# RECENT DEVELOPMENTS IN HEALTH INFORMATION

# AN INTERNATIONAL PERSPECTIVE

## *Paper Commissioned by the National Committee for Vital and Health Statistics for a Workshop on Developing the 21st Century Vision for Health Statistics*

***December 1999***

***Prepared by:***
***Jennifer Zelmer, Shazeen Virani, and Richard Alvarez***
***Canadian Institute for Health Information***

## Executive Summary

This paper provides a comparative overview of health information activities at a national level in selected developed countries world-wide. While the focus is on activities in a sample of major industrialized countries other than the United States (Canada, Australia, and the England), illustrative examples are also drawn from other countries[1].

National health information strategies and organization, health data collections, and common trends and future directions are discussed. The latter include:

- Renewing traditional data collections and extending the content and coverage of key data collections;
- Increasing the flexibility and integration of data;
- Ensuring personal privacy and the confidentiality and security of personal health information;
- Improving the utility and accessibility of data through innovations in analysis and dissemination; and
- Growing international cooperation in health information.

---

[1] The United States' perspective is covered in detail through other papers commissioned by the National Committee on Vital and Health Statistics.

## Table of Contents

## 1. Introduction

This paper was commissioned by the National Committee on Vital and Health Statistics in the United States as part of their initiative to develop a 21st century vision for health statistics. It is intended to provide a comparative overview of the status of health information at a national level in various developed countries, including common strategies, trends, and future directions.

The paper draws primarily on the experience of selected developed countries other than the United States (particularly Australia, Canada, and England). For specific information on national health information activities in these countries, see the country profiles in Appendix A or the reference list. The United States' perspective is covered in detail through other commissioned papers.

## 2. National Health Information Strategies and Organization

Over the past decade, the organization and delivery of health services has changed significantly in many countries. At the same time, our understanding about health and its determinants is evolving and there is an increased demand for evidence on which to base health and health care decisions. Every year there are also significant advances in information management and technology capabilities. As a result, expectations and demand for health information are growing.

In response, many countries, and jurisdictions within those countries, have initiated major strategies to enhance their health information capacity. These investments are seen as an important contributor to improving health and health care. For example, *Australia's Health 1998* affirms that "reliable information on the determinants of health, the causes of ill-health, and the patterns and trends of health and illness in populations is fundamental to development effective health programs and policies." Similarly, key goals of Canada's Health Info*way*, as identified by the federal Minister's Advisory Council on Health Info-Structure (1999) are to empower the public to make informed choices about their own health and the health of others, to strengthen and integrate health care services, and to crease information resources to support accountability and continuous feedback on factors affecting the health of Canadians.

Typically, programs include enhancements to basic infrastructure, information systems and networks, standards, telehealth, data collection and analysis, the capacity for timely access to relevant information, education and training, and much more. These broad, coordinated programs represent significant multi-year investments. They often aim to integrate activities in a range of areas to develop information resources that meet the needs of stakeholders in the health system, consumers, and the general public. The ultimate goal is generally to leverage information and information technology to improve health and health care.

In many cases, the strategies include the creation of an independent agency responsible for coordinating health information and statistical activities at a national level, often in cooperation with the national statistical agency and/or ministries of health. Examples include the Australian Institute of Health and Welfare (AIHW), the Canadian Institute for Health Information (CIHI), the Direction de la recherche, des études, de l'évaluation, et des statistiques (DREES) in France, and the National Research and Development Centre for Health and Welfare (STAKES) in Finland.

In Australia, for example, the National Health Information Agreement provides a framework for national health information activities and cooperation. It came into effect in 1993 and has recently been extended to 2003. The Commonwealth, State, and Territory health authorities; the Australian Bureau of Statistics; and AIHW are signatories to the agreement. Within this broad context, a number of key activities have been undertaken, including:

- *National Health Information Work Program:* a rolling triennial program of priority health information development projects;
- *National Health Information Development Plan:* providing key stakeholders with a list of accepted priorities for national health information;
- *National Health Information Knowledgebase:* an Internet-based site covering national health metadata (data about data), integrating the National Health Information Model, the data dictionary, and other material; and
- *National Aboriginal and Torres Strait Islander Health Information Plan:* a plan to improve the quality of indigenous health information.

In Canada, the publication of the report of the National Task Force on Health Information in 1991 initiated a period of considerable national activity related to health information. A key result of this report was the formation of the Canadian Institute for Health Information (CIHI) in 1993. The Institute is an independent, not-for-profit, organization mandated to coordinate the development and maintenance of a comprehensive and integrated health information system for Canada. Like Australia's AIHW, CIHI's plans are developed collaboratively with federal, provincial, and territorial governments, as well as a range of other stakeholders. Strong collaboration with Statistics Canada, the national statistical agency, is particularly important.

