk of ecological fallacy."

"Health and diseases are dynamic processes ... understanding these ... is impossible without continuing observations ... over time..." (Extracts from the Project Team Report on Information Required to Understand the Determinants of Health.)

"Data gaps at the national level arise from various sources. These sources reflect: the historical development of health care programs and health care statistics; development of surveys which respond to particular issues; geography; partial coverage of the health care universe; and uneven development of data collection at the provincial level." (Extract from the Project Team Report on Mapping.)

"Linking health care interventions to health outcomes has therefore become a prominent activity." (Extract from the Project Team Report on Health Information Analysis: Potentials and Impediments.)

"Several major problems limit the utility of present data for technology and quality assessment ... the lack of a unique identifier, the limitations of ICD-9, the quality of the data, the timeliness and uniformity of the data." (Extract from the Project Team Report on Information Needs for Health Care Quality Assurance and Outcomes.)

"Vast amounts of health data exist whose full analytical potential has been unrealized."

"One of the hardest data gaps to rectify is that of missing longitudinal data."

"More collective agreements to share and pool health data should be made among data producers (in particular, among provinces/territories and the federal government)."

"More longitudinal health information - both administrative and survey data - should be collected and should be developed from existing data sets." (Extracts from the Project Team Report on Health Information Analysis: Potentials and Impediments.)

"The development of a home-focused system of care ....more cost effective way of approaching health care needs in this country ... we clearly need national statistics and information to support both the development of new approaches to care systems in Canada and the analysis of the effectiveness of them."

".... and no one (is) collecting even complete funding information, let alone user statistics." (Extracts from HomeSupport Brief.)

"... very valuable work has been done by overcoming the difficulties in linkage of administrative data... it is (technically) possible... to revise... data collection... (systems) to make (them) more useful... without being unduly... demanding on the information sources." (Quoted from various Project Teams' Reports pertinent to Information and Data Needs.)
"Although there have been many surveys at the national level taken to address issues or groups of issues, these surveys, useful as they are, cannot replace longitudinal or cohort data or the connection between survey and administrative data..." (Extract from the Project Team Report on Mapping.)

"The information requirements of different users for the same type of information can be markedly different. For this reason it will be important not to rely on the perspective of any one kind of user when defining any given subset of information needs." (Extract from the Project Team on Health Policy Information Requirements.)

"The road leading to health for all by the year 2000 passes through information." (Quote from World Health Organization.)

"... if a province is not part of a national system, it won't be able to evaluate the information it has." (Comment received during Provincial/Territorial Visits - Charlottetown, P.E.I.)

"... belief that good information leads to good decisions which result in good systems..." (Comment received during Provincial/Territorial Visits - Regina, Saskatchewan)

"... very useful... to have... demographic information... (about)... accidents." "Any... data... to better understand how accidents... are caused would help... focus... our research and development." (Extract from Canadian Red Cross Society Brief.)

"Nurses have some broad health information concerns... i) clinical information that has an impact on patient care and patient information that has an impact on nursing; ii) the need to collect data beyond the institutions; iii) intensity of workload information; iv) health human resource planning and the development of a predictive model for anticipating supply and demand; and v) the continued collection of national data on nurses." (Extract from Canadian Nurses Association Brief.)

"The magnitude of the (Task Force) project is so incredible, to break it down into good-sized chunks for the appropriate audience, is... going to be the big challenge." (Comment received during Provincial/Territorial Visits - Victoria, B.C.)

"... there's an increase in the acceptance of the importance of information for running health systems." (Comment received during Provincial/Territorial Visits - Halifax, Nova Scotia)

"Health is personal, familial and social well-being and the absence of disease." (Comment received during Provincial/Territorial Visits - St. John's, Newfoundland)

"Provincial governments (should) establish an interprovincial agency which would:

i. establish national principles of health care;
ii. provide necessary co-ordination and information sharing;
iii. monitor the functioning of the Canadian health care system in terms of the established standards and publicly release regular performance audits."


"There should be a post-censal survey on health status or health-related factors to get a "basic national measuring tool."

"...to allow standardization and control of the process, as opposed to negotiating individually with provinces on issues of confidentiality, data collection methods and status of data systems."

"...issues of ownership of data, access to it and cost."

"...it should be up to the provinces to monitor such systems".  (Comments received during Provincial/Territorial Visits - Fredericton, New Brunswick)

"Response rates in health surveys are apparently very high, suggesting that the general public understands the central importance of health knowledge..."  (Extract from the Report of Project Team on Privacy and Confidentiality.)

"The current program (of CCHI) is a product of many decisions taken independently over time... in response to the issues of the day."  (Quoted from the Report of the HMRI/CCHI Interface Study.)

"We at CHEO have been concerned about Canada's health information systems, particularly those in paediatrics ... Our main interest lies in comparability of health services information, quality assurance and outcomes and the development of structural models for identifying information gaps and putting reliable, relevant and timely information into the hands of people who make decisions."  (Extract from Children's Hospital of Eastern Ontario (CHEO) Brief.)

" The greater the need/desire for objective information, the greater the need for recent data."

" there is a need for information brokerage. ... (to)... act as a user-friendly intermediary between policy analysts and information sources."

(Extracts from the Project Team Report on Health Policy Information Requirements.)
3.0 CONCEPTS

There is a paradox in the area of health information. On the one hand, the Task Force has uncovered evidence that many parties in our health system feel overwhelmed by the volume of data and information that already exists. On the other hand, many are frustrated that they do not have the information they need. The key to this paradox lies in the cacophony of concepts, terminology and perspectives brought to health-related matters by the very wide diversity of participants and stakeholders.

This cacophony operates at several levels. First, useful information is produced using data. However, such production is impossible if the data collected at various times and places are incompatible. In order to aggregate, compare or juxtapose data in short, to analyze it, the data must be based on common concepts and definitions. In the health field, this is generally not the case at present, and is one of the most serious problems raised in the work of the Task Force.

At another level, relevant information may exist, but the person who needs it is unable to find or access it. Medical research is producing publications at an accelerating rate; health care delivery institutions are increasingly automating their information systems and thereby producing tremendous volumes of data (though not necessarily information); and there is a diversity of community-level interventions providing all kinds of new experience on program impacts and effectiveness. Unfortunately, the vast majority of these data are localized -- either geographically, institutionally, or within subject matter or disciplinary specialties. One response is to establish one or more health information clearinghouses, an idea which will be discussed later. But a prerequisite for any kind of clearinghouse, again, is common concepts and definitions, this time at the level of descriptors of information.

There is yet a third more abstract level where concepts play a vital role in health information. This is the level of the overall conceptual framework, *Gestalt*, or paradigm from within which the information is viewed. The impact of such differing perspectives is perhaps most sharply exemplified by institutional medicine and community health. These two vital sectors in Canada's health system have very different conceptual frameworks, priorities and concerns. For example, institutional medicine is concerned with patients, visits, diseases, and acute interventions. Community health concerns with lifestyles, attitudes, well-being, self-efficacy, and the health of communities as communities.

These differences at the most general conceptual level raise important difficulties at the more immediate level of developing common concepts and definitions for specific kinds of data. The reason is that specific concepts and definitions inevitably draw on broader conceptual frameworks or paradigms, albeit often implicitly. In turn, agreement in developing common concepts and definitions will be hampered if the efforts cut across conceptual frameworks without explicit recognition of these fundamental differences.

For these reasons, one of the starting points of the Task Force has been the development of a frame of reference, conceptual framework or "Template" for health information. This conceptual framework seeks to encompass the variety of views, *Gestalts*, and paradigms that have evolved in the health field. This section begins by reviewing the key strands in these conceptual developments. Then the conceptual framework or Template developed by the Task Force will be described. The section closes with a discussion of the proverbial bottom line in the health field -- health and well-being status indicators for the population.
3.1 Paradigms of Health and Broadened Perspectives

There is a very long and richly textured history of ideas relating to human health. Starting relatively recently in the second half of this century, the beginning of the post World War II period was dominated by the so-called medical model of health. The miracles of modern scientific medicine were seen as the key to substantial improvements in human health. This was exemplified by the Beveridge report in the 1940s \(^1\) which led to the establishment of the British National Health Service. A key premise of this report was that by making modern health care services universally accessible, there would be a major improvement in health outcomes, particularly amongst the more disadvantaged segments of society. That this intended outcome did not follow was documented by a 1980s U.K. Report of the Working Group on Inequalities in Health (The Black Report).\(^2\)

In Canada, a major shift in the focus on health care services was signalled by the 1975 Lalonde Report (A New Perspective on the Health of Canadians).\(^3\) This document set out a critique of the traditional view "that the art or science of medicine has been the fount from which all improvements in health have flowed, and popular belief (that) equates the level of health with the quality of medicine." This critique was based on a diversity of evidence indicating that many other factors beyond the health care system were important determinants of health, and were themselves amenable to improvement. The Lalonde Report went on to suggest that there were four "principal elements" of the health field. In addition to the element health care organization, equal weight and importance should be given to the elements human biology, environment and lifestyle.

The extension of the health field beyond organized medicine in the Lalonde Report to encompass three additional elements can be viewed as another swing of the pendulum regarding the most important determinants of health. After a period of fascination with the often spectacular advances in medicine, attention has been shifting back to other determinants of health. The most important of these non-medical determinants, in terms of public policy, is almost certainly tobacco use. From the viewpoint of public fears and apprehensions, physical and chemical environmental hazards have clearly become much more significant as a determinant of human health since the Lalonde Report.

In turn, there have been many efforts to extend or redefine the paradigm or conceptual framework for thinking about the determinants of health. The central importance of such frameworks was noted in the Lalonde report:

"A basic problem in analyzing the health field has been the absence of an agreed conceptual framework for sub-dividing it into its principal elements. Without such a framework, it has been difficult to communicate properly or to break up the field into manageable segments which are amenable to analysis and evaluation. It was keenly felt that there was a need to organize the thousands of pieces into an orderly pattern that was both intellectually acceptable and sufficiently simple to permit a quick location, in the pattern, of almost any idea, problem or activity related to health: a sort of map of the health territory." (page 31)


Notable among the recent efforts to extend or redefine the conceptual frameworks in the health field are the Evans and Stoddart framework in "Producing Health, Consuming Health Care" (Reference 5.5), and the framework for health promotion in the 1986 federal health minister's paper "Achieving Health for All".

Evans and Stoddart is a direct extension of the Lalonde framework. It makes explicit several important distinctions and major causal pathways in thinking about the determinants of health. For example, one area of refinement of Lalonde’s four health elements is the connections between the economy and health. These connections or important causal pathways include the fact that at the level of individuals, ill health reduces workers’ productivity, and going in the other direction, that socio-economic status is an important determinant of health. Moreover, at a sectoral or macro level, the health care industry is itself part of the economy and according to some projections can be expected to grow to be a large burden on the public sector. In turn, health care costs under such scenarios could compete with expenditures in other areas such as improving the social and physical environment. These latter expenditures might be more effective in improving population health than resources devoted to the health care sector. As a result, one possibly perverse result could be that continued growth in the size of the health care sector would be associated with declines in overall population health.

Another extension of Lalonde’s four health elements in the Evans and Stoddart framework is the distinctions made among disease, health and function, and the organism’s resilience and responsiveness to threats and hazards. The latter distinction between health and resilience is important to understanding why, when two people are exposed to the same bacterium, say, only one gets ill. The former distinction between disease on the one hand, and health and function on the other, recognizes that there is often a disjunction between the medical perception and clinical classification of health problems, and the vernacular perceptions and classifications of the general population.

The "Achieving Health for All" framework for health promotion draws attention particularly to the community dimension of health. An individual’s lifestyle is not something that arises in a vacuum. It is intimately bound up in his or her social and cultural milieu. A vibrant and cohesive community will be better organized to provide support to ill members, and to lobby for a healthy physical environment. The very process of community participation and organizing is seen by many to contribute to a sense of personal efficacy which, in turn, is increasingly recognized as an important determinant of health.

3.2 A Conceptual Framework for Health Information

The Task Force recognized from the outset that a coherent approach to assessing needs for and strategies regarding health information required a conceptual framework. The diversity of areas claimed to be part of the health field by various stakeholders is so broad that some sort of road map was needed to give a comprehensive overview. In addition, this road map had to have sufficient structure so that various domains within the overall health field would make sense. These needs led to the development of an extended conceptual framework, the Health Information Template. (Reference 9.10.14)

The Template seeks to provide, at the most general level, a coherent structure for health information that recognizes and is compatible with the major thinking and frameworks that have been developed,

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4 Evans, R.G., Stoddart, G.L. (1990), Producing Health, Consuming Health Care, Social Science Medicine, Volume 31, No.12, pp 1347-1363.
particularly those of Lalonde, Evans and Stoddart, and Epp 5 just mentioned. The Template is the product of considerable work of a project team, plus comments and feedback from other project teams and participants in the many public presentations over the 1990-91 period. It represents a consensus that fundamental changes are required in the way we conceptualize the nature and domain of health information.

3.2.1 Template Objectives

More specifically, the Template has evolved as a series of graphic images of an overall structure for health information. It has been developed with several major objectives:

- the Template is intended to provide a general classification system -- a way of dividing the vast expanse of potential health information into a somewhat more structured set of domains and sub-domains, and of clarifying important distinctions among various kinds of health information;

- it is intended to be comprehensive in order to show the breadth and diversity of information that is possibly important to understanding and acting with respect to population health;

- the full realization of the template takes the form of a dynamic computer graphics software package. Thus, it can serve as an explanatory device and a series of visual metaphors in order to communicate ideas in a more effective way. Figure 1 shows the basic top-level image, but it must be emphasized that this gives only a pale (and colourless) impression;

- the Template software represents a prototype data catalogue / meta-data base. It therefore represents a possible evolution into a dynamic, graphical generalization of a library card catalogue containing pointers to the location of sources for the indicated kinds of information. Note that health information and the health information Template are not confined just to quantitative information. Anecdotes, conjectures, structured descriptions by participant observers, program evaluations and other qualitative information are also covered;

- the Template is intended to provide a framework for the subset of quantitative information, and the basis for the further structure that mathematical relationships can give -- analogous to the System of National Accounts for macro-economic data, and its series of structured data feeder systems. In addition, this aspect of the Template can provide the framework within which forecasting and policy modelling is developed, analogous to macro-econometric models. Examples of how this might be done are given in the conceptual description of a "System of Health Statistics" 6 and its prototype implementation in POHEM 7;

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more speculatively, the Template could evolve into a graphical data base user interface to a
distributed range of data bases; subject to a structure of access controls to assure
confidentiality and privacy. Such a user interface could include the capacity to browse the
classification structure; select, join and extract subsets of the available data found via the
browsing process; and read, print or export these data to a statistical package for further
analysis, or make use of new text search software for analysis of qualitative information.

A Template for Health Information: Main

Figure 1

3.2.2 Template Cautions

This is an ambitious set of objectives. At the same time, it is vital to help bring coherence to
information spanning the very complex health field, and to exploit the rapidly emerging opportunities
of informatics technology. However, it is important to bear in mind a number of cautions regarding
the Template:

- the Template will continuingly be a work in progress;
- the Template is intended as an articulation of goals for the scope and content of Canada's

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health information system, a longer term vision. It does not outline a series of immediate practical steps;

- the Template images are panoramic, not detailed. They show only the broad features, stages of exhaustive detail will have to evolve;

- the information structure and content of the Template pays no attention to the current (and limited) availability of health information. However, health information is not virgin land. The development of the Template and the underlying information sources will thus have to take detailed account of the various data feeder and classification systems already in place;

- the Template vision is ambitious, and may appear very costly. However, many costs are already being incurred in the creation of hospital management information systems and provincial automated physician billing data bases, for example.

- while the Template shows an overall structure, it is not intended as an all-encompassing monolithic data base, nor as solely a national data base. Local and provincial data bases that are complete and comprehensive in their own right will be needed. From a national perspective, it should be sufficient if these diverse data bases can be rolled up, juxtaposed or linked as needed;

The Template is intended as a coherent and comprehensive image of health information. Thus, it is not constrained to show only existing information. It freely refers to kinds of information that are not currently available, precisely to provide a framework for deciding on the development of new health information systems.

3.2.3 Template Classifications

The Template image is built from a series of boxes or shapes representing various categories of information. In every case, there is at least some anecdotal evidence and most often research literature indicating an important connection between the kind of information denoted and human health. Figure 1 shows three broad domains of information -- Individual Characteristics, the External Milieu, and Health-Affecting Interventions.

Individuals and their characteristics are shown as the central focus of these three broad domains. It is vital to start with people and their healthiness. This information should be central to any renewed plan for health information, especially to shift attention away from current pre-occupations with resource inputs to the health care system, and toward population health outcomes.

The visual nuance of a set of files for individuals is deliberate; it is intended to emphasize the idea of an explicit micro-data foundation for this information. This greatly enhances the flexibility and utility of the information. It also supports analysis and production of information on statistical distributions, so that disparities and differences in health status can be highlighted and subject to analysis.

The External Milieu is the second broad domain in the basic Template image. It surrounds, but does not completely envelop, the population of individuals. It is composed of a series of four environments or sub-domains, either natural or man-made, physical or social.
The Physio-chemical Environment is the domain covering information such as sources of exposure to airborne particulates, toxic heavy metals, and ultraviolet radiation. It represents the environment that has been of greatest concern in the popular media.

The Socio-Cultural Environment, on the other hand, is not considered as relevant to health. It is more subtle, but nonetheless, important. This environment includes such aspects as prevailing norms and beliefs about caring for ill friends and relatives, and peer pressure regarding the smoking habit picked up by children in the school yard. This environment also includes images of female roles and beauty as defined by advertising and rock videos, with their consequential impacts on the prevalence of anorexia, bulimia, and domestic violence.

Most people are not surprised when they hear of a new research study showing that the poor are also less healthy. More interestingly and less well-known, the middle class tends to be less healthy than the well-to-do. Health status seems to follow a gradient with socio-economic status. While the evidence is quite striking, the reasons are not well understood. What is more troublesome is the relative lack of research into the underlying causal pathways. One important reason is the lack of data. Thus, it is clear that information on the Economic Environment should be included in any comprehensive plan for health information.