Recent national consultations on health information needs and the report of the Federal Minister of Health's Advisory Council on Health Info-Structure led to significant additional investments in health information. Funding announced in the February 1999 federal budget will support enhancements to national surveillance activities; improved access to health information; the implementation of the *Health Information Roadmap*, a shared vision for modernizing Canada's health information systems; and other activities.

## 3. National Health Data Collections

Regardless of how a country has chosen to organize health information activities at a national level, most developed countries have implemented a common core set of data collections, including:

- Vital statistics (births, deaths, marriages, and divorces);
- National population-based health interview surveys;
- Statistics on key health risk factors, socio-economic variables, and other non-medical determinants of health from survey or other sources (e.g. unemployment, education, and income levels);
- Communicable disease statistics (e.g. tuberculosis, measles, and chlamydia);
- Hospital facility statistics (e.g. beds, services, and financial data);
- Hospital inpatient discharge statistics (e.g. length of stay, diagnosis, procedures, and patient demographics);
- Health human resources statistics for regulated health professions; and
- Macro-level health expenditure data.

Beyond this core, data collections vary depending on national priorities, progress of implementation efforts, and other factors. Particular countries have implemented a broad range of additional data collections, including:

- Immunization statistics;
- Expanded maternal and perinatal health data;
- Clinical registries for selected health conditions (e.g. cancer, diabetes, and end stage renal disease);
- Facility statistics for health care institutions other than hospitals (e.g. nursing homes and other residential care facilities);
- Data on outpatient hospital services, physician visits/payments, pharmaceutical utilization, mental health services, home care, dental care and other non-hospital services;
- Collection of physical measures (e.g. blood samples) as part of population health surveys; and
- Waiting list statistics.

The outcome is that the extent of countries' health data collections varies widely.

**Figure 1: Coverage and Timeliness (Median Year of Most Recent Data) of Health Data in OECD Countries**

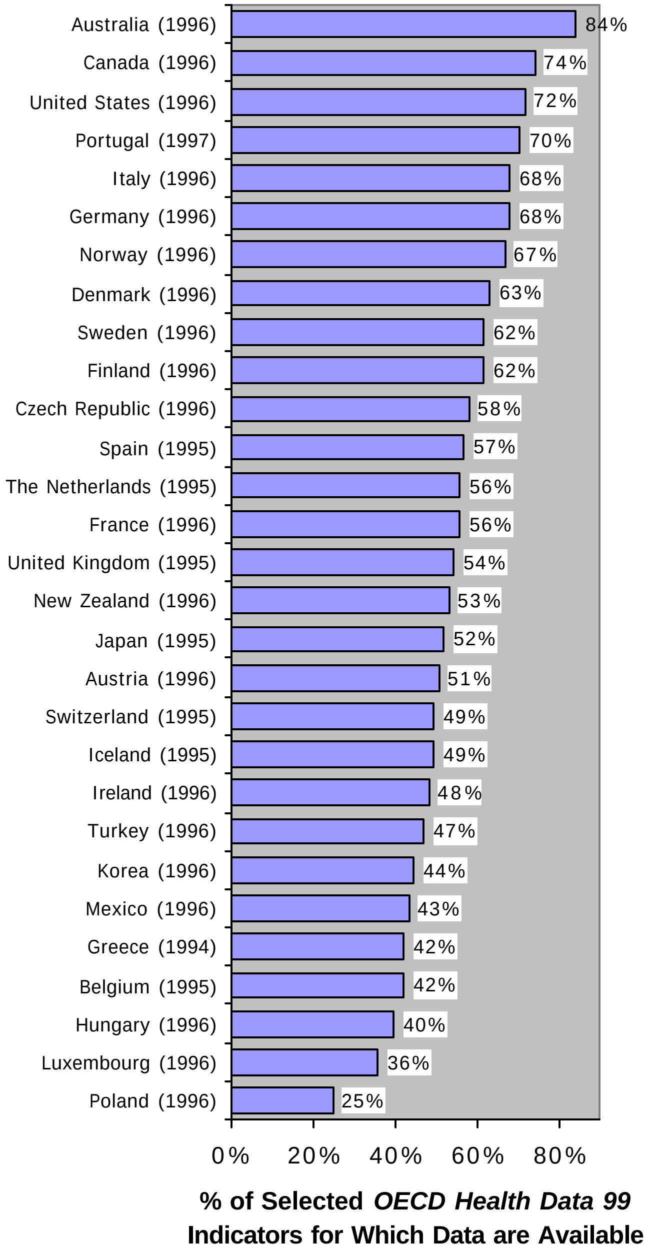

Figure 1 compares the availability and

timeliness (median year of most recent data) for 29 countries. The results are based on statistics reported in *OECD Health Data 99*[2]*,* the Organization for Economic Cooperation and Development's annual set of health indicators for member states.