Finally, the fourth sub-domain of the External Milieu is the Health System Environment. Many aspects, but not all (see below), are best considered as an environment—the accumulation of tradition, private enterprise, and past government policies and initiatives as embodied, for example, in the techniques and productive capacity of the pharmaceutical industry, and the stock of buildings and equipment which constitute hospitals.

The visual metaphors for the External Milieu appear at this level to show one diffuse box for each kind of environment. However, the idea of explicit micro-data foundations applies equally here. For example in the Socio-Cultural Environment, each community or peer group (at least in principle) would have its own unique set of descriptions.

The division of information into different visual domains and sub-domains for purposes of classification might be interpreted as a desire to pigeonhole information, but this is an incorrect impression. For example, data on a specific local physical environment should be connected to data on the individuals who come in contact with it. Also, individuals would be connected with other family members via such data elements as household IDs or relationship variables, exactly as in current household survey public use micro-data files.

The third major domain, which prevents the External Milieu (metaphorically) from completely enveloping individuals, is the product of conscious intended actions, Health-Affecting Interventions. This general phrase has been deliberately chosen, rather than the more conventional phrase "health care", to highlight the fact that a very broad range of government and collective activities may have profound effects on our health.

After much discussion within the project team, Health-Affecting Interventions have been divided into two broad groups—those directed to individuals, and those operating on a collective level.

Individual Health-Affecting Interventions are one-on-one, like a surgical procedure or a visit to the dentist. Collective Health-Affecting Interventions act on us in groups, like the closing of a beach due to high fecal coliform levels, restricting cigarette ads, or amending drug patent legislation.
One important question is how to distinguish these different domains of information. The basic classifying criterion is the natural "reporting unit" or "unit of observation".

For Individual Characteristics, it is individuals -- either directly by self-report as in an interview or self-completed survey, or by proxy via survey of another family member or the diagnosis of a health care professional.

For the External Milieu it is a micro-environment. This is reasonably well-defined in the case of a building in the Physical Environment and the amount of radon or formaldehyde exposure one would get there. It is less well-defined for something like an informal social-support network in the Socio-Cultural Environment -- though there is very strong evidence that the latter is at least as important to our health. 8

The "atom" or basic unit of observation for Individual Health-Affecting Interventions is the visit or service encounter, where a health professional or provider acts in a one-on-one manner with the individual -- for example filling a dental cavity, performing surgery, or providing advice on herbal remedies. The basic unit for Collective Health-Affecting Interventions is a program, policy or regulation, which acts on environments, and hence only indirectly on individuals.

Of course, all the information generally indicated in Figure 1 is embedded in calendar time. Time series data are essential to monitor basic trends. Moreover, at the micro-data level, longitudinal data are critical because of the widely demonstrated importance of cumulative exposures, and latent effects or processes acting over very long periods of time.

Comparisons across space are as important as comparisons across time. The Template is not only intended to define a national structure for health information. It should be equally applicable at the provincial, municipal, or community level. Given micro-data foundations and appropriately stratified samples as part of the underlying data feeder systems, any level of geographical aggregation or disaggregation (subject to sample size limitations) should be feasible, and is precisely what is envisaged.

There are, of course, all kinds of underlying causal connections among the various data elements -- the "laws of motion" for the variables classified by the Template. Some of these connections are reasonably well established, such as, risk functions in the epidemiological literature connecting smoking and lung cancer. Other connections are more speculative. As a practical matter, showing all the possible connections would make Figure 1 hopelessly complex. The Template software does, however, incorporate a visual metaphor for showing descriptions of dynamic interrelationships.

3.2.4 Decision Support

The description of the Health Information Template so far has focused on its classification structure. Figure 2 illustrates the potential role of health information in supporting decisions at broader levels.

Recall the earlier emphasis on an explicit micro-data foundation for health information. If such data were available, individual attributes could be aggregated to derive a summary measure of health outcomes for the population -- or for some relevant subgroup like a province or municipality.

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Data on the resources consumed by Health Affecting Interventions (assuming the underlying data were actually being collected in a comprehensive and systematic manner, which they most certainly are not at present) could be correspondingly aggregated.

Finally, one of the central rationales for improved health information, juxtaposing these two kinds of derived information -- costs and benefits -- will hopefully support decisions that will lead to more effective allocation of resources, and better health of the population generally.

The underlying data needs suggested by the Health Information Template do not imply a monolithic central population data base. The practical need is for a series of focused strategic data sets -- data sets that have been designed to be complementary, to use common concepts and definitions, that can be juxtaposed or linked on an "as needed" basis subject to appropriate safeguards for personal privacy, and that cover the priority domains of the Template.
The Template prototype provides a vision of a coherent and comprehensive national health information system. It can thus form the core of a strategic planning process. Further development of the Template will require a consensus process for agreeing on scope, elaborating the classification structure, and methods for organizing the quantitative portion of the information with a mathematical structure analogous to the System of National Accounts.

Moving from present data systems to those implied by the Template will be a lengthy and difficult process. However, the Task Force experience in presenting and consulting on these ideas as they have evolved suggests that there will be an enthusiastic response across a broad range of health constituencies. While there has been some sense of disbelief at the scope of the endeavour, the general mood is that the costs are not that great compared to the resources currently devoted to health care, nor to the various piecemeal administrative data systems being developed, and the analytical results could be profoundly rewarding.

3.3 Health and Well-being Status Indicators

The Template places individuals and their healthiness at the centre of the health information system. This is in marked contrast to the current state of affairs, where the cost of health care as a percent of GDP is a much more widely known statistic than the "average healthiness" of the population. Moreover, it is not an exaggeration to say that the most widely used measures of average healthiness or population health status, both within Canada and internationally, are based on death data.

Mortality statistics by age and cause are used to compute life expectancy and infant mortality rates, and to create league tables of the most important diseases according to the proportions of deaths ascribed to them (heart disease first, cancer second, etc.). Somewhat more complex indicators, based on extensions of the concept of life expectancy, are potential years of life lost due to a given disease (PHYLL), and cause-deleted life expectancy; but these are both measures derived from cause-specific mortality rates.

This is clearly a major area of dissonance with the expressed objectives, and the kind of paradigm shift described in Section 3.1. It is also clearly at odds with the World Health Organization's definition of health:

"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."9

This reliance on mortality data as the most common indicator of population health status is also incompatible with some of the more far-reaching statements of provincial health goals. For example, in a Quebec government document entitled "Orientations-Improving Health and Well-Being in Quebec"10 the primary goals are stated as:

- "add years to life by reducing mortality from disease and injury;


10 Orientations - Improving Health and Well-Being in Quebec, Ministère de la santé et des services sociaux, avril 1989, p 19.
• *add health to life* by reducing disabilities and acting on various health factors;

• *add well-being to life* by promoting the optimal use of functional capacity, whether total or partial, and by decreasing the impact of problems that compromise the stability, self-fulfilment and autonomy of individuals."

It is clearly problematic in the current milieu to continue to base the premier indicators of a population’s health on death rates. Moreover, there is at present simply no way to determine whether the average "healthiness" of the Canadian population (in the WHO sense) is improving.

The Project Team on Health Status Indicators (Reference 9.10.1) considered these issues in some detail, in large part by reviewing the most frequently suggested indicators for measuring the health of populations. Many other project teams noted the absence of good quality health outcomes or health status measures, not just at the level of a province or the nation, but also at the level of individual patient encounters with the health care system. The latter is essential for management of hospitals and for meaningful cost-benefit analyses of alternative interventions, for example. Finally, the Project Team on Health Determinants (Reference 9.10.12) developed some ideas relating to the measurement of health in the positive sense, rather than only as the absence of disease or the postponement of death.

This section provides a summary of the key findings in each of these areas of activity and is organized accordingly. However, one point bears emphasis at the beginning. This is the difference between "indicators" and "indicata". An indicator is some number, statistic or measure that is actually compiled and published. An indicatum is that which the indicator attempts to reflect, measure, or indicate. There is a wide gulf between these two, as evidenced at the most general level by the use of indicators based on mortality data for the ostensible purpose of measuring health.

It can be argued that there is a widespread confusion in the literature on health status indicators because this distinction is not explicitly recognized. Proponents of one indicator or another typically have some beliefs or theoretical views regarding the connection between a given indicator and their view of the concept of health status, but this is all too often implicit. One of the clearest manifestations of this confusion is the inclusion of measures of health care use and disease precursors or risk factors in various lists of supposed health status indicators.

In an imperfect world of limited data, these indicators may be acceptable rough proxies for underlying concepts of health status. But in the context of this Task Force, which is seeking long-term fundamental improvements in Canada’s and its constituent jurisdictions’ health information systems, it is crucial to keep the focus on core concepts. Thus, articulations of the concept of health stated by WHO, and as embodied in the goals of the Quebec government as noted above, are strongly commended as the "indicata" which various indicators of health status should be striving to operationalize and measure.

3.3.1 **Provincial Health Goals, Objectives, and Indicators**

Over the last few years several provinces have attempted to conceive and establish health goals, objectives and/or indicators for their own populations. All governments appear to accept the importance of the WHO definition of health, and the importance of the individual as a key player in the maintenance and improvement of health. Provinces have sometimes also distinguished indicators of determinants of health and indicators of health status as measures most appropriate for capturing population health, though most provinces do not make an explicit distinction between the two types of indicators.
Regardless of the approach used, several common health status indicators, have emerged from the various task forces and commissions studying health. For illustrative purposes Table 1 notes various health indicators by age group. An asterisk (*) beside a measure indicates an area of provincial divergence in the type of indicator being proposed to measure health status.

A main focus of provincial health indicators appears to remain on the measurement of illness or the prevalence of a particular disease. In part, this may be because the health information systems already in place gather extensive data on the population’s contacts with the health care system, rather than on the population’s health status or the determinants of health.

However, the measurement of illness and utilization of the health care system are not the best indicators of the health status of individuals and communities, and there appears to be a willingness to go beyond these fundamental health measures. To that end, several of the reviews acknowledge that there is a relationship between health status and family and social structures, as well as an impact of environmental factors on health. Provincial governments have also identified specific health information gaps in the assessment of the health of populations. The reviews agree that more information is required on disability, mental health and the impact of occupational and environmental hazards on health.

3.3.2 National Health Information Council / Canadian Centre for Health Information

In May 1989, the National Health Information Council (NHIC) and the Canadian Centre for Health Information (CCHI) released "Health Indicators for Canada and the Provinces", which is a consolidation of "key" and "additional" indicators of the health of Canadians. In total, 123 indicators were identified as being important to monitoring the health of the Canadian population, 53 of which were recommended as "key" indicators. These indicators are grouped under four main headings: determinants, health status, resources, and utilization. Table 2 shows the key indicators under the first two headings.

It is evident that this listing, as well as the provincially desired indicators listed in Table 1, are seriously incomplete in terms of the concepts of health embodied in the WHO definition and the Quebec goals noted above. These indicators do not come close to measuring the desired indicata, so further efforts are needed.

3.3.3 International Health Indicators

In 1982, the Working Party on SocialIndicators of the Manpower and Social Affairs Committee, Organization for Economic Co-operation and Development (OECD) released a list of social indicators that were approved by the OECD Council. \(^\text{11}\) This was the first international list of social indicators to be adopted by OECD member countries. The OECD Secretariat has been collecting and publishing a Compendium of Social Indicators ever since.

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<table>
<thead>
<tr>
<th>Age Group</th>
<th>Indicators</th>
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<tbody>
<tr>
<td>Infant (0-1)</td>
<td>Low Birth Weight</td>
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<td></td>
<td>Infant Mortality</td>
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<tr>
<td></td>
<td>Incidence of Congenital Anomalies (inpatient days)</td>
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<td></td>
<td>Breast Feeding (1,3,6 months)</td>
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<tr>
<td>Children (1-14)</td>
<td>Accidents (Home, Motor Vehicle)</td>
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<td></td>
<td>Minor Infections (Respiratory, Skin)*</td>
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<td></td>
<td>Incidence of Nervous Disorders *</td>
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<td></td>
<td>Incidence of Sexual and Physical Abuse</td>
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<td>Disability</td>
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<td></td>
<td>Lifestyle (Fitness and Nutrition)</td>
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<td></td>
<td>Dental Health (Participation - Fluoride Mouth Rinse School Program)</td>
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<tr>
<td>Adolescence and Young Adulthood (15-25)</td>
<td>Motor Vehicle Accidents</td>
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<td></td>
<td>Number of Suicides</td>
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<td></td>
<td>Sexually Transmitted Disease (AIDS, Gonorrhoea, Syphilis)</td>
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<td></td>
<td>Pregnancy and Abortion</td>
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<td></td>
<td>Lifestyle Indicators (Smoking, Alcohol, Drug Abuse, Physical Fitness)</td>
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<td></td>
<td>Mental Health (inpatient days)*</td>
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<td></td>
<td>Rates of Pap Smear and Breast Self Examination *</td>
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<td></td>
<td>Disability</td>
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<tr>
<td>Adults (25-64)</td>
<td>Incidence of Chronic Disease (Circulatory, Digestive)</td>
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<td></td>
<td>Accidents (Suicide and Industrial) *</td>
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<td></td>
<td>Mental Health (inpatient days) *</td>
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<td></td>
<td>Incidence of Back Pain *</td>
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<td>Days Off Work *</td>
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<td></td>
<td>Potential Years of Life Lost</td>
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<td></td>
<td>Incidence and prevalence of Hypertension *</td>
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<td></td>
<td>Lifestyle Indicators (Alcohol, Smoking, Nutrition, Physical Activity)</td>
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<td></td>
<td>Seat Belt Use *</td>
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<tr>
<td>Seniors (65+)</td>
<td>Incidence of Chronic Illness (Circulatory, Respiratory, Stroke)</td>
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<td></td>
<td>Incidence of Tuberculosis *</td>
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<td></td>
<td>Suicide Rates *</td>
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<td></td>
<td>Lifestyle Indicators (Physical Activity, Nutrition)</td>
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### TABLE 2 - NHIC Key Health Determinant and Status Indicators

<table>
<thead>
<tr>
<th>Determinants</th>
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<tbody>
<tr>
<td>1. Population Pyramid</td>
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<tr>
<td>2. Percentage of Elderly Population</td>
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<tr>
<td>3. Percentage of Elderly Population Living Alone</td>
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<tr>
<td>4. Percentage of Elderly Population Below Poverty Lines</td>
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<tr>
<td>5. Total Fertility Rate</td>
<td></td>
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<tr>
<td>6. Age Specific Fertility Rate</td>
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<tr>
<td>7. Number of Abortions and Births – Women Aged 13 to 19</td>
<td></td>
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<tr>
<td>8. Distribution of Births by Weight</td>
<td></td>
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<tr>
<td>9. Age When First Sexually Active</td>
<td></td>
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<tr>
<td>* 10. Percentage of Population Practising Safe Sex</td>
<td></td>
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<tr>
<td>11. Percentage of Population with High Blood Pressure</td>
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<tr>
<td>* 12. Percentage of Active Population in Selected High-Risk Occupations</td>
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<tr>
<td>* 13. Percentage of Active Population with Selected Job-Related Illnesses</td>
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<tr>
<td>14. Number of Recipients of Workers Compensation Board Payments</td>
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<tr>
<td>15. Distribution of Population by Type of Smoker</td>
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<tr>
<td>16. Average Number of Cigarettes Smoked Daily</td>
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<tr>
<td>17. Distribution of Population by Type of Drinker</td>
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<tr>
<td>18. Litres of Alcohol Consumed per capita</td>
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<tr>
<td>* 19. Distribution of Population by Immune Status</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Health Status</th>
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<tbody>
<tr>
<td>1. Life Expectancy</td>
<td></td>
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<tr>
<td>2. Potential Years of Life Lost</td>
<td></td>
</tr>
<tr>
<td>3. Number of Cases and Carriers of Specific STD’s</td>
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<tr>
<td>+ 4. Number of Institutional Separations per 100,000 Population</td>
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<tr>
<td>+ 5. Number of Hospitalized Days Due to Motor Vehicle Accidents</td>
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<tr>
<td>+ 6. Number of Ambulatory Care Visits per 100,000 Population</td>
<td></td>
</tr>
<tr>
<td>7. Number and Percentage of Persons With At Least One Limitation in Activities of Daily Living</td>
<td></td>
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<tr>
<td>8. Disability Due to Motor Vehicle Accidents</td>
<td></td>
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<tr>
<td>9. Age Standardized Mortality Rate</td>
<td></td>
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<tr>
<td>10. Perinatal Mortality Rate</td>
<td></td>
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<tr>
<td>11. Infant Mortality Rate</td>
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<tr>
<td>12. Number of Suicides per 100,000 Population</td>
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</tr>
</tbody>
</table>

* Health measures for which no indicators currently exist
+ These are not health status indicators according to the Project Team’s criteria and should be removed from the list.
There are three health components of the overall set of social indicators: life expectancy, perinatal mortality and disability (both short-term and long-term). The WHO definition of health is certainly consistent with these indicators. However, the OECD document notes that health analysts have long had to live with the inability to measure health other than "by its absence". Nevertheless, these three main health status indicators do provide a core of basic information for international comparisons of health status.

More recently, the OECD has been dealing with health outcome indicators. In preparation for the November 26-28, 1990 meeting of the OECD Working Party on Social Policy, a report on "Health Outcome Indicators" offered suggestions on how countries can answer the question "Are the populations of OECD countries becoming healthier?" 12 (Reference 9.10.1)

The report acknowledges that the health status of populations is influenced by other things than resources devoted to health care (such as the physical environment, "lifestyle" trends and government policy on social and welfare matters). The purpose of the report was to bring together comparative information on a number of different aspects of health and sickness at various ages.

The report found that most of the current literature on health status measures for international comparisons involve three types: behaviourally defined disability, disability-free life expectancy, and avoidable mortality and morbidity. The report notes that these measures are inadequate for the assessment of the health of populations, that there is no precise and generally accepted way of defining disability, that there appears to be a bias towards perceiving disability as an issue for only the older population, and that indicators such as avoidable mortality provide very partial information.