The 1999 edition covers health status, health care resources, health care utilization, health expenditures, financing and remuneration, social protection, the pharmaceutical market, non-medical determinants of health, and contextual demographic and economic variables. Countries report national data for standardized indicators based on health surveys, administrative data, and other information sources.

## 4. Common Trends and Future Directions

Fiscal, demographic, technological, and other factors are contributing to rapid change in the organization and delivery of health services in most developed countries. Health information must keep pace. Enhancing the capture, dissemination, and use of quality information is often cited as one of the keys to improving health and health services. In the words of the World Health Organization: "The road to health passes through information."

As a result, many countries are initiating significant investments to enhance their health information infrastructures. Considerable effort is also going towards improving health information capacity at a national level. Common themes emerging from these efforts include:

- Renewing traditional data collections and extending the content and coverage of key data collections;
- Increasing the flexibility and integration of data;
- Ensuring personal privacy and the confidentiality and security of personal health information;

---

[2] *OECD Health Data 99* includes over 800 variables. Many of these variables are closely related (e.g. life expectancy for females at birth, age 40, age 60, age 65, and age 80); for these indicators data availability and timeliness rarely differ significantly. The analysis described above was therefore performed on a 10% random sample of the OECD indicators. Note: these results may partly reflect a country's commitment to international comparative reporting, as well as the availability of health data at a national level.

- Improving the utility and accessibility of data through innovations in analysis and dissemination; and
- Growing international cooperation in health information.

These themes are examined in further detail below.

### *4.1. Renewing and Extending Health Data Collections*

Vital statistics were among the first data collections to be widely implemented in most countries. In the past 20-30 years, however, the emphasis has shifted towards statistics related to the health system and the utilization of health services, particularly in the inpatient hospital sector.

In many countries, these traditional data collections are now being revised to reflect evolving patterns of practice and trends in information management. For example, in some countries, considerable effort has been invested in the development of national health information models, data dictionaries, and meta-data. A case in point is Australia, where the *National Health Information Knowledgebase* integrates a broad range of material in an accessible Internet-based application.

Significant changes are also being made to the data collections themselves. Information systems are being upgraded; some minimum data sets are being revised; diagnosis and intervention standards are being updated world-wide; and options for reducing survey respondent burden and facilitating the capture of administrative data are being explored. New data collections, such as those used to monitor waiting lists, are also being introduced to address emerging policy questions.

Other, more profound, changes are also taking place. Several countries are designing and implementing an expanding range of data collections that will cover more of the continuum of care and track post-care outcomes. For instance, Australia, Canada, New Zealand, and others are developing new minimum data sets in areas such as mental health and home care. The number of clinical registries that follow individuals with particular health conditions (e.g. diabetes or end stage renal disease) or interventions (e.g. transplants or joint replacements) longitudinally is also growing. In addition, there is increasing appreciation of the need to reorient health information activities to move beyond health services and focus on health and its broad determinants – from data on illness to data on health.

### *4.2. Increasing Data Integration*

Addressing fundamental questions about health and health services requires data on the health status of individuals, how it changes over time, and their encounters with the health system. Historically, data have tended to be divided into silos – one for vital statistics, one for health surveys, one for hospitals, one for physician services, and one for financial data. Given that the determinants of health and illness are complex and that successfully addressing health issues frequently requires the collaboration of multiple institutions and professionals, this fragmented approach is no longer sufficient.

Many countries are recognizing that the ability to readily integrate different types of micro-level health data – within the context of stringent privacy, confidentiality, and security safeguards – is essential. Otherwise, systematic connections cannot be made between surgery in one hospital and complications treated in another. Likewise, the ability of an individual to return to his or her normal daily tasks after a knee or hip replacement and the amount of time spent in rehabilitation care in the interim are not routinely connected to the data on the surgery itself. These types of connections are necessary in order to assess the cost-effectiveness and long term outcomes of different health interventions and to disentangle the effects of a broad range of risk factors on health.

Already, several countries have made significant progress in building the infrastructure required to effectively integrate a wide range of health data. This includes establishing an appropriate policy and legislative framework and the professional and technical capacity to integrate data sets.

Standards are also needed to reduce fragmentation and ensure comparable and integrable data. Examples include common geographic references, consistent data standards, and common “identifiers”. For instance, a uniform anonymous linkage code is created for each hospital patient in Switzerland. Other than a subset retained for epidemiological purposes (children under 15 years of age, adults over 64 years of age, and a sample of the population between 15 and 64 years), these codes are destroyed after 10 years.