The report raises a number of other related issues. For example, should there be a large number of specific health status measures, or should they be combined into some form of overall health index? What should be the roles of governments (e.g. primarily a source of data collection and provision of international comparisons) vis-à-vis the role of researchers and universities (e.g. elaboration of concepts, analysis and publication of research findings)? What criteria should be used for choosing health status indicators (e.g. relevance and quality, predictive value, availability of data, relative ease of collection and analysis etc.)? Should age-specific health outcome measures be developed (since tomorrow's seniors, for example, may have quite different patterns of morbidity and supportive environments)?

The OECD paper argues in conclusion for the adoption of a multidimensional approach to health status indicators for the 1990s. This would reflect the complex nature of health and provide profiles of various age groups. Health status indicators would also change over time and there is no single measure which would enable governments to understand the health status of their populations.

Among many individual countries, and as part of the WHO program initiative to promote "Health for All by the Year 2000", 13 the U.S. has also been active in the specification and development of health

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status indicators. "Healthy People 2000: National Promotion and Disease Prevention Objectives" contains a strategy for improving the health status of Americans over the decade of the 1990s and includes goals regarding the prevention of major chronic illnesses, injuries and infectious diseases.

Part of the strategy is to have the National Centre of Health Statistics (NCHS) develop a set of indicators that shows whether the health status of the nation is improving in the way the objectives state it should. The set of indicators are to be appropriate to federal, state and local agencies, and NCHS is to encourage their use in 40 or more states by the year 2000. To that end, a representative committee of professionals is identifying candidate indicators in each of the four groupings of Healthy People 2000: health promotion, health protection, preventive services and age-related objectives (i.e. children, youth, adults and older adults).

As part of this process, several hundred candidate indicators are to be ranked to provide about 10 key indicators in each category. Broad measures of the social environment (poverty rate and percent of population without health insurance) have been proposed, and this has generated a debate as to whether "health" indicators should deal with issues of disparities, social justice, and differences between minority and majority communities.

3.3.4 Health Outcomes and the Health Care System

The Project Team on Information Needs for Health Care Quality Assurance and Outcomes has noted major issues regarding the efficacy and appropriateness of many of the medical interventions currently performed by the health care system. At the level of individual hospitals and surgical departments, there is no systematic population data on patients' health status before and after the intervention.

Except for limited and partial ad hoc studies, there are simply no data with which to assess in a rigorous, ongoing, and systematic manner what is being produced by the most expensive parts of the provinces' and Canada's health care systems. The enormity of this strategic gap in information is difficult to overestimate.

The most crucial gap is in longitudinal health status information for individuals both before and after interventions, including follow-up over periods of years. This is recognized in such phrases as "severity adjustments" assessing case mix for specific hospitals, and "outcomes management".

The discussion so far in this section has generally focused on broad indicators of health status at the level of large jurisdictions and international comparisons. In contrast, these concerns at the level of single health care institutions highlight the need for health status measures at the individual level. These should be captured routinely (though perhaps only on a sample basis) for individuals coming in contact with the health care system, both before an intervention and on a follow-up basis.

In general, these micro- or local-level needs for health status measures for individuals will have an inexorable tendency to result in an explosion of questionnaires and measures, each tailored to the specific circumstances at hand. To some degree, this is reasonable. Severity of illness for an arthritis patient has some very different aspects than those for a coronary heart disease patient. On the other hand, it is essential that these tendencies be countered to the extent that there is a common core of measures of health status that span all the diverse circumstances. Without such a common core, there

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will be major regress rather than progress to one of the most strongly voiced concerns uncovered by the Task Force -- the cacophony of concepts and definitions.

In addition to the need for a common core of health status measures at the micro-level, it would clearly be desirable to have coherence and consistency with macro-level indicators. Ideally, macro-level health status indicators should be an aggregation of micro-level indicators. This conception is clearly well beyond the general discussions of health indicators as evidenced by the list given in the tables above, and the embryonic state of the "outcomes assessment" and "quality assurance" discussions in the hospital sector described in the report of the Project Team on Information Needs for Health Care Quality Assurance and Outcomes.

A central requirement for progress in this area will be the development of a core set of micro-level health status measures that are widely agreed upon, well tested, and easy to use. A very promising start in this regard is the block of questions that has been included in the 1990 Ontario Health Survey and the 1991 General Social Survey.

3.3.5 From Illness to Health

Virtually all currently used measures or indicators of health status are based on measures of death and morbidity. Health in a positive sense as more than the absence of disease, and premature death is nowhere to be seen in the ostensible health indicators currently in use. One key reason is highlighted in the report of the Project Team on Health Determinants, and is ascribed to the general absence of longitudinal micro-data on individuals.

Health in a positive sense has to do with such notions as resilience, ability to cope, and homeostasis -- the ability of the organism to maintain an equilibrium or high level of functioning through a sequence of assaults (e.g. infections) and changes in environment. At any point in time, this notion of health is either absent (i.e. the person is ill) or it is observable only as a potentiality. The reality of good health (or resilience in the sense of rapid recoveries from "assaults") only is manifested over time as an individual is observed to be "chronically healthy".

While this point may be simple and obvious once you think of it, the implications for health information are profound. There will never be good indicators of health in this positive sense until there are good micro-level longitudinal data on individual health status.

3.3.6 The Role of Overall Measures of Health Status

This discussion of health status indicators has shown the kinds of measures currently in use or under discussion. It has also pointed out the wide gulf between these indicators and the desired indicata. One final topic concerns the question of whether the health information system should include an overall aggregate index of population health -- some sort of gross domestic product or consumer price index of health. The recent OECD report summarized earlier argued against this idea. This may be a reasonable position in an international context of countries with widely varying health care and data collection systems. However, this Task Force's works and recommendations offer the opportunity for a longer view and coherent planning, so that the idea need not be rejected on these grounds.

A key question is whether it is feasible to develop such an overall population health status index that satisfies basic requirements of plausibility, reliability, and having a sound theoretical foundation. There are positive and negative parts to answering this question.
The main negative part of the argument concerns the alternatives or opportunity costs of not having an overall population health index. This is the situation now, where ministers of health and Canadians in general are basically at sea regarding the relative priorities to be attached to a broad range of nominally health-improving interventions. As discussed in the Project Team Report on Information Needs for Health Care Quality Assurance and Outcomes (Reference 9.10.10), there is evidence that as much as one third of the resources devoted to health care are "wasted" in the sense that the surgical procedure or treatment did not improve the patient’s health, and may, in fact, have worsened it. Lacking a common numeraire or unit of measure for the results of health interventions, there is no empirical basis for determining their benefits, and hence no strong foundations for reallocating these resources to more effective uses. The budget allocation process, as a consequence, is continually at risk of being driven by tradition, vested interests, and the loudest voices.

The principal positive argument is the promising prototype result of research efforts such as the Population Health Model project at Statistics Canada. This project is endeavouring to assemble research results and the fragmentary data that do exist into a mechanism for estimating a summary index of population health status. Feasibility is being demonstrated by constructing a working prototype. The major constraints are not conceptual; the key problem is the lack of appropriate data.

It is important to emphasize that an overall summary index is not a substitute or alternative for a large family of more detailed and specific indicators. On the contrary, the two are complementary and indeed, synergistic. Ideally, the various specific indicators should be components of a coherent framework within which the summary index is but the culmination or aggregation of the sub-indices. This is currently the case with the Consumer Price Index (CPI), where food and housing prices are sub-indices of the overall price index. The development of such a coherent framework would have the further benefit of imposing some order on the diversity of health status measures outlined earlier, for example, by making clearer the distinction between health status and health determinants. Finally, it would aid in bringing health status indicators more closely in conformity with the desired indicata.

3.3.7 Conclusions Regarding Health Indicators

A major shortcoming of the current set of health information is its lack of balance. Statistical compendia are dominated by the resources consumed in health care (financial costs, bed-days, laundry, physician visits). The most common measures, especially over time, of Canadians’ "health status" are actually based on death status -- infant mortality and life expectancy. There is very little measurement of health status and function while people are alive.

This imbalance is pervasive. The lack of health status data at the level of individual patient visits to hospitals, for example, means that high quality evaluations of the efficacy and effectiveness of various surgical procedures, let alone whether they are being performed appropriately, are rare. The lack of health status data at the national level, at the other end of the spectrum, means that it is simply unknown whether the health of the Canadian population is generally improving, let alone the relative priorities of allocating resources to acute care, chronic care, social services, or early childhood interventions, for example.

There is a major need for systematic, well-founded, and reliable measures of health status. This need is increasingly recognized at the level of individual contacts with the health care system. It is also essential for health status measures to extend to large population groups, up to and including all of Canada. The health information system should include an overall aggregate index of population health -- some sort of GDP or CPI of health, which would be the culmination or aggregation of a coherent family of health status indicators.
4.0 INFORMATION NEEDS

The Task Force received many representations concerning the wide-ranging need for health information. Uses and users revealed themselves at all levels. An impressionistic, but non-exhaustive list includes:

- providers of health care who require information to better understand the characteristics of the populations they serve and the efficacy of the procedures they use;
- administrators of health care institutions and programs requiring management information and information to compare their performance against that of peers;
- policy analysts and researchers requiring information to support the study of health determinants, their impact on the demand for health care, and the contribution of health care to the health status of the nation;
- politicians and policy makers requiring information to better inform their decision making;
- consumers of health care who require additional information to help them determine if health care is required, and make informed choices concerning the most appropriate type of health care.

As we have seen in the preceding chapter, a paradigm of health is emerging which demands access to integrated information, portraying not only those factors traditionally associated with health -- such as mortality and clinical diagnoses -- but also concerning medical and non-medical determinants of health status, use of health care and outcomes of health interventions.

At their most general level, the data needs uncovered by the Task Force can be generally characterized as:

- having a time dimension extending beyond the individual medical interventions (the principal current unit of analysis) to measurement of individuals' status and interaction with the care/support system through time;
- having the capability of servicing information needs of a system with an increasing level of decentralized or "bottom up" control (as well as the continuing need to produce information of country-wide and provincial/territorial relevance);
- serving the information needs, not only of governments, but also of non-governmental and private sector organizations;
- focusing on four broad areas of concern;
  - the health status of the population,
  - the status of the environment as it may affect the health of individuals,
  - the (macro) organization of the health care system, and,
  - the (micro) interventions used by the system to support or maintain the health status of individuals.
This last characterization builds upon the Template (Reference 9.10.14) and the Project Team on Health Policy Information Requirements (Reference 9.10.2). Figure 3 provides another visualization of the interaction of these areas of concern and of the information implication.

Needs for information on the health status of the population include information on the incidence and prevalence of disease, as well as improved information on vital events -- namely birth and death. Availability of additional information on the risk and prophylactic factors would enhance our understanding of the future trajectory of the population's health status. Risk factors include not only those of a bio-medical character but extend to both subjective factors (for example, self-esteem, self-will, empathy) and the way in which the individual interacts with his or her environment, including a range of socio-economic factors. Measures are required to characterize the health status of both the individual and the community.

The environment may pose risk or prophylaxis for the individual. It physically may provide a potential threat to the individual through exposure to toxic substances. At a more subtle level, through its economic, cultural, social or political institutions, it may systemically play a positive or negative role in fostering the health status of individuals. The environment to which individuals are exposed is not characterized well by existing information.

Additional information is required on persons who experience disease or illness but who are not treated by the health care system. Little is known about chronic diseases for which care is infrequently sought. Similarly, limited knowledge exists concerning the self-limiting nature of many diseases and the implications that this may have for the way in which individuals are brought back to full healthiness.

Better information is required on the dynamics of an individual's search for health information, care and support. How do individuals decide that they should seek treatment or care? Where in the continuum of service providers is this care sought?

Currently, there is no complete statistical picture concerning the range of interventions made by health care and support systems. Although information does exist pertaining to treatment received, on an inpatient basis in Canadian hospitals, it counts individual treatment events rather than consolidating the multiple treatment events so that we may view the individual in the context of all treatments received. Virtually no national information is available concerning other, non inpatient treatments received. This becomes an increasingly important information gap, as treatments formerly carried out on an inpatient basis are moved to ambulatory settings, such as day surgery, surgi-centres and physicians' offices. Such developments are facilitated by advancements in medical technology and encouraged for both economic and health reasons.

Similarly, there is no national information on community interventions such as active treatment or support provided in the community. Pilot project experiences with provision of such community-based support seem to support the notion that an important source of supplementary assistance can delay or obviate the need for higher intensity institutional care.

A crucial question concerning health care interventions deals with efficacy and effectiveness -- is the procedure beneficial and, if so, does it represent the most cost-effective approach to obtaining the desired result? To examine such issues, information is required not only on the intervention itself but on its outcome, as well as the severity of the underlying condition for which treatment was provided. Diagnostic information must have the capacity to be related to information on procedure cost. This again suggests the need for information on an individual's
status and his/her interactions with health care and support systems over time.

As made clear by the Template, interventions may be directed at specific individuals, and at the population as a collectivity. Whether a lifestyle modification campaign or a disease screening program, better information is required on program coverage and impact.

Although most of the information available on the health of the population focuses on the organization of the health care system, substantial information needs even in that arena have yet to be met. Apart from physicians and registered nurses, little is known of the distribution of human health care resources in Canada. Although the existing system provides substantial information on the financial dimensions of Canadian health care institutions, information is lacking concerning the manner in which human resources are managed and used in provision of care. More information is needed about the technical and clinical capabilities of the existing health care system. For example, in most provinces and at the national level, routine collection of the prevalence and use of "high tech" diagnostic and life support equipment is lacking.

Before additional data are collected, work needs to be undertaken on appropriate conceptual models to characterize institutional and community-based health care systems. Such formulations are a logical precursor to the development of standard nomenclatures and comparable units of service, through which the organization and outputs of the health sector can be better understood.

Following is a summary of the needs for health information for a variety of uses based on the reports of the Task Force project teams which examined each of these areas of interest. The full text of these reports is available upon request. (Reference Section 9.0)

### 4.1 Determinants

#### 4.1.1 Background

Questions about the determinants of human health are among the most profound areas of scientific inquiry. They can range from basic biological and biochemical research to philosophical questions about the concept of health itself. The Project Team on Information Required to Understand the Determinants of Health (Reference 9.10.12) set itself the somewhat narrower, but still very broad task of trying to articulate a series of population-based data sets that might serve as the foundation for significant advancement in understanding. The key conclusions of the project team are that innovative "breakthrough" data sets can be articulated; they are essential to making major headway; and that significant progress can be expected, given such data sets.

#### 4.1.2 Methods

These innovative data sets can be characterized along two dimensions -- methodological and substantive. The essential methodological points can be summed up in the phrase, *"multi-multi-milo"*. The kinds of data sets required for important breakthroughs in understanding should be:

- *multivariate* -- with data on a variety of attributes of the sampled entities;
- *multi-level* -- with linked data on a range of related entities, in other words micro-data on the individuals whose health is under investigation linked to micro- or meso- or macro-
data on their families, social networks, workplaces, neighbourhoods, or environments as appropriate;

- micro-data -- the raw data are collected at the level of the individual entities; and

- longitudinal -- the data are collected repeatedly from the same person or entity over an extended period of time, for example, annually for 5 to 25 years.

These characteristics reflect some of the key impediments to analysis found by the Project Team on Health Information Analysis: Potentials and Impediments (Reference 9.10.13). The utility and importance of these generic "multi-multi-milo" data sets derive from the following considerations:

- The range of important factors in human health is extremely wide and the underlying causal pathways highly complex. As a result, conventional scientific methods such as randomized controlled trials and other experimental methods are technically (e.g. combinatorially) infeasible, if not unethical, as the central method for generating and testing hypotheses. Carefully designed observational approaches in the spirit of the "population laboratory" of the seminal Alameda County Study by Berkman and Syme, (See Section 3.2.3) are the best method.

- Health should be viewed in a positive sense rather than merely as the absence of disease. Health is a continuing ability to cope with various assaults on the bodily organism, a form of resilience and homeostasis. This concept of health simply cannot be observed cross-sectionally because at any point in time, it is only a potentiality. Positive health is only observable as a dynamic process over a period of time. In turn, in order to elicit the risk factors for chronic good health, longitudinal analysis is an essential prerequisite.

- Current observational studies in crucial areas still are dominated by macro- or meso-data -- that is, at least partially aggregated data rather than full micro-data. For example, as outlined in the report of the Project Team on Health Information Analysis: Potentials and Impediments (Reference 9.10.13), a large proportion of published analyses regarding socio-economic status gradients rely on observations aggregated to small geographic areas or occupational groupings. Such analyses suffer from the fundamental methodological risk of ecological fallacy.

- Still, many current observational studies are based on detailed micro-data, but among these, the large majority are cross-sectional rather than longitudinal. Health and disease are dynamic processes. A major advancement in understanding these processes is impossible without continuing observations of the same person or entity over time, i.e. longitudinal data.

- With the dramatic decrease in computing costs, new and promising methods of analyzing complex longitudinal data sets are now feasible which would hardly have been thought of a decade ago. It is now relatively straightforward to estimate multivariate hazard functions with complex forms and time-varying co-variates for $10^4$ or more observations. Such analysis has the potential to give a range of important new insights. This is true even in the reanalysis of existing (albeit rare) longitudinal data sets, such as the Framingham heart disease cohort.
• The utility of multivariate data is generally accepted. In statistical analysis of observed relationships, it is important to examine a range of variables which may be correlated, to determine whether a presumed relationship is "real" or a given variable is acting as a proxy for the actual causal but unobserved variables. For a variety of reasons including respondent burden or the exigencies of a particular administrative system, any one data set may be frustratingly limited in the range of variables it contains. Thus, major advances in "multivariateness" will increasingly require linkage of diverse data sets.