Personal identifiers are generally developed for administrative, rather than statistical purposes. Their sources and scope of use vary considerably from country to country. In some cases, civil registration numbers are used. In others, specific identifiers are created for use in the health system. The structure of identifiers also varies. For example, Denmark, England, and Sweden have 10 digit numeric codes; New Zealand uses a 7 digit alphanumeric National Health Index; and in Canada 8-12 digit numeric or alphanumeric codes are assigned by the provinces/territories.

Many countries are regularly performing analyses that take advantage of those data that can already be integrated consistently. For example, expanding record linkage for research and statistical purposes was one of the priorities identified in Australia's National Health Information Development Plan. In partnership with others, the Australian Institute of Health and Welfare will be investigating and implementing linkages between a variety of health data sets within legislative constraints. Discussions are also underway regarding the possibility of linking person-level census data across censuses and with other health data for statistical purposes.

Canada has also made considerable progress in this area. For some time, research institutes in several provinces have successfully brought together a wide range of data. These include administrative data on physician visits, hospitalizations, and pharmaceutical utilization; survey data from health interview surveys and the census; and a variety of other sources. The commissioned paper by Charlyn Black, Noralou Roos, and Leslie Roos (*From Health Statistics to Health Information Systems: A New Path for the 21st Century*), provides further information regarding the goals, results, and transferability of these efforts.

Similar initiatives are also underway at the national level. For instance, respondents to Canada's National Population Health Survey (NPHS) are routinely asked for consent to link their survey responses with health services data from administrative datasets for statistical purposes. The vast majority of respondents agree to this linkage. Over the coming years, Statistics Canada will be using the NPHS and other sources as part of their on-going effort to develop person-oriented information, integrating individual-level microdata across time and data collections, to answer key health questions.

Similar programs also exist in several other nations. For example, Denmark regularly integrates a wide range of individual-level data using the Danish civil registration number. Data collected from services performed by general practitioners (generating approximately 72 million records per year), dispensed prescriptions, and hospitalizations are brought together in the Health Statistic System. Access rights depend on the user's professional affiliation.

Likewise, Finland's National Research and Development Centre for Welfare and Health (Stakes) links their register-based data collections for statistical or, in special cases, scientific purposes. Identifiers are typically encrypted. In some cases, the integration of data is performed by third parties to ensure confidentiality.

### 4.3. Ensuring Privacy and Confidentiality

Privacy is a fundamental value that is widely recognized. In most developed countries, the collection, use, linkage, disclosure, and retention of health information take place within established privacy and confidentiality principles and policies. This framework builds on ancient professional pledges of confidentiality, such as the Hippocratic Oath:

> *Whatever, in connection with my professional service, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret. (Hippocrates, 5th Century B.C.)*

Professional pledges of confidentiality remain a key component of the privacy protection landscape. However, today's multi-faceted and increasingly-computerized health systems also require a more complex set of legislative, policy, regulatory, and technical strategies to protect personal privacy and safeguard the confidentiality and security of health information.

Recent legislation is generally modeled on the core principles outlined in the Organization for Economic Cooperation and Development's (OECD) *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data*:

- Data collection limitation,
- Data quality,
- Purpose specification,

- Use limitation,
- Security safeguards,
- Openness,
- Individual participation, and
- Accountability.

For example, Australia and Canada have broad, cross-sector, federal privacy legislation covering the activities of associated government agencies. As in most countries, this legislation is supplemented by state/provincial/territorial privacy laws and confidentiality clauses in health-related legislation. National guidelines and standards (e.g. Standards Australia's AS440 *Personal Privacy Protection in Healthcare Information Systems*) also play an important role.

Members of the European Union were required to implement the EU's *Directive on Data Protection* (Directive 95/46/CE) by October 1998. Several European countries have revised their existing legislation as a result. For instance, an updated *Data Protection Act* received Royal Assent in England in July 1998 (provisions come into force over the following decade). Information related to an individual's health is categorized as 'sensitive', requiring special protection.

In addition to general legislation, New Zealand has a *Health Information Privacy Code 1994* that specifically covers health information. It grants individuals the right of access to public health sector records and provides for the development of codes of conduct in liaison with the Privacy Commissioner, who is responsible for implementing access and other privacy policies in the private sector. The Code covers all health agencies and protects all personal information related to an identifiable individual. Health information protection legislation is also in place in some states/provinces in both Australia and Canada.

Technical security and other measures complement legislation and national standards/guidelines in most countries. The protection of privacy, confidentiality, and security is rapidly becoming a central design feature of health information systems in many countries. For example, some health authorities are investigating the use of innovative technological solutions to prevent unauthorized access to confidential data.

### *4.4. Making Health Information More Accessible*

Data are useful only when they are analyzed and when the resulting information reaches its intended audience in a form that is accessible and easy to use. Many nations are taking advantage of advances in technology and improved health data to develop tools that make health information more accessible to a variety of audiences, including the general public. These tools are often supplemented with regular reports that present an overview of health and the health system based on current statistics in an understandable form.