• Finally, there is a growing recognition of the need for multi-level data. This is a form of multivariateness. It is recognized that data on individuals must be supplemented by data on other aspects of their milieu. For example, individual micro-data on the use of social support services have to be linked to data on the kinds of services available in their communities to be analyzed in a meaningful way.

From the viewpoint of current practical data development efforts, such as the initiation of a regular cross-sectional survey of population health status, the multi-multi-milo data sets described might appear extraordinarily ambitious, and perhaps unrealistic. The project team noted that it is necessary to be able to walk before trying to run. It is clearly vital to initiate the regular production of much more basic data feeder systems, such as a regular population health survey, and to begin adapting existing administrative data systems to serve analytical as well as administrative purposes.

It must also be recognized from the outset that instituting a periodic cross-sectional health status survey in Canada will not provide the basis for fundamental advances in understanding the determinants of health. Such cross-sectional data sets are crucial for describing the current state of the population's health -- indeed it is remarkable that we, as a society, have not attached the priority required to having such basic information. These data will also be rich sources of systematic patterns and correlations, and thus hypotheses regarding the determinants of health. But cross-sectional data alone will not be sufficient to assess or evaluate competing explanatory hypotheses. More ambitious data collection programs are essential for major advances in understanding the determinants of population health. Fortunately, multi-multi-milo data sets are a natural extension of periodic cross-sectional health status surveys. The latter kind of survey can evolve into a multi-multi-milo data feeder system by:

• re-interviewing a substantial sub-sample of respondents to previous surveys over time, thereby making the data longitudinal;

• having special topical modules in questionnaires that vary over time or across subsets of the sample in order to make the data more multivariate;

• occasionally collecting data at the same time on a linked sample of other relevant entities, such as the respondent's workplace, community, or social network to make the data multi-level; and,

• selectively linking responses of sampled individuals to administrative data files, such as encounters with the health care system -- subject, of course, to mechanisms for the protection of individual privacy and the assurance of ethical objectives. This will also make the data more multivariate and longitudinal.
Thus, multi-multi-milo data sets can be seen as an evolutionary extension of existing and currently planned data collections. Planning for shorter term improvements in health data collections should take into account such extensions, since planning now for these multi-multi-milo extensions will substantially reduce their costs in future years.

4.1.3 Substantive Content

The Project Team on Information Required to Understand the Determinants of Health (Reference 9.10.12), concluded that the approach of a series of strategic, substantively focused data sets was most appropriate. The subject matter areas broadly cover the human life cycle, plus several cross-cutting topics. There is no attempt, nor is there any need, to make these topics mutually exclusive; some overlap is inevitable and desirable. Also, there is no reference to an overall conceptual framework or classification system for the various kinds of variables, attributes or entities. Such a classification has been developed in the Template for Health Information (Reference Section 3.2), and can be taken as implicit.

Following is a very brief listing of the data set topics (see Reference 9.10.12 for details).

1) Healthy Childbirth

One of the major concerns with newborn children is low birth weight (LBW). A substantial portion of the incidence of LBW is considered to result from behaviours of the mother during pregnancy. As sequela, many LBW babies require heroic interventions in expensive neonatal intensive care units to survive. Once an LBW infant goes home, if it is disabled or developmentally abnormal, it may impose a tremendous strain on the parents and siblings.

We have no comprehensive picture of this crucial phase of the life cycle. There is insufficient understanding of the relative efficacy and costs of interventions, both pre- and post-natally to make informed reasoned policy choices on the allocation of health resources.

The data set required to advance understanding in this area could be a longitudinal sample of women from before they became pregnant, (e.g., diet, substance use/abuse, etc.), with associated data collected on other family/household members, prenatal, hospital maternity and postnatal programs in the community (irrespective of utilization).

2) Coping Skills and Early Childhood Development

There is a general intuition that in early childhood, key cognitive and other patterns of behaviour are formed which endure throughout adult life. These characteristics influence later ability to cope and resilience, generally.

In order to assess these kinds of hypotheses, a longitudinal sample would be required, starting at age two or three and following them for at least 30 years. Such a study should be multi-level, with continuing links to data collected from other family members and from community institutions.
3) **Successful Adolescence**

Adolescents go through major changes in life and outlook. This is a particularly risky period with respect to substance abuse (e.g. tobacco, alcohol, drugs), teen pregnancy, sexually transmitted diseases, eating disorders (anorexia, bulimia), motor vehicle accidents, dropping out of school, and suicide. There are hypotheses suggesting that parental socio-economic status is a strong correlate of successful adolescence; and early childhood environment is very important, including such aspects of parenting as expression of anger toward the child and consistency of punishment.

The kind of cohort study required to assess these views could be an extension of the previous "early childhood" cohort data set, or to advance the timeliness of the results, starting with 10-year-olds. As with the previous study, multilevel and continuing linked data collection regarding family members and community institutions is essential.

4) **The Workplace Milieu**

The traditional health concerns about the workplace have been injuries from falls and machinery, and exposures to toxic substances. However, there is increasing evidence that there are important psycho-social factors such as the "safety culture" of the firm, hierarchical level in a large white-collar organization, and job characteristics like repetitiveness, scope for discretion, and pace.

An appropriate multi-multi-milo data set would start with a sample of workplaces, and then draw nested samples of workers in those workplaces. Both workplaces and workers (as well as the workers' families) would have to be followed longitudinally for a period of years to provide the needed kinds of data.

5) **The Physico-Chemical Environment**

The public is bombarded with stories of environmental threats and hazards. However, there is almost no information on the relative risks presented by the different items. PCBs and 60 Hz electromagnetic radiation are presented with the same or higher levels of concern in the popular media as tobacco use and unsafe driving -- though, at currently prevalent levels of exposure, the orders of magnitude of PCBs and electromagnetic radiation are less risky for those exposed. A key factor in this perception may be the difference between self-inflicted risks, and involuntary insidious exposures.

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There are virtually no population-based data on exposures. Human experiments are impossible, so that current knowledge of the dangers of various hazards in the physical environment derive from extrapolations from animal models and (unfortunate) unplanned and typically poorly observed "natural experiments" in human populations. Still, much of the evidence clearly suggests that hazards have very long-acting and subtle effects. Biologically, this is not surprising, given that our physical environment now contains tens of thousands of substances that were unknown as recently as a century ago, while to paraphrase (Canadian born) British epidemiologist Thomas McKeown, we still have the genetic endowment of hunter-gatherers.

Addressing these concerns will require concerted efforts to collect data on individual characteristics like health status which can, in turn, be linked to the characteristics of the various physico-chemical environments to which the individuals are exposed. Longitudinal follow-up is essential, and could be greatly enhanced by linkage to health care and mortality records.

6) Lifestyles

Individuals' lifestyles include behaviours relating to diet, physical fitness, substance (ab)use, stress, risk-taking, and utilization and compliance with health care interventions and prescriptions. These lifestyle factors are major determinants of health and in turn, are strongly associated with individuals', their families' and peers' knowledge, attitudes and beliefs.

Lifestyle has been seen as a key determinant of health, and a central focus for health-promoting interventions. There has also been an evolution in thinking with respect to individual lifestyle behaviours, recognizing that many are the result of peer pressure or implicit norms. Simple "you shouldn't do that" directives are increasingly seen as "victim blaming".

Major challenges need to be faced in the designing of survey instruments and other modes of data collection to shed light on these important questions, but there is no doubt that the data sets will have to be substantially multi-multi-milo.

7) Prosperity and Income

New evidence that poorer individuals are less healthy is generally not greeted with surprise; it is a broadly accepted fact of life. It raises the question of why apparent equality of access to health care provided by Canada's universal system has not been translated into greater equality in health outcomes. While evidence of the correlation of health and wealth has accumulated, the reasons for this association are not well understood. In addition to an association at the individual level, there is sketchier data based on cross-national comparisons, suggesting that average health of individuals in a society is correlated with the levels or expected levels of prosperity of the society, and the degree of equality in the distribution of economic position within the society.

There is a range of possible explanations. For example, better general health among the population requires a smaller health care sector and thus frees up more monies for investment, growth, or current consumption -- a "virtuous" circle. Another possibility is that a general social ambience of prosperity and success is, itself, health-inducing. Yet a third kind of relationship is that an appropriately organized work environment is conducive both to higher worker productivity and to better health of workers (and, indirectly, their families). In terms of inequality, a key set of factors might be education, the diffusion of healthy lifestyles among the population, and feelings of self-efficacy.
These are clearly very broad hypotheses, and many of the conjectures require cross-national analyses that are beyond the scope of Canadian efforts. However, there is enough natural variation in lifestyles within Canada that some of the ideas can be explored by new research data sets. These might be organized with local communities as the key units of observation for the extent and character of prosperity.

8) Aging Well

For the elderly, aging well is health in the dynamic sense. It includes individuals adopting various coping mechanisms that help them maintain their range of functioning and avoid premature institutionalization and unnecessary dependency.

Understanding the determinants of aging could help explain recent trends, and more importantly, could provide major benefits. Unfortunately, knowledge in this area is very weak. It is not even known whether overall age- and sex-specific morbidity rates among the elderly are increasing or decreasing. Consistent measures applied to representative populations repeatedly over time are essential, and would be even more valuable if they were linked to contemporaneously collected data on the range, character and use of community support programs.

4.2 Epidemiology

Epidemiology is the scientific discipline that studies the incidence and prognosis of diseases, discovers factors which influence them, and evaluates the interventions that are aimed at their modification.

Although this science has developed substantially over the past century, there are vast areas where our epidemiological knowledge is swamped by our current ignorance. In part, this is a function of inadequacies in our information base. Epidemiology should be a major beneficiary of improved health information.

To determine where improved information is required, the Project Team on Information in Support of Epidemiology (Reference 9.10.11) began with an examination of the methodologies used in epidemiology, each of which has specific requirements for data and information. The methodologies can be characterized as belonging to one of four classes (or being a hybrid of them): descriptive studies, case control/cohort studies, quasi-experimental studies and randomized controlled trials. The last two methods use national statistical information as a context against which studies are carried out. The first two methodologies draw most directly on information such as that found in a nation-wide information system.

Descriptive studies use incidence, morbidity and mortality rates within defined geographical units to monitor the general health status of the population. Comparison of these rates across time and geography can be used to detect new health problems, and to search for risk and prognostic factors. More globally, such information can be used to evaluate the impact of health programs on the population.

At the national level, the existing health information sources service provide only a portion of the data needed for descriptive analysis. Such data gaps do not necessarily require new data systems. For example, studies of the health status of the population would be enhanced if changes to existing information systems were made. The interpretation of perinatal death rates would be facilitated by information on the mother. Better information is required concerning demographic
risk factors, including birth order, maternal age, age at first pregnancy and parity (such information is currently not available for all women). Information on disease risk factors (low birth weight, smoking, high blood pressure, serum lipids, physical fitness, alcohol consumption and diet) should be collected regularly, using comparable methodologies.

Data on incidence of non-communicable disease in Canada are insufficient. Currently, incidence data are available only for three disease entities: cancer, renal failure and congenital anomalies. Whether measured by the large proportion of deaths that they cause, or by the burden they place on Canadian society, non-communicable diseases are of major importance to Canadians and their health status. The project team noted that this dearth of information on incidence is a concern. (Such data would be much easier to build, if earlier suggestions regarding the construction of longitudinally linked health care encounter data were acted upon.)

Descriptive studies of risk and prognostic factors take one of two forms: the calculation of factor-specific rates (when information on risk factor and morbidity/mortality events are available for the same individual) and the correlation of disease incidence or mortality with risk factor prevalence for groups of individuals. Although the latter approach can result in "ecological fallacy" and misleading results, it is a useful tool providing supporting evidence or clues for further study. One major limitation to correlation studies with existing national data is the lack of sufficiently disaggregated data for some risk factors, such as environmental pollution and incomparable geographical boundaries. At the national level, studies of risk factors are generally restricted to those that focus on the association of risk and mortality (rather than risk and morbidity).

Nation-wide data can play a role in the evaluation of health interventions by portraying the extent to which they have been implemented in the population at large and the outcomes, both favourable and unfavourable, that have resulted. At present, only information on surgical interventions is collected on a national basis -- no information is collected on other methods of treatment or on diagnostic tests relevant to early detection. In addition, extremely limited information is available on non-medical interventions affecting the health and functional status of the population, such as informal support structures which can delay the need for medical intervention or socio-legal structures to decrease smoking.

There is increasing interest in having the capacity to follow disease episodes longitudinally through to their outcome, with outcomes ranging from full recovery to death. Even basic measurements of disease outcome -- the case-disability rate for chronic diseases and the case-fatality rate, the proportion of patients who are disabled or die as a consequence of the disease under study -- cannot be calculated from existing data sets for the majority of disease conditions.

Another methodology used in epidemiological investigations is case control study. Such studies are used to explore the cause of particular diseases by questioning patients with and without the disease to determine previous exposure to risk factors. Although national sources such as hospital admissions and separations records, could be used to identify those with the disease conditions under study, the information is too dated for such use.

In a related type of investigation, the cohort study, risk and prognostic factors are studied by following up subjects with and without the factor under study to determine what disease or death outcome occurs. Nation-wide data sources can be used in a number of ways to support such studies. For example, information on individual exposure can be linked to death records to ascertain mortality status and thus calculate indices such as person-years of risk. Such studies would be greatly facilitated if the risk and prognostic factors were capable of being analyzed with
information on the disease and mortality status for the same person.

Based on the work of the Project Team on Information in Support of Epidemiology (Reference 9.10.11), four areas for priority improvement have been identified:

- extending information available on the incidence of disease;
- producing information on disease prognosis and outcome;
- increasing the information available on the prevalence of disease risk factors;
- providing focus to the development and maintenance of environmental information with special emphasis on finding ways to maintain consistent geographical coding.

4.3 Health Promotion and Lifestyles

Health promotion is a relatively new field, with rapidly evolving concepts and methodologies that result in frequently changing information needs. However, the need for basic information with which to plan, take action and evaluate is a priority.

The First International Conference on Health Promotion\(^{18}\) defined health promotion as

"...the process of enabling people to increase control over, and to improve, their health. Health Promotion is the process of empowering individuals to influence the systems (socio-economic, physical, institutional and political) in which their health behaviours take place."

For data systems to be relevant to the study of health promotion and lifestyle modification, they must be constructed to collect information within a broader paradigm than the traditional medical model which focuses on illness and health care. Greater emphasis must be placed on the determinants of health and disease prevention and the role of health promotion in this process. Determinants range from health risk exposure and bio-medical status to information on socio-cultural, economic and political factors that affect health. Moreover, there must be concern with information on how public policies outside the health sector impact upon the health of individuals and communities. The project team saw a need for information that views health in the context of interactions and interdependencies between individuals and their "ecospheres", which include family, community, social structure and physical environment.

Information should focus not only on individuals, but also on communities (the latter defined as any group of people with similar needs or interests). In portraying the relationship of individuals with their community, care must be taken to capture qualitative, as well as quantitative, dimensions (for example, how the individual felt about the service as well as how many times the service was received). In addition to capturing information on outcomes of medical and non-medical community-based interventions, there will continue to be a need for information on processes used to bring about specific outcomes. Also identified is the need to find better ways

\(^{18}\) First International Conference on Health Promotion; November 1986; Ottawa Charter for Health Promotion (Reference 8.10.5)
to share such information among communities.

In addition to data characterizing the objective health status of individuals, information is required on the subjective factors -- such as self-esteem, self-will, empathy, intimacy, loneliness, isolation, perceptions of health, spirituality, beliefs and values -- that affect individual lifestyle and behaviour and thus, may create risk, or conversely, may provide a prophylaxis.

Analytic breakthroughs concerning the determinants of health status could clearly have a profound impact on understanding how individuals and societies can be maintained in a state of good health and how the health care system may be most appropriately used.

4.4 Comparisons Among Jurisdictions, Institutions and Intervention Programs

The issue of comparability was dealt with primarily by the Project Team on Comparability of Health Services Information (Reference 9.10.7), although other project teams also considered the need for comparability and reached similar conclusions.

There is general agreement that health service managers need better information to evaluate program efficiency and effectiveness. They cannot operate in a vacuum, ignoring other institutions and jurisdictions. Comparable information does lead to more efficient and effective service delivery. The Project Team on Comparability concluded that our present systems are largely inadequate in supplying comparable information. In some cases, this is due to the lack of national comparative reporting systems, while in others, it is due to inconsistent data definitions, improper analysis, lack of standards and guidelines, poor data quality management and lack of incentives.

It is recognized that attention has been placed on acute care hospitals, physicians' services and resources, and vital statistics, rather than on community health and continuing care. Reporting of expenditures and counting of resources consume most of the information systems, and even in these areas, comparability is a problem. While national Management Information System (MIS) Guidelines for hospitals have been developed, they have not been fully accepted and implemented despite the fact that the project has been under way for over 10 years.

The best attempt at nation-wide comparative reporting has been the fee-for-service expenditure reporting systems carried out by National Health and Welfare (NHW), such as the "Payment Schedule Comparison", and the "Statistical Summary: Number of Physicians and Fee Payments per Physician by Specialty". Other attempts of note are the annual reports prepared by the Canadian Centre for Health Information (CCHI) dealing with hospital facilities and utilization. The concern here is about timeliness -- many hospitals and provinces fail to report on a timely basis thereby delaying the final report. Hospital Medical Records Institute (HMRI) prepares comparative reports but only for its own clients -- it is not currently a national system.

An overall finding of the Task Force is that comparability of information is made more difficult because several different organizations are involved in setting standards, collecting and storing data, and analyzing and disseminating results.

The project team concluded that the best way to ensure the availability of high level comparative reports is to start at the bottom. The lack of standard data definitions, minimum data sets, standard edit rules, as well as quality control and security procedures is completely unacceptable.
Grassroots data captured at source must be improved and standardized, and national comparative reporting systems should be developed as by-products of the operational, administrative and patient/client service delivery systems. The project team made the following observations:

- The highest priority recommendation is to develop information systems and standards in the non-acute care settings. These gaps should be filled as soon as possible, as there are almost no comparable data available in areas such as community health and long-term care.