In recent years, there has been increasing emphasis on the value and importance of reporting standardized comparative health data. Internationally, this has led to sustained efforts by the World Health Organization, the Organization for Economic Cooperation and Development, and others to compile and disseminate consistent data for a range of indicators for member states. These data are also included in regular broad-based reports on health, such as the *World Health Report*.

The World Health Organization's Regional Office for Europe has also called for countries to provide user-friendly access to an integrated set of national and sub-national health statistics that would complement international efforts[3]. Already, activities in many nations are well advanced. For instance, according to a recent study, 6 of 18 European countries surveyed have expanded national health information and monitoring systems to track progress against health targets[4]. Another 8 nations were expanding their systems or had plans to do so. The remainder were using existing information systems.

To meet the needs of a broad range of users, many countries are beginning to disseminate health statistics through flexible, user-friendly, web-enabled applications and regular reports on the health of the population (often designed for the general public). In this way, data can be used for a wide range of purposes, including health surveillance, planning and management of the health system, and public reporting.

---

[3] World Health Organization, Regional Office for Europe, Unit of Epidemiology, Statistics and Health Information. *Strengthening National Health Information Systems: The Concept of National Integrated Statistical Health Database* [sic]. Joint ECE-WHO Meeting on Health Statistics, Rome, Italy, 14-16 October 1998.

[4] Van de Water, Harry P.A. and Loes M. van Herten. *Health Policies on Target? Review of Health target and Priority Setting in 18 European Countries*. The Netherlands: TNO Prevention and Health, Public Health

Achieving easy access to quality comparative information, however, is not a simple task. Building effective systems requires considerable financial and human resources. In addition, a number of complex issues must be addressed, such as:

- preserving privacy, confidentiality, and security;
- identifying, compiling, and integrating high quality comparable data of different types from a wide range of sources;
- achieving consistent and accurate statistical estimates for communities and regions, particularly if geographic boundaries change over time or if the population is highly mobile; ensuring that non-specialists can appropriately interpret the data, including on occasion making information available in multiple languages and formats; and
- preparing comprehensive easy-to-understand reports for the public on health and the health system.

Nevertheless, a number of countries have made considerable progress in the development and dissemination of sub-national comparative data. For example, Germany has developed a Health Information System (HIS) as part of the *Setting up a Federal Health Monitoring System* Research Project. The project's goal was to report comprehensively on the health status of the German population, as well as on factors affecting health (including health care). Topics covered include health status, behavioural and risk factors, diseases, health care resources, production and consumption of health services, and health care expenditures. The system brings together a range of national and sub-national data, standard indicator definitions, and associated meta-data. The overall cost was close to 4.5 million DM and required approximately 10 person-years[5].

Likewise, France is establishing a *Regional Public Health Base* that will provide an integrated set of data on demographics, causes of death, morbidity, hospital diagnoses, and a variety of other topics at a regional level. A similar concept, called *Net-Hilmo,* has been implemented in Finland. In both cases, the initiatives include a set of health and health care indicators that are available to the general public, with more sophisticated

---

Division, 1998.

[5] For more information, see *The German Health Information System* , an invited paper submitted by the Federal Statistical Office of Germany to the Joint ECE-WHO Meeting on Health Statistics (Rome, Italy, 14-16 October, 1998).

access for authorized users. Comparable projects are also underway or planned in several other countries, including Canada, Denmark, Japan, Lithuania, Norway, Sweden, the United Kingdom, and others.

Just as the World Health Organization publishes an annual *World Health Report*, individual countries are producing regular reports to the public on health and health care based on these types of statistics. These reports vary from vast compendiums of available statistics to descriptive reports that draw on a range of data. Topics frequently covered include health status; the major determinants of health, including key risk factors; health expenditures; utilization of health services, particularly acute care hospitals; and focused analysis related to special populations (e.g. children and the elderly).

### *4.5 Increased International Cooperation*

While differences remain between the approaches taken and degree of implementation in various countries, there is considerable convergeance in national health information activities and strategies. In part, this may be the result of sustained international cooperation and information exchange.

For years, countries have collaborated in the compilation of mortality and a limited range of other health statistics. Examples of efforts initiated more recently include:

- The acceleration of international health informatics standardization efforts, including the formation of CEN (European) and ISO (international) standards committees;
- The expansion of comparative health statistics reporting, including the World Health Organization's *Health For All* indicators and the OECD's indicators;
- Joint ECE-WHO meetings on health statistics to share information on issues such as the coordination in national and international health statistics, the role of information technology in the collection and dissemination of health data, the development and use of health output indicators, and progress in implementation of health classification systems; and
- The projects under the Global Healthcare Applications Project as part of the G7/G8 Information Society initiative, including GPHIN, a Global Public Health Intelligence Network that uses the Internet to create an information base to

detect world-wide communicable disease outbreaks, assess risk, manage response, and implement control and prevention measures;

## 5. Conclusion

As knowledge about health and the organization and delivery of health services evolves, so must health information. In most developed countries, significant activity is underway at a national level to meet changing health information needs. Focal points are developing to ensure national coordination; historical data collections are evolving and being extended; and there is increased emphasis on the dissemination and reporting of comparative information. At the same time, both awareness of the need to protect personal privacy and safeguard the confidentiality and security of health information and the demand for increased integration of health data for statistical purposes are growing. While the approaches taken by particular countries may differ, they share many opportunities and challenges. In general, they also share a common goal: leveraging better health information for improved health and health care.

# 6. Selected References and Information Sources

### *General*

EUROSTAT: Statistical Office of the European Communities
http://europe.eu.int/en/comm/eurostat/serven/home.htm

Global Public Health Information Network Feasibility Study (GLOPHIN)
http://www2.ehto.lu/telematics/health/g7-glophin.html

Guidelines on the Protection of Privacy and Trans-border flows of Personal Data
http://www.oecd.org/dsti/sti/it/secur/prod/Priv-en.htm

Implementation of ICD-10 by WHO Member States
http://www.who.int/whosis/icd10/implemen.htm

International Organization for Standardization (ISO)
http://www.iso.ch

Joint ECE-WHO Meeting on Health Statistics (Rome, Italy, 14-16 October 1998).
Various background papers.
http://www.unece.org/stats/documents/1998.10.health.htm

Organization for Economic Cooperation and Development
http://www.oecd.org

Rogers R, Reardon J. Barriers to a Global Information Society for Health: Recommendations for International Action. Amsterdam: IOS Press 1999.

World Health Organization
http://www.who.org

### *Australia*

Australian Bureau of Statistics
http://www.abs.gov.au

Australian Institute of Health and Welfare
http://www.aihw.gov.au

Australia's Health 1998
http://www.aihw.gov.au/publications/health/nhdd08/nhdd08-co1.pdf

Australian Privacy Commissioner
http://www.hreoc.gov.au.privacy

Joint ECE-WHO Meeting on Health Statistics (Rome, Italy, 14-16 October 1998).
Sharing the Fruits of Coordination of Health Statistics in Australia
http://www.unece.org/stats/documents/1998.10.health.htm

National Centre for Classification in Health
http://www.cchs.usyd.edu.au/NCCH/ncch.html

### *Canada*

Advisory Council on Health Infostructure. *Canada Health Infoway: Paths to Better Health. Final Report.* Ottawa: Advisory Council on Health Infostructure, 1999.

Canadian Institute for Health Information. *Health Information Needs in Canada*. Ottawa: CIHI, 1998.

Canadian Institute for Health Information. *Health Information Roadmap: Launching the Process*. Ottawa: 1999.

Canadian Institute for Health Information. *Health Information Roadmap: Responding to Needs*. Ottawa: 1999.

Canadian Institute for Health Information
http://www.cihi.ca

National Health Information Council. *Health Information for Canada: Report of the National Task Force on Health Information*. Ottawa: National Health Information Council, 1991.

Office of Health and the Information Highway, Health Canada
http://www.hc-sc.gc.ca/ohih-bsi/

Statistics Canada
http://www.statcan.ca

### *United Kingdom*

National Health Service. *Information for Health: An Information Strategy for the Modern NHS, 1998-2005*.
http://www.nhsia.nhs.uk/strategy/full/contents.htm

Office for National Statistics
http://www.ons.gov.uk

National Audit Office for the United Kingdom
http://www.open.gov.uk/nao/home.htm

National Health Service Information Authority
http://www.nhsia.nhs.uk/

Statistics Division of the Department of Health
http://www.doh.gov.uk/public/stats5.htm

United Kingdom Department of Health
http://www.doh.gov.uk

### *Other Countries*

Direction de la recherche, des études, de l’évaluation, et des statistiques (DREES, France)
http://www.sante.gouv.fr/drees/drees.htm

Finland’s Net-Hilmo (web-based access to health statistics)
http://info.stakes.fi/nettihilmo

German Institute for Medical Documentation and Information (DIMDI)
http://www.dimdi.de

Italian Health Network
http://www.sanita.it

MEDIS-DC: Medical Information Systems Development Centre (Japan)
http://www.medis.or.jp

National Research and Development Centre for Welfare and Health (STAKES, Finland)
http://www.stakes.fi/english/index.html

New Zealand Health Information Service
http://www.nzhis.govt.nz

Nordic Medico-Statistics Committee
http://www.nom-nos.dk/NOMESCO.HTM

Nordic Social Statistics Committee
http://www.nom-nos.dk/nososco.htm

Social Welfare and Health Care Statistics in Finland
http://info.stakes.fi/meksiko/Finnish/The%20Finnish%20model%20of%20statistics.htm

# RECENT DEVELOPMENTS IN HEALTH INFORMATION

# AN INTERNATIONAL PERSPECTIVE

## *Appendix A*

## *Health Information Status and Directions: Profiles for Australia, Canada, and England*

### Australia's Health System

Australia is a federation of 6 States and 2 Territories with a central (Commonwealth) government. The States operate the majority of the Australian hospital system and most community services. The system includes a large private sector (most doctors, pharmacists, some hospitals, and the bulk of allied health services). The Commonwealth is a major funder of health services provided by the States and the private sector.