- In every sector, there is a need for the development and implementation of a Standard Service Encounter Record that would include, as a minimum, site of service, patient/client profile, reason for encounter, goods and service(s) provided, provider(s), resources used and time. It should also include the provincial/territorial unique lifetime identifier (ULI). Jurisdictions that have not already done so are urged to implement the ULI and extend its usage throughout all sectors of the health system.

- Nation-wide comparative reporting systems should be developed for all sectors, with statistics regarding patients/clients obtained by high level roll-ups from raw data captured at the lowest possible level. There should be standard data definitions and minimum uniform data sets. Standard coding and classification systems, such as those for diseases and procedures must be agreed upon, implemented and managed on an integrated basis. Standard codes are also required for ambulatory care service encounters, continuing care, mental health, and all sectors of the health system.

- In the hospital sector, it is recommended that the MIS Guidelines be implemented to the departmental dimension on a national basis by April 1, 1994.

- Global dimension reporting is highly desirable for large hospitals. It is further recommended that the minimum hospital data set should integrate financial, statistical and clinical information and support standard case-mix grouping systems for purposes such as resource use measurement, outcome measurement and quality assurance.

- In the professional services sector, a national minimum data set should be implemented that includes standard coding methods for services and diagnoses, as well as provider identification. Data concerning non-fee-for-service clinical practice and non-clinical areas of teaching, research and hospital/university administration should also be captured in accordance with the National Physician Data Base project.

4.5 Information On Health Care Quality Assurance and Outcomes (Reference 9.10.10)

For many decades, the effectiveness of the health care system has been implicitly measured in terms of the amount spent on health care. As spending on health care rose, it was assumed that the health of the population would increase commensurately. More recently, this assumption has been tested severely, and there is a general perception that may not be so.

This perception is further fuelled by studies that indicate large variations in some surgical procedures that cannot be explained using currently available data. Other clinical studies have indicated that, notwithstanding their cost, the efficacy of some procedures is questionable.
To provide a more balanced view, the measurement of health care system inputs must be supplemented with measures of the efficacy and efficiency of health care. For many illnesses and diseases, this translates into an examination of specific procedures and treatments and their outcomes – did the treatment eliminate the biological presence of the disease; did it restore the functioning of the individual to some predetermined level; was the treatment the most cost-efficient way to deal with the disease/illness? If Canadian experience follows that of the United States, the impact of review of outcomes can be substantial – authors have estimated the payback at $8.00 for every dollar spent on use and outcome review in American hospitals.19

An ideal assessment of outcome should have the following attributes:

- it would use valid, reliable outcome measures;
- it would measure the patient’s condition at discharge and at appropriate intervals following discharge;
- it would control for all relevant patient risk factors by capturing information on all elements of the patient’s medical history, behaviour and financial status that could possibly increase the risk of adverse outcome.

Ideally, a national-wide data set which meets these criteria should be available to enable such assessments. To meet this challenge, work will have to be undertaken on several fronts.

Work needs to proceed on the development and validation of outcome measures. Although such measures must be sensitive to the differences in outcomes, ways must be found to develop measures that allow cross-cutting comparisons of outcomes across illness/disease groups and for different treatment options.

Measurement of outcomes is relatively new, but addressing this important issue should not wait for a "perfect solution". Mortality, re-admissions and subsequent visits to health care providers, and many current survey questionnaires can immediately serve as useful proxies as more sophisticated outcome measures are developed and validated.

Clearly, patient outcome is a function of both the type of disease or illness experienced and the procedure or treatment received, and the severity of the individual’s condition. Severity can be defined from a number of perspectives. It can be defined in relation to the functional capacity of the individual – the more severe the disease, the more disabled (functionally limited) the individual may become. It can be defined in relation to the intensity of health care that must be brought to bear in the treatment process or the difficulty in treating the individual. It may relate to the patient’s level of medical risk. Or, it may relate to the stage to which the disease or illness has progressed and co-morbidities, and hence to its consequent amenability to successful treatment (cancers which can be successfully treated at an early stage may become inoperable and have a predictable mortal outcome at later stages). All of these dimensions of severity should be considered for nation-wide data systems.

19 Issues & Recommendations from the Proceedings of the National Workshop on Patient Care Outcome Measures, Page 21

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Severity should be measured at several points, namely, prior to treatment, on separation, and at fixed time horizons after separation. If severity and outcome are to be defined in functional terms, it is important that definitions be integrated with those used in population-based surveys. Such integration will allow for assessment outcomes, not only in terms of status prior- and post-intervention, but also against the context of the functional status of the general population.

The need for a data base which captures individual risk factors, in addition to information on treatment and outcome, is a similar theme to that advanced by the project teams examining data needs for health determinants, epidemiology, lifestyle and health promotion. (References 9.10.12, 9.10.11, 9.10.5 respectively)

4.6 Health Human Resource Information Needs

In the last decade of the 20th century, keeping health care costs down has become a main focus of health services research. As a proportion of total health care expenditures, those for human resources figure prominently, ranging from 60 percent to 80 percent of the total. Research efforts to better understand the dynamic relationship of health resource supply and demand and to examine the source of expenditure have been severely limited by the existing data.

Kazanjian and Friesen\(^{20}\) have defined three broad areas of weakness in our current research:

- First, on the demand side, better information is required to assess population health status and the consequent needs for care. This "needs-based" approach to health resource planning uses the prevalence of disease and its burden to the community as the primary determinant of the human health resources required. Currently, such a management process - while conceptually clear and feasible - is, in practice, unlikely to be undertaken due to data limitations. For example, planning requires information for a relatively small geographic areas, a municipality or a health region, within which the services will be provided. Such detailed information is not available for most types of data at present.

- Second, on the supply side, better information is required on the extent and distribution of human health resources and the technological and clinical capabilities which are available to them. Although baseline information concerning human health resources is collected in Canada, information is not available which adequately details the "human capital" represented by these personnel, the technology available to them, their use of it, and their resultant output. Organizations that provide health care, employ the majority of health care personnel. Such organizations vary appreciably in organizational structure. Their evolving structures and characteristics in areas such as recruitment, retention, turnover and attrition influence not only the size of the work force, but the quality of care, productivity and overall cost. Better information is required on the prevalence and characteristics of the various organizational models which are in use.

- Finally, information on implementation strategies and their subsequent political/socio-economic implications is of primary importance.


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In theory, if it were possible to forecast the demand for and supply of human health resources, managing the human health resourcing process would be much simpler. However, forecasting is complicated by a number of problems. On the demand side, these include the aforementioned lack of data on the characteristics of the population to be served, and lack of an objective methodology for translating these population characteristics into an effective estimate of the demand for human health personnel. Difficulties in supply forecasting arise from the current inability to verify underlying assumptions regarding the characteristics of the current human health resource stock (such as career histories, turnover rates, inactivity ratios, etc.) and the diversity and fluctuations in service content and delivery patterns.

The definition of professional groups often presents great difficulties for planners. The information supporting supply forecasting should allow distinctions to be made among resources so that assumptions such as "a nurse is a nurse is a nurse" are not made.

Current sources of human health resource information are generally insufficient. Most provincial data on human health resources are limited to head counts. There is an absence of comprehensive national data on groups other than physicians and registered nurses; data on registered nursing assistants/licensed practical nurses, aids, orderlies, etc., is limited. While sources, such as personal tax returns and the Census, may be used to obtain some information concerning numbers and their labour market status, these sources may, as a result of respondent error, blur important occupational distinctions and provide virtually no information on area of specialty, career histories, or practice patterns. Provincial data bases that do exist, depending on professional legislation, may not be comparable. Similarly, employment data are available only in a few provinces from special surveys, and cannot be used for interprovincial comparisons.

Information that relates human resource inputs to specified outputs is currently limited to activities carried out in hospitals and to some professions. Very limited information exists on community-based services, and no systematic information exists on health professionals practising in the private sector.

The report on Information Needed to Support Health Human Resources Management (Reference 9.10.9) states that, at a minimum, a priority should be placed on the continued development of the National Physician Data Base and on improving the content and quality of the existing survey of Registered Nurses. Also advocated is a systematic review of data currently published in "Health Personnel in Canada", a National Health and Welfare publication that is the current focus for the dissemination of information on human health personnel in Canada. A review should be undertaken, with all interested constituencies, to enhance its accuracy and completeness and to reconcile its estimates with those from provincial sources. Enhancements to rectify gaps in existing workload measurement systems through the implementation of the MIS Guidelines also should be promoted.

4.7 Community Health Information Needs (Reference 9.10.6)

The domain of community health includes all health functions and activities which take place outside health care institutions. Community health programs can be delivered by a range of providers, from health professionals to members of non-governmental organizations and advocacy groups. In principle, care provided by family members and friends would also be considered as an element of the community health mosaic. Although information needs for community health are similar to those of other users, an important element of the requirement is the need for data
for small geographic areas. This requirement cannot be met by the majority of existing health information sources.

Community health information needs include a number of areas where basic information is required -- for example, information to support needs assessment, program planning, development, implementation, and evaluation. Information is required on which to base community action, to market community-based programs and to support fund raising. Given the broad nature of these interests, it was difficult to reach a consensus on a precise definition of the data elements required.

Drawing on the Template, another way to view community health information requirements would be to think of them as focusing on three themes. First, information is needed that profiles the characteristics of the members of the community (both individuals and families), the resources they possess, the problems they face and their unmet needs. Second, information is needed that characterizes the many dimensions of the community environment within which the individual members function -- for example, the physical environment, the economic environment, the existing "service delivery" resource base and its current use and impact. Finally, information is needed to allow comparison of a community to other, similar communities, in order to identify other communities facing similar challenges and evaluate its own performance.

4.8 Information Needs in Support of Health Care Economics

Information needs in support of health care economics focus on issues related to allocating health care resources and to choosing between competing methods/techniques for maintaining and improving the health status of Canadians.

A general demarcation can be defined between the need for information in support of micro-analysis of individual programs or treatments (for example, the type of substitution that may be possible between inputs of different types to achieve a given outcome), and information required to support macro-analysis of health at the provincial and national level. The Project Team on Information for the Economic Analysis of Health (Reference 9.10.8) found that there was room for improvement in the collection and standardization of both micro- and macro-economic data. As progress is made in characterizing health outcomes, choosing between alternative delivery methodologies, making decisions concerning age-sex specific use and evaluating programs, more micro-data will be required. Although macro-data may be created from micro-data, the reverse is not true.

A major source of macro-economic data for users is the Health Care Expenditure series of Health and Welfare Canada. It has been suggested that this series could be further improved if better estimates were possible in the area of private spending for items such as drugs, eyeglasses and appliances. This could be facilitated through changes to existing consumer expenditure surveys. Common approaches to health care expenditure data by the provinces should be encouraged.

Although the development of a satellite account to the System of National Accounts for health might be considered, the need for better micro-economic data and data pertaining to outcomes is judged to have a higher priority. However, the manner in which expenditure data are compiled should be in keeping with the requirements of the System of National Accounts.

A better conceptual structure is required to characterize the institutional and community-based sectors and programs within the institutional care, acute and long-term care sectors. Additionally,
the use of standardized nomenclatures and measures of units of service should be used across the continuum of health care provision; the capture of diagnostic data in ambulatory care should receive special attention. More emphasis should also be placed on the collection of price data that will allow for comparisons between inpatient and outpatient costs.

In order to better identify the health needs of the Canadian population and to monitor health status gradients, regular collection of population-based data is indicated.

In recent task forces and health care commissions across Canada, three common themes have emerged:

- Greater emphasis on disease prevention and health;
- Greater emphasis on community-based care alternatives;
- Greater emphasis on accountability.

For all of these themes, health economics analysis can act as a powerful evaluative tool.

### 4.9 Policy Information Needs

Current policy frameworks in the health area consider the absence of disease as a necessary, but not sufficient condition for optimal health; consequently, policies for health encompass a great deal more than health care policy.

Health related policy can be divided into three types:

- policy concerned with the overall structure of health care delivery and allocation of resources (systemic policy);
- policy concerned with health facilities programs (organization level policy);
- policy concerned with the allocation of resources to specific treatments, procedures, or services in support of health (intervention policy).

In each type of policy development, a number of stages can be identified, including problem identification, issue definition, the search for options to deal with the issue, the choice of a preferred alternative, implementation of the chosen policy and its subsequent evaluation.

To support these policy types and their development, three generic types of information are required:

- population-based information that describes the target population of policy interest;
- organization-based information that describes the organizational arrangements for the production and delivery of services and programs;
- intervention information about the characteristics and performance of specific procedures, treatments and services.
As well as servicing these general policy needs, information must have certain attributes to be useful.

Information must be timely -- the need to make a decision is often so critical that the decision cannot await the production or even the retrieval of desired information. The greater the need for objective information, the greater the need for recent data.

Information is not the same thing as data; quality and relevance are among the attributes which enables data to be transformed into meaningful information. It is the degree to which data can be combined with or contrasted to other information, which enable them to be interpreted and given significance. Aggregate measures are not necessarily meaningful if, at the level or unit of aggregation, there is little or no relationship to the phenomenon at issue, or if the data do not lend themselves to disaggregation and linkage with other data.

Not all information sought and used by policy makers is objective; the mix of subjective and objective information can vary. The evaluation phase at all policy levels seems amenable to a good deal of objective information content -- have we or have we not produced better health? Unfortunately, the focus tends to have been on system outputs rather than outcomes.

Policy issues in need of support are numerous. Systemic issues include:

- information to help contain the cost of health care;
- information bearing on determinants of health and alternative forms of care and support;
- information that sheds light on the values and beliefs held by the public with respect to health and health care.

Organizational issues include:

- information that can be used to assess the impact of an aging society on the demand for health care;
- information on inducements for organizations to develop alternate treatment regimes;
- information to help organizations deliver health care in a more efficient manner.

Intervention issues include:

- an aging society which will demand efficacious interventions;
- in the face of pressure on health budgets, intervention policy will become increasingly oriented toward effectiveness (i.e., outcomes);
- intervention policy will increasingly be shaped by public values and there will be additional impetus for quality assurance mechanisms, whether or not through the intermediary of tort actions;
- effective health promotion interventions still need to be developed and tested.
These policy issues, which have existed for some time and can be expected to have continued relevance, are likely to generate a need for a body of core information:

- objective measures of population health status, health-related behaviours and disease burden will continue to have relevance to policy makers at all levels;

- time-series information concerning individual values and beliefs is needed to provide insights into emerging health policy issues and the public's capacity to accept alternative health care strategies;

- intra- and inter-organizational information characterizing production efficiencies is needed to identify the most efficient approaches to health care delivery;

- diagnostic information must have the capacity to be linked or related to other information sets, such as those which portray procedure cost. Information sets that relate health status/illness burden of relevant catchment populations need to be linked to variables such as practitioner practice styles, service volumes and organizational configuration, and also to the presence or absence of inducements or incentives aimed at altering or sustaining organizational configurations or approaches to service delivery;

- there is a need to link resource utilization information to intervention-type information in respect of health outcomes, and to population-type information in respect of health status, health-related behaviours and disease burden.

Many of these needs could be facilitated by a common denominator, a unique identifier, which could be used to link all types of desired information.

Information needs cannot be prioritized, let alone articulated with any precision, in the absence of insights into what the most appropriate measures and indicators may be. Further work needs to be done -- indicators and measures are needed to reduce reliance on proxy measures and proxies need to be selected to reduce reliance on "best guesses".
5.0 NATION-WIDE HEALTH DATA SYSTEM AND
CONVERTING DATA TO INFORMATION

The previous section examined the need for health information and related these needs to four
general "poles" of interest -- individuals, their environment, institutions which provide care, and
the interventions made to maintain or improve their health status.

This section examines how such data needs are or may be met, how data can most effectively be
transformed into information, and how the resulting information may be better marketed.

5.1 Current Information Sources

Traditionally, the "preferred source" of health information in Canada has been administrative
systems. Although the use of information from administrative systems for statistical purposes is
cost-efficient, it is not without limitations. For example, it is difficult to compare the health care
information collected by the different systems because of the varying definitions and information
collection methodologies. Current administrative sources do not fully cover the health care
universe. More generally, these sources contain information specifically of interest to
administration and some clinical practice, but are less successful in meeting broader needs, as
characterized by the Template. (Reference 9.10.14, Development of a Structural Model.) This
incompleteness and inability to integrate (or compare) information transcends all other weaknesses
in existing health information at the national level.

Data from administrative sources have been supplemented with information from specially
designed surveys. Such surveys provide additional information which is either too costly or not
easily collected from current administrative records systems. Under current systems, surveys can
provide faster access to needed information. While surveys can be mounted in a matter of
months, developing new administrative systems or modifying existing systems can take years.
Small surveys can be used to explore hypotheses and relationships, and more generally to "scope
the size" of an issue before making much larger expenditures, and to obtain more detailed
"confirmatory" information from modified administrative/clinical feeder systems or larger survey
undertakings. However, if properly designed, future administrative data systems could provide
the framework for quick and cost-effective samples. For example, the complete population
coverage of provincial health care information systems provides a potentially excellent sample
frame. Also, moves to automate the collection of health service encounter information at the time
of the encounter could provide a very good collection vehicle for special surveys.

A review of administrative data sources currently used for statistical purposes reveals that a
relatively limited range of sources have been tapped to provide information.

The financial characteristics of hospitals have been obtained through audited financial statements,
while their operating characteristics are obtained through an annual supplementary survey. An
annual special survey of the financial and operating characteristics of residential care facilities is
carried out. However, no information is acquired about the operation of other health care settings,
such as physicians' offices, clinics, and outpatient departments of hospitals.

For many years, information has been collected from hospitals on the volume, characteristics,
diagnosis and treatments received by inpatients. The usefulness of this data is limited, as the unit
of measurement is the treatment event. For four conditions -- cancer, tuberculosis, renal failure
and therapeutic abortion -- additional information is available from registries covering the first
three conditions and from a special survey covering therapeutic abortions in Canadian hospitals. The incidence of a limited set of notifiable diseases is recorded by an ongoing collection system. Although information systems are being developed which will provide information on selected outpatient procedures such as same day surgery, virtually no other information is available concerning clinical/therapeutic interventions provided by other parts of the health care and support system. 21

In the area of human health resources, a lack of comprehensiveness in existing data sources is apparent. Although information from licensing bodies for physicians and nurses is available for statistical purposes, only basic counts are available for most other health specialities. More recently, information from provincial/territorial medicare systems has been used as a source in the estimation of physician fees by jurisdiction and specialty.