### Health Information Strategy, Organization, & Recent Directions

Australia has a well-established infrastructure to develop and provide national health information. The foundation of the framework is the National Health Information Agreement. The Agreement, signed by the Commonwealth Department of Health and Family Services, each of the eight State and Territory health authorities, the Australian Bureau of Statistics, and the Australian Institute for Health and Welfare came into effect in 1993 and has recently been extended to 2003. The Agreement aims to provide co-operative national structures and mechanisms to improve the collection, quality, and dissemination of national health information. Its objectives include improvements in access to consistent health information by community groups, health professionals, government, and non-government organizations.

The Australian Institute of Health and Welfare (AIHW) is a statutory authority of the Australian (Commonwealth) government. Established in 1987, the AIHW aims to 'inform community discussion and decision making through national leadership in the development and provision of authoritative and timely information and analysis on the health and welfare of Australians.' Activities include:

- Identification and response to the information needs of governments and the community to enable them to make informed decisions on improving the health of Australians and their health and community services;
- Provision of an 'honest broker' service for the Commonwealth Government, the State and Territory governments, and non-government clients in collecting, analyzing and disseminating national health and community services data;
- Development, maintenance and promotion of information standards for health and community services in order to directly compare national, state and territory data; and
- Making recommendations on the prevention and treatment of diseases and on the promotion of health and health awareness in

Australia (provision of the information that governments and the community use to discuss policy and make appropriate decisions).

AIHW works with the Australian Bureau of Statistics (ABS), the national statistical agency. Among other things, the ABS is responsible for compiling statistics on annual causes of death and private health establishments and for conducting national household surveys, including regular health surveys. The next such survey will be held in 2001. In addition to regular core content, more detailed information on topics such as mental health and nutrition will be collected every 6-9 years.

### *National Health Data Collections*

The National Health Information Development Plan has provided information planners, collectors, and users with a list of priorities for national health information. It identifies eight directions as the highest priority health information issues requiring national action:

- Work with Aboriginal and Torres Strait Islander peoples to develop a plan to improve all aspects of information about their health and health services;
- Develop a national health and welfare information model;
- In consultation with health service consumers and providers, examine the feasibility and usefulness of enhancing the ability to link health records, and identify the linkages that will result in the greatest community benefit;
- Develop a plan to improve health outcomes information by developing clinically specific measures of health outcomes for major health problems and enhancing the usefulness of clinical information systems for measuring the effectiveness and outcomes of interventions;
- Develop and collect standardized information on the incidence, prevalence, consequences, and outcomes of care of severe mental illness;
- Develop and collect standardized information on primary and other non-institutional health care encounter data;
- Undertake a systematic review of current major health data collections and make recommendations regarding rationalization and improvements in the cost effectiveness of collections; and
- Develop ongoing surveillance of potentially modifiable, major disease risk factors, including biological measurements where necessary, ensuring adequate coverage of small, priority populations.

### *Standards*

The National Health Information Agreement provides the basis for a national infrastructure, including a number of standards-related products.

These include the National Health Data Dictionary, the National Health Information Model, and an internet-accessible metadata registry – the National Health Information Knowledgebase. The latter provides integrated access to the full range of Australia's national information development products, providing logical links between them, and presenting the various elements within the framework of the National Health Information Model.

The National Centre for Classification in Health (NCCH) is the Australian centre of expertise in classifications for morbidity, mortality, and health interventions. Its objectives include the development, publication and recommendation of classification system for use in Australia health services and the application of international standards for classification. The NCCH has recently developed ICD-10-AM (International Statistical Classification of Diseases and Related Health Problems-Tenth Revision-Australian Modification) and a new classification of surgical procedures and interventions based on the Medicare Benefits Schedule (MBS-Extended or MBS-E). The Australian Health Ministers Advisory Council has endorsed implementation of these standards in all Australian hospitals. Three States have implemented them in 1998. The remainder are scheduled to do so in 1999. The Australian Bureau of Statistics is also scheduled to implement ICD-10 for mortality purposes in 1999.