Information on vital events (such as births, deaths and marriages), collected through provincial/territorial vital registration systems, historically represents the first use of administrative information for health information purposes. The collection was one of the charter programs when the Dominion Bureau of Statistics (the predecessor to Statistics Canada) was created in 1919.

Surveys of health status have been conducted only infrequently and sporadically in Canada. An early population-based survey of sickness was conducted in 1952, 26 years passed until the next population-based survey of health status was conducted. More recently, population-based surveys of health status have been conducted periodically as supplements to Statistics Canada’s Labour Force Survey (for example, the Canada Health Promotion Survey and annual surveys on the smoking habits of Canadians). Currently, every fifth year, health is a focus topic in the General Social Survey series of Statistics Canada. Specialized surveys focusing on topics of fitness and disability were undertaken during the 1980s. Occasional provincial health surveys have been conducted, such as Santé Québec and the Ontario Health Survey. Questionnaires have not been standardized. Surveys relating physical environment to health and health effects have not been undertaken to date in Canada.

A more extensive summary of existing data sources may be found in the Project Team report concerning Mapping of Systems Names to the Template Classification, Identification of Data Gaps and their Relationship to Provincial/Territorial System Development Plans (Reference 9.10.15).

5.2 Future Sources of National Health Information

Consolidated Patient Care Records

The number and sophistication of data systems that exist to support patient care, medical practice and management of the health care system is increasing. If consensus can be reached on the frameworks, concepts, definitions and standards embedded in these systems, they may serve to provide increasingly useful sources of information on health status and health care.

21 Initiatives to explore the secondary use of medicare records for research and statistical purposes is underway in some provinces and at Statistics Canada’s Canadian Centre for Health Information.
Building on the Template, Dr. Howard Platt of Alberta has envisaged a consolidation of health information from a variety of sources and across time into an individual record. First and foremost, the consolidated record would be a vital tool in the patient care process. Second, it would provide a rich source of health information which would meet many of the information needs identified in this report. Enriched with population-based information, such records could provide a basis for measuring the health status of populations and of individuals, both cross-sectionally and over time. These records could aggregate individual information to the family and household levels, could incorporate both perceived and actual physical/medical measures of health status, and could provide a rich source of data on individual encounters with the continuum of health care providers (Figure 4).

Consolidated records could also be used as a sample frame for special surveys of sub-populations of individuals with selected characteristics (for example, the status of individuals who receive a surgical intervention such as a coronary artery bypass could be followed up at multiple time points after surgery).

Although this conceptualization is appealing, concern has been expressed that if such a database were to become a reality, a substantive threat would be posed to the privacy of individuals, especially if such records were to be centralized. Although individuals might agree with the establishment of a database at the local or provincial level, little support was expressed for a comprehensive national database containing the records of individuals.

A system can be conceived where databases for provincial/territorial levels or for sub-provincial areas are developed using standardized concepts and definitions to describe patient interaction with the health care system. In turn, subsets of information from these standardized records could be accessible, using mutually agreed upon protocols, to a nation-wide health information system. Such an approach obviates the need for one national unified database containing individual records, yet avoids the need for expensive and complex post facto linkages of data sets. As such information bases would have active use in the patient treatment process, improved quality and timeliness of information should be possible.

**Post Facto Linkage of Data Sets**

If realization of Dr. Platt’s vision of consolidated health records is not possible in the short term, a second technique, post facto linkage of data sets can be used to integrate data from diverse sources. This methodology has already been used extensively in the Canadian context in occupational health studies. The process integrates event-based records for individuals within a data set, (for example, by linking medicare records to create patient profiles that show interaction with primary care givers). It can also link records for the same individuals from different data sets (for example, by looking at mortality records for deceased nuclear workers to study differential mortality patterns for the exposed population). Linking records and creating integrated data files depends on both files having a sufficient number of accurate and common identifiers to allow record matching to take place.

Common identifiers can take a number of forms ranging from unique personal identifiers (currently being adopted by health care systems in many provinces) through to the provision of sufficient personal information to discriminate between individuals (for example, age, sex, date
of birth, maiden name, etc.). Current computerized matching processes use both exact matching and probabilistic matching techniques. (In the latter case, records are matched based on the best "fit"). Current ability to link data on a post facto basis is limited by a number of factors:

- inadequate identifiers appearing on the files to be matched;
- concerns about the propriety of linking (administrative) records without the express permission of the individuals concerned;
- the relatively high cost of linking large record files with one another.

Integration Through Simulation Modelling

A significant methodology for integrating diverse data sets and drawing new inferences is micro-simulation modelling. This can be thought of as an extended form of multiple imputation, where data from several different sources are woven together. For example, to the extent that risk factor prevalences are known, and disease incidence is related to risk factors, and patterns of disease progression have been systematically observed -- even though all from different data sets -- an overall statistical picture of disease processes can be constructed, albeit based on the simulation of a sample of synthetic life histories. In turn, such a micro-simulation modelling approach to annealing or integrating different data can support a range of new kinds of analysis, such as determining what portion of a given health outcome can be attributed to a particular risk factor or health care intervention.

Micro-simulation modelling has already been successfully developed by Statistics Canada for use in analyzing transfer programs and income tax provisions. Such simulations depend on the availability of information concerning the baseline state of the health of the population, the health care system and the dynamics of change. Unfortunately, there is a dearth of information on dynamics from existing sources and, consequently, recourse must be made to "expert opinion" to fill in our information gaps.

There are substantial advantages to the use of micro-simulation modelling. The methodology enables the integration and representation of various types and sources of information in one data base. Having created the baseline (synthetic) data base, modelling allows the investigator to modify assumptions and observe the consequent impact. Simulation models can be used to determine areas for priority information development by identifying factors which have minor "system" impacts, as well as those factors for which a small relative change in value results in a large change in the system’s status. Finally, this approach satisfies the concerns of privacy advocates, as the records do not represent real individuals.\footnote{22}

5.3 A Future National System of Health Information

Although a number of sources have been identified that contribute to the existing national health information data base, the preceding discussion indicates that we do not currently have either comprehensive or integrated information.

\footnote{22 It should be noted that the methodology does not replace, but builds upon the need for records which consolidate information on individuals - only with such consolidated information linking events across time, can the dynamics of change be accurately estimated.}
The attributes of a system of national health information have been identified by Dr. Michael Wolfson of Statistics Canada. Such a system should represent a "complete and systematic set of data on health matters where the data have some coherence or 'adding up' properties." Its coverage should be complete -- in terms of the Template, all cells conceptually should be included. It should encourage explicit "consideration of the theories that either underlie the data or analyses for which the data will be used." Such a system would represent a "higher order" integration than the simple juxtaposition of information from various health information sources. Existing information cannot be juxtaposed to carry out descriptive analysis, let alone be "added up" in any coherent manner.

Such a system of nation-wide health information would relate to national health information sources in a manner similar to way the System of National Accounts relates to the data feeder systems upon which it is based. In an era of sophisticated telecommunications, the physical location of these feeder systems and sources is an issue of diminishing importance. It is important however, that long-term agreements be struck between the owners of these distributed sources of information and those administering the national system of health information, guaranteeing access to the information and establishing standards to enable integration and protocols to facilitate transfer.

Drawing on information from feeder systems and other sources, the nation-wide health information system should integrate the information flows through analytic processes as well as the use of simulation models. The resulting data sets and knowledge base generated from this integrative process would form the basic product of the system.

Clearly, such a system would not be the repository of all conceivable information. Rather, its products would include an integrated set of indicators, periodically updated, which would portray the key dimensions of the health status of the population and of health determinants, including the performance of the health care system. As discussed in Section 3 of this report dealing with concepts, the development of global summary statistics, similar in concept to the Gross Domestic Product, should be pursued. The system must also be capable of capturing more detailed information from its data source systems to help explain the movement of indicators as well as carry out special studies.

Both post facto record linkage and simulation modelling would be used extensively in the conduct of pan-Canadian analyses of specific health-related issues. Responding to societal concern, a common consensus policy on scrutiny of all record linkage activities, on a case-by-case basis, should by developed and observed by all stakeholders. Linkage should be undertaken only when the benefits of the linkage activity are judged to exceed real or perceived concerns regarding individuals' privacy. (This policy has been practised religiously at Statistics Canada for many years.)

This information generation capacity will have to be thought of in evolutionary/adaptable terms. Many issues will change either in tone or in substance with the passage of time. The work of the Task Force has pointed to the need for improved mechanisms to support the generation of information that will support the analysis of emerging issues -- a recurrent criticism of the existing

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5.4 **Data Management Issues**

Data management concerns the manner in which information is handled from data acquisition through processing, dissemination and finally, storage. The objective of data management is to ensure data integrity -- in other words, to ensure that data are managed in such a manner that they meet prescribed standards as measured in terms such as data quality, coverage, definitional basis, etc.

**Unique Identifiers and Common Information Standards**

If consolidation of information is to take place, the existence and use of unique personal identifiers is a crucial requirement to ensure information integrity. Most provinces/territories are in the process of introducing such identifiers, but it must be remembered that these identifiers will be used only for transactions involving primary and hospital care in most jurisdictions. Care received in other treatment settings will be recorded using different administrative systems and identifiers. Also, it should be noted that the identifiers are unique in the issuing jurisdiction. As individuals move between provinces and receive different "unique" identifiers, their interactions with the health care system cannot be followed.

A general consensus has emerged concerning the initiatives needed to increase the integrity of the data collected:

- Implementation of a unique individual lifetime health identifier should be undertaken in those jurisdictions that have yet to do so. Consideration should be given to introduction of a nation-wide unique personal lifetime identifier or, at a minimum, developing methodologies to "track" patients who migrate inter-provincially.

- Unique individual identifiers should be included on both administrative records and statistical surveys to permit linkage of different information types, of information across episodes of illness, and of interactions with the health care and support system.

- Where unique individual identifiers cannot be collected, guidelines should be developed regarding other identifying information that should be included on administrative and survey files to allow linkage with other data sets.

To enable information from different systems to be compared, additional guidelines should be developed. Such guidelines should facilitate standard service encounter recording and should provide standards for the integration of financial, statistical and clinical information. They should also provide standard nomenclatures to be used in methodologies for grouping clinical cases, resource use measurement, outcome measurement and quality assurance.

The need for common standards has already led to the adoption of the MIS Guidelines by many hospitals. The guidelines describe standards for information systems development and integration, provide accounting guidelines for determining the costs of programs and services, and describe workload measurement systems for different kinds of health care departments.
Guidelines should be created which would enable compatible information collection from the continuum of health care settings -- hospitals, long term care, ambulatory care, public health, home care, community care, etc., which simultaneously meet administrative and clinical needs as well as provincial/territorial and national information needs.

Other classification structures that should be developed include diagnostic classifications for primary care and standard occupational and professional classifications for health providers.

**Record Creation and Data Capture**

As noted, health data are captured both by health care providers in administrative and clinical records and through surveys. To improve the quality and salience of the information captured by these systems, a number of concerns must be addressed. Whether the information is to be used to support individual patient care at the local, provincial/territorial or at the national level, these concerns tend to coincide:

- Systems should capture basic information only once -- an example cited from the care-provider setting is the creation of separate sets of clinical notes by physicians and nurses.

- Classification systems used in the recording of such information should, where possible, ensure that the captured data can be used for multiple purposes -- this implies the capture of "atoms" of information which can be recombined into a variety of other higher order classification schema.

- Informatics should be used to facilitate accuracy in recording information, and to facilitate error detection and correction as close as possible to the information source. Such computerized support is increasingly available in both clinical and survey settings.

- Compliance in providing data, improved accuracy and completeness will be facilitated if data elements are collected only when demonstrated necessary and as economically as possible.

- Common aggregation and disaggregation rules should exist to ensure that reports produced at various levels of abstraction complement one another and are capable of being integrated.

- A common understanding of the roles, responsibilities and obligations of data providers, processors and users concerning, confidentiality and data security should be promoted.

The substantial amount of time and resources invested in the collection of health information might be significantly reduced if information could be captured once. Current experimentation with capture of information where the service is being provided (e.g. in hospitals) well exemplifies the promise of this technology. Informatics is the key to other improvements in the local information environment, including access to the latest available information, and access to software "tools" that support the patient care process, such as expert systems to aid in case management or in the interpretation and display of information.

Informatics is also having an impact on data collection in surveys. For example, it was recently reported that 50 percent fewer errors were made when computer-assisted interviewing was used.
on the monthly Canadian Labour Force Survey.\textsuperscript{24} This improvement has significant implications not only for data quality, but also on the extent of resources required subsequently to process the file.

There are indications that more work must be done to ensure that individuals who develop information for data feeder systems -- be they nurses, physicians or respondents to population-based surveys -- be better informed of why specific data elements are collected. This is especially true of those data elements that are not of apparent use. There is a need for continuing assessment that the "right" information is being captured to meet local, provincial/territorial and national information requirements.

Data records should meet explicit acceptance criteria -- for example the contents of records must correspond to expected values. It is especially important that key fields on records (such as those used for subsequent linkages) be validated. Data capture should be subject to a quality assurance program or at a minimum, a program to measure the level of error introduced by the capture process. Controls must exist to ensure that the same record is not entered more than once.

**Data Processing**

The numerous, decentralized data sources which use multi stage information acquisition processes (the dynamics of which are little understood) present a significant challenge for national health information. Differences in data can result not only from embedded concepts, but also from the manner in which the data are processed.

This problem can be reduced through the development of common "best practice" approaches to data acquisition and record processing and the provision of guidelines that are maintained and updated as required. Using such an approach, the MIS Guidelines have improved information processing practices in Canadian hospitals. This model clearly needs to be extended to other areas.

Documentation of changes to records as information is processed represents an important method of assessing the quality of the information. For statistical purposes, processing may include the imputation of values for missing information. The aim of such a process must focus on the preservation of the multivariate character of the data set without introducing bias. Care must be taken that files are not "over processed". Not only does excessive processing increase cost, it may introduce the probability of making "corrections" to data when no underlying error existed. Guidelines concerning documentation of the imputation processes and their impact should be established.

**Storage and Archiving**

Although information in storage or archives is not usually modified, data integrity may continue to be at risk from factors such as decomposition of the media on which information is stored (e.g. computer tapes, diskettes, etc.) or inadvertent exposure of electronic data files to electromagnetic sources. Loss of data can cause substantial expense and time loss resulting from the need to reprocess information; at the extreme, such accidents may result in irreparable data loss. Common

guidelines should be developed to avoid data file corruption and to enable quick backup and recovery.

Data Inventories and Data Dictionaries

There is currently no inventory of information on holdings in the health sector, either pertaining to data sets under development or to those that have existed for many years. Information is needed to determine the location of data holdings and to provide technical documentation on their source, concepts, definitions, coverage, and quality assessment.

Lack of such information diminishes any collective ability to manage the overall data system. Moreover, it has been identified as a significant problem for researchers and other data users who seek information and need to assess its appropriateness. The Template may be an appropriate anchor for any data dictionary as it provides users with a visual metaphor of data domains and their interrelationships.

Data Security

Information on the health of individuals is most sensitive. The public concern expressed with the occasional, inadvertent disclosure of such information has led, in the recent past, to both Royal Commissions and resignations by ministers of the Crown. Such disclosures not only have political consequences, but may well jeopardize the collection and retention of the information itself. Maintaining data security is further complicated by the flow of information between data bases. With telecommunications comes the possibility of third party compromise of data bases through electronic interception of signals or direct access to the data base. Development and use of common security guidelines by all participants in a nation-wide system would facilitate the maintenance of data security, and would demonstrate to society that those who are entrusted with health information consider security to be a high priority.

5.5 Data Analysis

The Task Force project team dealing with data analysis (Reference 9.10.13, Project Team on Health Information Analysis: Potentials and Impediments) defined this activity as the application of a process or technique in order to increase human perception of data. Analysis may be exploratory -- searching for insights, or confirmatory -- evaluating the evidence that is available. The analytic process is often iterative, with one analysis producing data and information which leads to further thoughts and conjectures, which lead, in turn, to additional analysis. Data form the grist of the analytic process. Data may be quantitative or qualitative, numerical or non-numerical. Information is a value-added product that results from the combination of data and analysis and theory to yield a perception of the significance of the underlying data and makes data useful for the benefit of society.

If analysis is to reach its full potential, various barriers and impediments to analysis will have to be reduced or eliminated.

* Insufficient quantities of data may exist to allow analysis of small geographic areas or rare sub-populations of individuals. For example, most of the national population health surveys carried out in Canada have had insufficient observations for the province of Prince Edward Island to allow detailed analysis.

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Analysts have substantial difficulty in locating and accessing data appropriate to their interests. Adequate documentation of data sets is needed to determine whether the data set is suitable for use, and an important element of the analytic phase.

Restrictions are often placed on access to data sets and their linkage in order to maintain confidentiality, thus hindering analysis.

Data may pass through many hands and undergo numerous processes prior to analysis, with the possibility of errors being introduced at each stage. Effective analysis requires a better appreciation of the non-sample error present in data sets.

Data are expensive to produce. There is usually a trade-off between the amount spent on producing a data set and its analytic usefulness. Future net reductions in the cost of data and data analysis will likely come from advances in computer and communications technology, improvements in statistical methodology, increased sharing and comparability of data, and reduction in under-utilization of data.

Lack of data comparability from various sources is a major problem.

Researchers may be reluctant to share data, as data are considered a fundamental resource.

Analysis is impeded by the scarcity of good analysts.

The production of data and the subsequent analysis are often too slow to be useful to end users.

Problems can exist in communication of both analytical needs and results.

Technological and methodological limitations may inhibit analysis. A methodology which chooses a mathematical model by fitting a regression with each subset among the possible independent variables to find "the best" fit, can outstrip the capacity of available computing technology.

Improved co-ordination of both analytic effort and data collection is needed to enhance the efficiency of analysis. Duplication in either activity represents an undesirable waste of resources.

Because of the complexity of health science and health issues, productive analytical efforts may be dependant upon trans-disciplinary collaboration.

Many of the recommendations for reducing barriers in the area of analysis mirror those made in other parts of this report -- for example, use of a unique personal identifier, collection of longitudinal health information, collection of information on health interventions related to outcomes, capacity to link data sets. Additional suggestions for reducing impediments include the following:

- the development of directories of health data bases and analytic projects;
- collective agreements to share and pool health data;
• the legitimization of use of health data for research purposes through legislation and regulation;

• the creation of "safe houses" at various points across Canada, where confidential health information may be maintained, linked and analyzed and the linking of these "safe houses" through protected computer networks;

• the creation of educational and marketing programs for various constituencies, including the public, to inform them of the importance of health data and the benefits of health data analysis;

• the development of policies by the various stakeholders to promote analysis and to support the conditions which make it possible (for example, access to data);

• the enhanced capacity to undertake analysis in data collection agencies as well as in organizations focusing on data user.

5.6 The Marketing of Health Information

The value of health knowledge to society can only be fully realized if that knowledge is absorbed and acted upon by the population at large. This contrasts with traditional scientific fields, such as polymer chemistry, where the discovery and developments of one individual need not be understood by society as a whole to be beneficial.

Identifying the audience for information products, and designing a marketing plan should be a determining factor in the development of the information collection strategy, not an afterthought. The process of marketing determines the client's needs and ways in which these needs can be met, by defining the product, its price, how the product is distributed, and how the product is best promoted. The blend of these marketing strategies must take into account the differing needs of clients for health information -- the needs of researchers may be quite different than those of the general public.

Different approaches need to be established for the marketing of health information to:

• "key influencers" such as physicians, politicians, and bureaucrats, who determine health policy and program content and who, in turn, disseminate information to the public; and,

• specific segments of the general public, who use the information as the basis for making personal decisions affecting their health and to better understand judgements and decisions of "key influencers", thus creating a climate of support among the public for the collection of information pertinent to the health of the population.

Concerning user needs for products, although many users expressed interest in receiving data in machine-readable form (especially on diskette, for use with commercially available spreadsheet and data base software packages), the larger market continues to be for hard copy paper products. Traditional statistical products with page after page of tables were of less interest to many users than products that present digested information. There appears to be a growing market for "niche" products which specifically serve the needs of various groups -- hospital administrators, membership and boards of voluntary non-profit organizations, educational institutions, etc.
With respect to product price, views were expressed that the prices of many existing products were proving a barrier to access and use. The research community and non-profit organizations were especially concerned about this issue. Future reductions in the cost of products may emerge from advances in computer and communications technology.

The promotion and dissemination of health information products need to be given a higher priority. A "success story" is the strategy used for the dissemination and promotion of the results of the 1984 Health Promotion Survey. Based on market analysis, products included both technical and popularized reports of the survey findings, media kits, slide presentations and workshop handouts. These materials were used in association with a national news release, and news conferences at national and provincial levels. Copies of the popularized reports were sent to local interest groups. At the time of evaluation of the activity, it was reported that the results of the 1984 Health Promotion Survey had been used as the basis for 40 published papers, the research findings had been included in a variety of university curricula and new health promotion and lifestyle policies and programs were being developed.
6.0 IMPLEMENTATION CONSIDERATIONS

The Task Force investigations indicate almost unanimous support for improved health information systems. Naturally there is a wide spectrum of recommendations on information needs and, inevitably, differing judgements on priorities, the resolution of which is a subject for negotiation and compromise. But the general consensus on principles does not carry easily into issues of practice. While consultations strongly suggest the need to enhance co-ordination processes (which was one objective in the formation of NHIC), and to increase or improve health information operational capacities, one cannot assert uniform support for any significant specific proposal to advance the operational status quo.

The ensuing discussion will attempt to outline various roles and attitudes, and summarize various implementation issues which have been advanced in certain of the project team studies and in many oral consultations.

6.1 Roles and Relationships

The complex of institutional roles and relationships pertinent to health information development is an uneasy, unstable structure of many, many constituencies and several key institutions. Some categories of these are:

- Health ministries and the conferences of ministers and deputies
- Users of health information (including the public, other government agencies, non-government organizations and industries, professionals, etc.)
- Data providers (including physicians, nurses, patients, respondents, pharmacists, etc.)
- Information managers (including Statistics Canada, Health and Welfare Canada, provincial health ministries, the MIS Group, HMRI, etc.)
- Information analysts (including various health science research centres, Statistics Canada's Canadian Centre for Health Information (CCHI), provincial ministries, Canadian Institute for Advanced Research (CIAR), professional associations, the Ontario Premier's Council on Health and Well-Being, etc.)

The main existing "operational" entities seem to be:

- CCHI, which is largely oriented to collecting and providing statistical information of general public relevance;
- HMRI, which collects and provides information derived from hospital discharge records;
- The MIS Group, which develops and promulgates health care costing standards;
- Various Health and Welfare Canada units which collect and provide some selected registries, financial and disease data.
Statistics Canada has agreed to treat the National Health Information Council (NHIC), as a "de facto" board of directors for CCHI. In addition, CCHI has the guidance of a Health Statistics Advisory Committee composed of health-related professionals. CCHI has many advantageous characteristics insofar as health information development is concerned -- empowerment of the Statistics Act; being part of an excellent centralized statistical agency; access to vast bodies of potentially relevant associated data; a reputation for integrity, credibility and objectivity; a status of neutrality on controversial issues of health policies and practices; legal and technical capacities for executing linkage; an unblemished record of commitment to protect confidentiality and respect privacy.

While CCHI is an indispensable component in the development of Canadian health information systems, it is not most appropriate for provision of several essential features for several reasons.

1. Statistics Canada does not provide "privileged information". Though the Agency will undertake some cost-recovery projects on specific customer demand, the outcome of those projects is in the public domain despite customer payment. Moreover, the Agency must perform be highly selective in its cost-recovery work in keeping with its general mandate.

2. A great deal of expertise, professional judgement, networking and persistent negotiation is necessary for the development of appropriate and acceptable standards for health data. This is a major challenge for health professionals. CCHI can contribute to such an effort but could not be the prime focus of it.

3. Many expressed the need for a clearing house or broker role for health information. The resourcing (personnel and funding) for such a role in the byzantine world of health information would be difficult to impossible for CCHI. Again, CCHI would be a key contributor or partner for such a role.

4. Many have emphasized that effective development of health information requires major enhancement of analytical work. While CCHI can and should expand its analytical efforts, Statistics Canada's analytical work will generally not be oriented to specific customers. It will be in the public domain and will be especially careful with interpretations which might have political relevance/sensitivity. Obviously, in the spectrum of health constituencies information needs, both privileged and "provocative" analytical interpretations and conjectures are required.

It is noteworthy that the MIS Group emerged from a government-initiated project as a non-profit, non-government organization to develop hospital costing standards and guidelines. In addition HMRI was formed by initial collaboration of the Ontario Hospital Association and the Ontario Medical Association as a non-government, non-profit institute to provide certain information on customer demand.

Past interactions among CCHI, the MIS Group and HMRI have been minimal.

While CCHI cannot by itself meet the information needs of health constituencies, it hardly needs argument to assert that CCHI is an absolutely essential component in the effective evolution of Canadian health information systems.
It seems equally clear (and unchallenged) that the MIS Group, HMRI, and Health and Welfare Canada’s information units are also providing important services. No doubt efficiency or quality gains might be made by better rationalization of the boundaries of these operational organizations and by closer co-operation and collaboration among them. But criticisms of their performances (by the organizations and by their clients) are not directed at what (or even how) they do, but rather on what they don’t do!

6.2 Functions Required for Effective Health Information Systems

A comprehensive assessment of all required functions is beyond the scope of the Task Force efforts -- and likely quite beyond the capacity of any investigation. Functional requirements for highly complex objectives typically are established by evolutionary processes.

However, Task Force consultations and investigations have identified several general functional requirements, including:

- establishment of health information concepts, definitions, standards and guidelines;
- health information services on customer demand;
- marketing of health information to the public and identified constituencies;
- health services analysis and health science research;
- data bases catalogue and clearing house (broker) role;
- management of a continuing consensus "bottom-up" planning process to identify needs, priorities and opportunities.

In addition, a number of fundamentally important "technical" functions are required, such as data collection, data base management, confidentiality protection, data linkage capability and authority, etc. all of which are well-practised by the pertinent organizations.

Some aspects of each of the functions identified above are currently being performed by one or more existing instrumentalities. Some examples are:

- standards and guidelines for hospital costing by MIS Group;
- hospital discharge information services on demand by HMRI;
- marketing of information by Health and Welfare Canada;
- health services analysis by various health science research centres;
- data base catalogue and clearing house by CCHI;
- bottom-up consensus planning by National Task Force on Health Information.
What is missing from this constellation is:

(a) full continuing coverage of functional requirements in "non-technical" categories;
(b) mechanisms for developing co-ordination among the functions and operating entities;
(c) mechanisms for establishing co-operation amongst the many pertinent health constituencies whose participation as information users, providers and facilitators is essential to enhancing the scope and effectiveness of health information systems.

6.3 Institutional Interfaces

An important initiative in the Task Force efforts was to stimulate a review of several institutional interfaces among organizations involved in health information development. Those investigations involved personnel from the organizations concerned, with general guidelines from the Task Force.

The interface studies covered:

(a) HMRI - MIS Group
(b) HMRI - CCHI
(c) MIS Group - CCHI
(d) CCHI - Health and Welfare Canada

In addition, an examination was undertaken of relationships among organizations doing health services analysis work.

The reports of those project teams are listed as references in Section 9.0. Some observations regarding interfaces and these reports may be in order:

(a) The Task Force received cordial co-operation from all the institutions involved.
(b) The tenor of all the reports is supportive of the desirability and intention of enhancing inter-institutional collaboration and rationalization.
(c) During the course of Task Force activities, the MIS Group invited Statistics Canada to become members of its board of directors for the first time. It has been proposed that Statistics Canada nominate a representative to sit on the HMRI Data base Advisory Committee.

Not unexpectedly, the interface reports tend to raise cautions about aggressive changes, pose questions for deeper investigations, and make "promises" of potential progress and improvement of relations.

But, it is no secret that existing systems tend to be stiff and self-continuing -- unless additional "energy" is injected, such as major external pressures or the initiatives of the National Task Force on Health Information. Thus unless the momentum of Task Force work is sustained, one should expect a continuance of the status quo.
This comment does not connote a criticism of the work or the management of any of the relevant institutions. One of the true imponderables is identifying responsibility for broad-based advancement in an information field so complex in substance and peopled by so many independent jurisdictions, professions, institutions and constituencies -- all jealous of their autonomy, righteous in their cause and many having competitive relationships.

6.4 Implementation Scenarios

There is a broad consensus that health information systems need significant improvement, and that this is possible in principle. With some variation in intensity, there is also general agreement that augmentation of co-ordinating mechanisms and of operating capacities is needed. The question of "implementation scenarios" has not, however, led to unambiguous consensus.

Following is an attempt to formulate the range of views on implementation by outlining a number of canonical "positions":

(a) The matter of implementation (or of specific proposals) needs further study.

(b) Detailed business plans need to be constructed for each possibility, with resources, budgets, benchmarks, mandates and source of funding specified.

(c) Present arrangements are adequate for incremental adjustments leading to improvements.

(d) Ideas for substantial change to enhance co-ordination and operating capacity make sense -- but the fiscal climate makes these initiatives impractical at this time.

(e) Some relatively bold "breakthrough" measures are needed to establish a fully representative health information co-ordinating body and to mandate the establishment of a non-government operating arm acting as a complementary partner to CCHI.

The response of the Conference of Deputy Ministers of Health and the Chief Statistician to the implementation scenario put forward in the Task Force presentation of May 31, 1991 (roughly position (e) above, see Reference 9.8) was not an easy consensus. Reactions challenged any need for change; required full access to all Task Force work prior to any assessment; objected to the proposed involvement of the private sector; voiced uncertainties about including NGOs and expressed pessimistic reservations about funding. Some opinions favoured merger of the MIS Group and HMRI and supported bolder initiatives.

The results of that session was agreement to augment NHIC by two federal and two provincial deputies along with representatives of the MIS Group, HMRI and possibly some NGOs, with that steering group now charged with further deliberation to carry recommendations to the next meeting of the Conference.

The outcome position of the Conference of Deputy Ministers of Health might then be identified as having deferred decision and action pending additional efforts to reach some general consensus among government deputies of health on how to proceed.
6.5 Discussion

It is particularly difficult to articulate non-consensus with a semblance of integrity. The preceding versions of positions on implementation should therefore be taken as "stylized" and overly simplified. They may, nonetheless, serve as useful benchmarks for discussion.

(a) The position that implementation deserves deeper study is clearly cogent in general principle. The question is whether that deeper study is a necessary or productive prerequisite to initial commitments and actions to change the status quo. The elaborate committee structure of the Conference of Deputy Ministers of Health has been studying health information needs for decades; and Statistics Canada has certainly been making progress over many, many years. NHIC was formed to facilitate improvement in health information, and after two years of meetings and study endorsed the formation of the present Task Force to carry out a planning study. Some situations are inherently so complex that advance study can never be fully illuminating, yet a commitment to appropriate processes of action will bear fruit. Further, insofar as health information is concerned, just what instruments would be employed to produce definitive studies?

(b) The position that detailed business plans for various alternatives are required has the appeal of being careful and practical. Of course, the production of business plans is not a major challenge -- the difficulty is for them to be meaningful in application. Projected milestones and resources requirements can be useful in relatively well-established business projects. The present case of structural initiatives needed to encourage evolution of improved health information systems is hardly in that category.

(c) The position that incremental adaptations to the status quo will suffice for improvements is a basically attractive one. Generally, that is the productive approach to advancements in systems' performances. But certain attributes in the health area suggest that the status quo structure in health information will not suffice. Some of those characteristics are: that NHIC is strictly a body of Ministries of Health officials, reporting to the Conference of Deputy Ministers; that NHIC has no formal connection to the operation of HMRI or the MIS Group; that non-government health constituencies -- who are important information users and important information providers -- want a full partnership status in health information systems development; that current fragmentation of operational initiatives among organizations, jurisdictions and associations is wasteful and counterproductive in terms of standards, comparability, etc.; that there is no foundation for extended operational capacity; that a much broader (co-ordination) base is needed for guidance and support from a full spectrum of health constituencies.

(d) The position that current fiscal problems make it impractical to make structural changes to enhance co-ordination and operating capacity maybe reasonable, but is it correct? After all, the proposal to establish a co-ordinating body, acceptable as representative to all health constituencies, hardly implies a major cost incremental to the funding of present deliberations of NHIC, Statistics Canada’s Health Statistics Advisory Committee, the boards of directors of HMRI and the MIS Group and many, many other bodies attempting to oversee or direct health information development for various constituencies.

Furthermore, the proposal to take steps to establish a non-government health information organization with a broad mandate, as a complementary partner to CCHI, does not imply major initiating costs if HMRI and the MIS Group were merged to form the nucleus of
such a broadened institution. The closer co-ordination of CCHI, HMRI and the MIS Group would promise increased productivity. Incremental expansion of resources would be subject to incremental demonstration of value to users. Identified expenditures on Canadian health care come to $60 billion annually. Expenditures to enhance information systems which might greatly influence the effectiveness of health care, and which have additional benefits to health, would be measured as minute fractions of that cost.

(e) The position recommended in the May 31, 1991 Task Force presentation to the Conference of Deputy Ministers of Health (Reference 9.8) has many uncertainties and a few downside risks. How would representatives acceptable to Canadian health constituencies be identified? If the body involved 30 to 40 persons would this be workable? Who would mandate that body? To whom would it report? Could such a body (involving government personnel, health care providers, private sector persons, health science researchers, etc.) properly act to provide oversight and direction both to a non-government operating entity and to the government entity Statistics Canada's CCHI? If the MIS Group and HMRI were merged into an institute with a broadened mission, is there not a danger that the valuable work and user connections of those organizations might suffer?

There are no definitive answers or analyses for these and a host of related questions. What one can recommend in this situation is consideration of the downside risks to the public interest in the event of failure, and the benefits to the public interest in the event of success -- and to make a judgement based on that comparison. One should also assess the downside consequence of failure of structural initiatives against the implications of continuing the decades-old inadequacy of health information systems. Of course, if the assessment is based on parochial interests or fears of particular constituencies, jurisdictions or individuals, then no general examination of logic or fact will modify the judgement.

(f) The position to defer decision pending arrival at a supportive consensus in the Conference of Deputy Ministers of Health is bound to be frustrating to the many persons and institutions who responded enthusiastically to the Task Force work sponsored by the Conference. But this position may be the only avenue available. For a variety of reasons, the Conference of Deputy Ministers of Health may be the only consortium with the capacity to exercise leadership in this area, if it chooses to do so.

Serious questions have been raised in Task Force consultations:

- Should consortia of professional associations take the launching initiatives for broad-based co-ordination and integrated non-government operational capacity?
- Why do all jurisdictions need to be in consensus for Deputy Ministers of Health to take action?
- Should other government departments (such as Labour, Social Programs, Environment, Housing, the Ontario Premier's Council on Health) have any influence on judgements?
- Should the need for some structural actions, as demonstrated by information needs of constituencies and the inadequate progress of three decades, be raised to the political level for decision?
6.6 Examples

Some examples of identified health information needs may be useful for perspective on implementation issues -- particularly the need for inter-constituency co-operation and coordination.

(a) Nursing homes and rehabilitation centres are essential links in the health care system. Some of these institutions are operated for profit, others non-profit. All receive some tax-based funding. Their residents generally depend on a variety of medical devices supplied by the private sector, (wheel chairs, lifts, prosthetic aids, etc.) in addition to medications. Some residents are financially aided by non-government health or disability insurance. Such institutions solicit and depend upon support from volunteers and community aid.

Little organized, comparable information is known concerning such institutions. There is a general perception of a shortage of accommodation in nursing homes, and that expensive and inappropriate chronic care facilities are thus used. Informed policy on devolution (acute care, chronic care, home care, family support, community care) needs reliable and comparable data on costs, anticipated demand (from demographic trends), effectiveness of programs and devices. The pertinent constituencies not only will need to co-operate in supplying this data, but will also need to participate in formulating data standards and guidelines, and should have a voice in overseeing and accessing the information production processes. Obviously the objective of comparability with other modes of health care, to enable cost-benefit estimates to be made, requires close co-ordination with unit costing procedures for hospitals, home care, etc.

(b) Surveys of population health and well-being (or disability) status occur sporadically at the federal and provincial levels. Though typically sponsored by governments, such surveys have not been co-ordinated as to concepts, definitions, questionnaires, coding, etc. Moreover, questions have been raised whether surveys of respondents would be more effective in information production if they were linked with health care encounters (with hospitals, physicians, chiropractors, workers' compensation, etc.). Evidently, the approaches will require intimate co-operation among the various constituencies of which a health ministry is but one.

(c) The adoption of a uniform coding standard for disease classification would greatly improve comparability of costs, utilization, incidence, and outcomes. Many stakeholders must co-operate.

(d) Medications are widely prescribed and expected in health care encounters. Indications are that medications may be overused and misused. Currently, no organized data are available on the extent and intensity of medication use. Public and private insurance and subsidy costs may be significant. Development of information systems would require concurrence and co-operation of pharmaceutical producers, pharmacists, physicians and of course the public, among others. Private insurance companies would have an evident interest in such information development.

(e) Much political and public attention has been directed to the cost of health care -- with suggestions: that this is "unaffordable" for Canada; that users' fees are needed as a deterrent to misuse; that resource allocation should be influenced by the "cost-benefit" of treatments or technologies; that medical facilities are operated inefficiently; etc.
Regrettably, there is little in the way of comparable unit cost data; virtually nothing on the longer run outcomes of treatments; and data of questionable standardization on illness classification or severity. The essentiality of co-operation, and involvement in control, by a variety of constituencies is obvious.

The case of developing meaningful information or "unit costs" deserves special comment. Cost accounting, even more than financial accounting, is inherently arbitrary in certain aspects, because of joint and common costs needing to be allocated. Cost accounting also depends upon the application of allocating factors which may derive from occasional statistical studies. Since the management use of unit cost data is in making comparisons, it is evident that general conventions and guidelines have to be broadly accepted and followed if such data are to have value. The health community needs "generally accepted costing principles" promulgated to support management and resource allocation and policy decisions.

(f) The accumulation and analysis of health data will certainly be perceived and challenged as invasions of privacy. Whatever the care and commitment to protect confidentiality of identifiable records and the stringency of legislations, there is a real conflict of desiderata in respect of the public interest in developing health information systems (to improve health and health care, to optimize expenditures) and in protecting privacy. The difficulties of this balance are many. Consider the trials and tribulations of the proposed pilot feasibility proposal (finally approved after a 15-month hiatus) to link a small sample of health care administrative data to census information, without use of names in the linkage. Decision on, and support for, health information development vis-à-vis privacy would be fundamentally aided by the existence of a co-ordinating body which is "autonomous" and accepted as broadly representative of all health constituencies.
7.0 TRANSITION

The evidence of health information needs and value to many constituencies is unambiguous. There is also no doubt of the consensus perceptions that current systems, in general, are grossly inadequate (with some important exceptions). No one can doubt that the challenge of improving health information systems is more complex than that of understanding human health. The recognition of deficiencies is not a recent phenomenon; serious attempts at improvement have been made, in Canada and elsewhere, over many years, with limited success.

As with health science research investigations, the core requirement for health information development is that systemic structure and processes be established, both conceptually and operationally. Both the conceptual and operational aspects of such systems are formidable complex. Effective information systems will only emerge by evolutionary advances subject to a combination of the discipline of knowledge and a disciplined co-ordination/ co-operation of operations.

The broad-based support and enthusiasm for the Template work of the Task Force (see Section 3 and Reference 9.10.14) suggests the promise of general acceptance of a common "discipline of knowledge" in health information. However, a similar spontaneous agreement on the need for, or form of, a discipline of co-ordination/co-operation in operations cannot be asserted. One must face the need for a (perhaps lengthy) transition process to establish trust and understanding of mutual benefit and dependencies among the pertinent constituencies. Leadership is essential, and its focus in Canada will likely be government institutions, but its effectiveness will be inversely proportional to its insistence on control.

7.1 Action Priorities

Earlier sections of this report have outlined and referenced Task Force recommendations on priorities for health information areas and methodological requirements. What follows are recommendations regarding governance and operational matters.

Governance for Co-ordination/Co-operation

Critical to progress is a requirement for co-ordination and co-operation among more-or-less autonomous constituencies. At this time, accepted forum for co-ordination among the host of information users, data providers and information managers.

The establishment of NHIC was a major step toward co-ordination of provincial and federal ministries of health with Statistics Canada. But NHIC has no non-government representatives, despite the key role of non-government entities as data providers and information users. Moreover, NHIC has no relationship as such to the boards of directors of the MIS Group and HMRI, and until a few months ago, no member of Statistics Canada sat on those boards. The boards of MIS and HMRI are formally disjoint. Furthermore, in addition to guidance from NHIC, the CCHI has a Health Statistics Advisory Committee which has no formal connection with NHIC.

As a background for consideration of some organizational recommendations, it may be useful to check back to some judgements of the 1964 Royal Commission on Health Services:
"... the data required... must be organized as a co-ordinated system of health statistics."

"the present jurisdictional dispute between... the Department of National Health and Welfare and the Dominion Bureau of Statistics must be resolved."

"... continued planning is needed to ... ensure that health statistics provide the answers to questions arising in the sciences and ... in health services."

"... a clearing house and co-ordinating agency ... is absolutely necessary."

"Deficiencies must be made good, overlapping... reduced... statistics... collected must be analyzed... results published promptly... obsolete... series abandoned. Such... development can only come about through... the establishment of some body charged with... ensuring improvement..."

To provide a forum and an instrument for developing co-ordination/co-operation, based on negotiated compromises for mutual benefits, it is recommended that:

**A Health Information Co-ordinating Council (HICC) be established, acceptably representative of all Canadian health constituencies.**

The identification of acceptable representatives must follow an untidy "bottom-up" process.

The role of HICC would include:

(a) de jure Board of Directors for a non-profit, non-government Institute for Health Information (IHI), discussed below;

(b) de facto Board of Directors for Statistics Canada’s CCHI, (a role now performed by NHIC);

(c) oversee operational practices, priorities, plans, budgets, senior appointments for IHI and CCHI;

(d) assure the effective collaboration of IHI and CCHI in the public interest;

(e) exercise influence toward achieving effective relationships of IHI and CCHI with all relevant health data providers and information users, including federal/provincial/territorial government departments, universities, professional associations, health services organizations and the private sector.

The need for co-ordination is paramount and pervasive. Considering the reality of the many independent jurisdictions, professions and institutions whose co-operation is virtually essential for health information development, it seems clear that co-ordination requires a forum for decisive compromise and consensus, to yield decisions which will be responsive to the views and needs of all participating constituencies. It was the uniform judgement of all non-government persons consulted that non-government institutions must participate as founding partners in the co-ordinating mechanism.
7.2 Operational Effectiveness

A number of entities now provide health information services, including CCHI in Statistics Canada, several units in Health and Welfare Canada, the MIS Group, HMRI, various units in provincial ministries, professional associations, research centres, private sector organizations, and advocacy groups. Many of these organizations are supported, directly or indirectly, with public funds. Communication amongst them is almost accidental. While it would be impossible and undesirable to coalesce these operational entities, some formal integrating of their activities would promise major gains in productivity and effectiveness.

Accordingly, it is recommended that:

A non-government, non-profit Institute for Health Information (IHI), be established to operate under the direction of HICC, as a collaborating partner of CCHI.

The charter of IHI should include the following responsibilities:

(a) managing the consensus establishment of common concepts, definitions and guidelines. (This generalizes the ongoing work of the MIS Group.);

(b) providing data services on customer demand. (This generalizes the ongoing work of HMRI.);

(c) managing a bottom-up consensus planning process. (This institutionalizes the work of the present Task Force.);

(d) providing a clearing house for results of health science research and health services analysis;

(e) maintaining a catalogue of relevant health data bases and collaborating in the evolution and promulgation of the Template as a common conceptual framework for health information;

(f) establishing a focal point for co-ordination and stimulation for the marketing of health information to the public and to identified stakeholders;

(g) establishing non-redundant boundaries and collaboration with CCHI and other health information institutions, under the guidance of HICC;

(h) providing staff support, in conjunction with CCHI, for HICC (this generalizes the present work of the NHIC Secretariat).

The development of a CCHI - IHI health information partnership, under HICC direction, would provide a unifying focus for all health information entities, with the potential for major public and private interest benefits.

Since the MIS Group, HMRI, CCHI and others are now performing some of the roles recommended for IHI, it seems appropriate to contemplate building IHI on a nucleus from those institutions.
Accordingly, it is recommended that:

**Consideration be given to merging the MIS Group and HMRI to provide the formal nucleus for IHI.**

In addition, in the formation of IHI, both functions and personnel of other relevant institutions (government and non-government) should be solicited and recruited, for mutual benefit.

It is critically important that IHI activities be relevant to participating health constituencies, and perceived to be operating under their control. The HICC governance is a necessary element. To add to that aspect, it is recommended that:

**Staffing of IHI should draw heavily on secondments and rotational assignments from participating health constituencies.**

This approach has several important advantages:

(a) provides for career development of the well-qualified individuals who are essential;

(b) encourages proprietorship of IHI by participating constituencies;

(c) assures the continued applied relevance of IHI work;

(d) reduces the likelihood of redundancy and competition of IHI with other groups;

(e) facilitates a quick realization of the usefulness of IHI.

The several project team reports on institutional interfaces (see References) indicate a recognition of the need and desirability of improved co-operation and rationalization of missions. However, further maturing and acceptance of the concepts advanced above is necessary to allay concerns and encourage change among current operational entities.

It is not that current health information work by various entities is inappropriate, rather it is grossly insufficient and obviously unco-ordinated. Whether or not current organizations are now overlapping in their activities is relatively unimportant. The critical planning issue is how best to direct and co-ordinate major essential enhancements (formulated elsewhere in this report).

**Resources**

Three resources are necessary for the evolution of more effective health information:

(a) leadership to evolve a mechanism of governance that will enable effective co-ordination/co-operation;

(b) professional and technical personnel having competence and commitment;

(c) financial support.
Though there is a tendency to emphasize the last item, the challenge of the first two is undoubtedly much larger.

In terms of financial and related resources, it is recommended that:

**Resource support for IHI should include revenues (or the equivalent) from direct customers of IHI and from all constituencies who are represented (directly and indirectly) in HICC.**

The funding of the MIS Group and HMRI, and the cost-recovery work of CCHI, demonstrates that a revenue flow from consumers of health information is practical. Of course most of this funding is derived from budgets funded by governments, which, in turn, draw on public taxes. Nonetheless, the market feedback from customer payments is of immense importance.

On the expectation of significant voluntary contribution and participation from health constituencies (as experienced by the Task Force) incremental funding required to initiate IHI and HICC and demonstrate their value might be in the region of a few million dollars -- the same order of magnitude as a single health status survey. This assessment contemplates voluntary resourcing support from a broad spectrum of government and non-government institutions, including the private sector, in facilities availability, in staff participation and in indirect financial contributions (such as travel expenses).

In many cases, funding already exists for many of the proposed IHI functions. The co-ordination and pooling of these hold promise of both synergy and efficiency.

While pro forma business plans, with proposed benchmarks of priorities, budgets and cost-sharing arrangements could be developed, this kind of activity would not be productive until there is an acceptance of threshold structural concepts among a leadership consortium of health constituencies.

**Transition Mechanism**

The Task Force performed a useful function in forming networks and raising expectations among health constituencies. That momentum needs to be maintained. The leadership for transition has been initiated by the Conference of Deputy Ministers of Health in establishing an implementation steering committee of two provincial deputy ministers of health, the Chief Statistician, the Deputy Minister of Health and Welfare Canada, representatives of the MIS Group, of HMRI, of CPHA, the executive of NHIC and possibly others. Some working support personnel have been designated.

This steering committee faces formidable challenges:

- developing adequate consensus among government entities;
- bringing in committed participation by non-government institutions;
- laying the foundation for voluntary co-operation among equals;
- removing the illusion, perception and reality of government control of health information development.
These are the major obstacles. Other relatively minor obstacles, while not trivial are the arrangements for organizational changes and developments.

The motivations for improved health information systems are very powerful:

(a) to improve the health of Canadians;
(b) to support health care technologies and services;
(c) to improve management and policy processes;
(d) to help resolve the contradiction of the public expectation of expanded health care services and the perceived need to control health care costs.

Those motivations must confront the propensity of existing institutions to sustain their current momentum. This is the test of leadership of the steering committee.
8.0 RECOMMENDATIONS

Information Recommendations

8.1 The Template should be developed as a conceptual framework for health information, and for an integrated system of health statistics, with consideration of its use as a data catalogue.

8.2 Consensus should be established on concepts and definitions for associating costs with services, covering a full range of health care providers.

8.3 Information on health outcomes should be pursued as a follow-up to patient care experiences, and also to monitor trends on population health status.

8.4 An information program responsive to the development and management of community-based services is needed.

8.5 Information should be systematically provided on the dynamics of population health status, extending beyond longevity and morbidity to "healthiness".

8.6 Special and adaptable attention is needed for information development to support health science research and health services analysis.

Methodology Recommendations

8.7 A major effort is required to establish consensus information standards, guidelines, indicators and classifications.

8.8 Analytical attention to health data is crucial to harvesting useful information from expensively accumulated data bases.

8.9 Capacities to link data elements are of crucial importance for health information development and those capacities must be expanded and exploited.

8.10 Focal points or clearing houses should be established to facilitate:
   • access to data bases;
   • health information marketing to the public;
   • sharing of health services analysis work;
   • knowledge of community services programs;
   • collaborating networks for administrative data systems development;
   • sharing of plans for survey work.

Organizational Recommendations

8.11 A Health Information Co-ordinating Council (HICC) should be established which is acceptably representative of all Canadian health constituencies -- government departments, non-government organizations and the private sector.

National Task Force on Health Information
8.12 The MIS Group should be merged with HMRI to form the nucleus for an Institute for Health Information (IHI), with a broad charter. (The ongoing work of HMRI and MIS must not be impeded while their commitments are evolved within the broader responsibilities of IHI.)

8.13 Staffing of IHI should draw heavily on secondments and rotational assignments from participating health constituencies.

8.14 Resource support for IHI should include revenues from direct customers of IHI and from all constituencies who are represented (directly and indirectly) in HICC.

**Transition Recommendations**

8.15 An Implementation Committee should be established to work with NHIC in assessing Task Force findings and recommendations, and to consult broadly toward establishing acceptably representative membership of a Health Information Co-ordinating Council.

8.16 The Implementation Committee should be directed to:

- recruit a Project Manager;
- negotiate the establishment of IHI;
- draft the mission and mandate of HICC;
- plan the founding meeting of HICC;
- identify current resource expenditures by various health constituencies on health information;
- develop proposals for shared resourcing of IHI.
9.0 REFERENCES

9.1 Strategic Directions for Health Information in Canada: A Discussion Paper of the National Health Information Council

9.2 Terms of Reference: National Health Information Council

9.3 Terms of Reference: Canadian Centre for Health Information

9.4 National Task Force on Health Information: An Opportunity to Renew Canada's Health Information Systems

9.5 Producing Health, Consuming Health Care: A Paper by Robert G. Evans and Gregory L. Stoddart (1990)

9.6 Health Statistics: Extracted from the 1964 Royal Commission on Health Services Report - Volume II

9.7 Progress and Process of the National Task Force on Health Information: Notes for Remarks to Conference of Deputy Ministers of Health (November 1990)

9.8 Selected Findings and Recommendations of the National Task Force on Health Information: Preliminary Report Prepared for Presentation to the Conference of Deputy Ministers of Health (May 1991)

9.9 Participants/Contributors

9.10 Reports from Project Teams and Interface Studies

9.10.1 Health Status Indicators

9.10.2 Health Policy Information Requirements

9.10.3 Requirements for Marketing Health Information

9.10.4 Implications of Privacy & Confidentiality Concerns

9.10.5 Information Needs Relating to Lifestyles

9.10.6 Information Needed to Support Community Interactions & Interventions

9.10.7 Comparability of Health Services Information

9.10.8 Information for the Economic Analysis of Health
9.10.9 Information Needed to Support Health Human Resources Management

9.10.10 Information Needs for Health Care Quality Assurance and Outcomes

9.10.11 Information in Support of Epidemiology

9.10.12 Information Required to Understand the Determinants of Health

9.10.13 Health Information Analysis: Potentials and Impediments

9.10.14 Development of a Structural Model (Template)

9.10.15 Mapping of Systems Names to the Template Classification, Identification of Data Gaps and their Relationship to Provincial/Territorial System Development Plans

9.10.16 Data Acquisition Alternatives

9.10.17 MIS/HMRI Interface Study

9.10.18 MIS/Statistics Canada Interface Study

9.10.19 HMRI/CCHI Interface Study

9.10.20 STC/NHW Interface Study

9.10.21 The Structure and Problems of Relationship Among Canadian Health Information Producers and Consumers: An Interface Study Among Institutions Doing Health Services Analysis
**REFERENCE REQUISITION FORM**

Please indicate your selection(s) and return form to Administrator, National Task Force on Health Information, 24-A, R.H.Coats Building, Ottawa, Ontario, K1A 0T6

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