Standards Australia, an organization whose primary role is to prepare Australian Standards through an open process of consultation and consensus, has also recently become increasingly active in the development and dissemination of technical health information standards. For example, working groups have been active in creating guidelines for Australian implementation of the Health Level Seven (HL7) standard in a number of areas.

### *Privacy and Security*

The *Commonwealth Privacy Act 1998* requires Commonwealth and Australian Capital Territory Agencies to comply with 11 information privacy principles based on the 1980 *OECD Guidelines Governing the Protection of Privacy and Trans-border Flows of Personal Data*. This legislation also empowers the Privacy Commissioner to approve guidelines for the use of personal information in the possession of Commonwealth agencies for health research. In addition, national principles for the fair handling of personal information were published in 1998 and Standards Australia produced *Personal Privacy Protection in Healthcare Information Systems* (standard AS4400). The *Australian Institute of Health and Welfare Act* also protects data held by the agency.

Individual states have also implemented information protection legislation and guidelines. Some health-sector legislation also includes specific clauses safeguarding the confidentiality of health information.

C
A
N
A
D
A

### *Canada's Health System*

Fiscal, demographic, and other factors are contributing to a rapid rate of change within Canada's health system. Today, health care in Canada is mostly publicly financed and privately delivered. In 1998, approximately 9.1 percent of the nation's gross domestic product was spent on health services. Management and delivery of health services is primarily the responsibility of the ten provinces and three territories, based on core principles established in federal legislation. Hospital inpatient and outpatient services, physician services, and some pharmaceutical products and public health services are covered by interlocking health insurance plans.

### *Health Information Strategy, Organization, & Recent Directions*

At local, regional, provincial/territorial, and national levels, informatics and information have consistently been identified as key to maintaining and improving Canada's health system and the population's health.

Nationally, the publication of the report of the National Task Force on Health Information in 1991 marked the beginning of a period of considerable activity related to health informatics. A key result of this report was the formation of the Canadian Institute for Health Information (CIHI) in 1993. The Institute is an independent, not-for-profit organization mandated to coordinate the development and maintenance of a comprehensive and integrated health information system for Canada. CIHI is responsible for providing accurate and timely information needed to establish sound health policies, manage the Canadian health system effectively, and create public awareness of factors affecting good health. Its mission is based upon collaborative planning with the provincial, territorial, and federal governments, as well as other major players in national health services. Statistics Canada is one of the key partners. Among other things, the agency is responsible for vital statistics data, the cancer registry, and the National Population Health Survey.

In the early 1990s, many provinces also initiated reviews of their health care systems. A common theme of the resulting reports was a recognition of information systems as a key enabler (and lack of quality information as a key barrier) to health sector reform. As a result, many provinces are allocating significant resources to the enhancement of health information systems in their jurisdictions. It is estimated that Canada will spend over 1.5 billion dollars on information technology in the health field by the year 2000. Much of this will be spent on health infostructure at the provincial, territorial, and regional levels.

More recently, national consultations on health information needs and the report of the Federal Minister of Health's Advisory Council on Health Info-Structure have led to significant national investment in health information. In part, these funds will support the implementation of the *National Health Information Roadmap*, a shared vision for modernizing health information in Canada.

From this vision, priorities have been identified for immediate investment. Areas for action include:

- Establishing an on-going process to consult with key stakeholders across the country;
- Fostering common data and technical standards to ensure the consistent collection, exchange, and interpretation of comparative health data;
- Addressing priority data gaps on health services and costs, outcomes, health status, and factors that affect health;
- Creating a Canadian Population Health Initiative that aims to become a strong and independent source of new information and insights on health and the health system; and
- Producing regular, easy-to-understand public reports and conducting special studies on the health of Canadians and our health system.

### *National Health Data Collections*

National health data collections are primarily held by the Canadian Institute for Health Information (CIHI), Health Canada, and Statistics Canada. CIHI maintains a wide variety of health service encounter data (e.g. the Hospital Morbidity Database and the Hospital Mental Health Database), disease/condition registries (e.g. the National Trauma Registry and the Canadian Organ Replacement Register), health human resources data (e.g. the National Physician Database and the Registered Nurses Database), and health expenditure data (e.g. the National Health Expenditure Database and the Annual Hospital Survey).

Health Canada primarily holds data on the incidence of notifiable diseases, including sexually-transmitted and vaccine-preventable diseases. Statistics Canada data collections include vital statistics, the National Population Health Survey, the Canadian Cancer Registry, and a number of surveys that provide information on health status and non-medical determinants of health (e.g. the Census and the Labour Force Survey).

A variety of additional specialized data collections are maintained by other national organizations and at provincial/territorial and local levels.

### *Standards*

Although health services are primarily a provincial/territorial responsibility, the potential benefits from establishing standards at a broader level have long been recognized. This realization has lead to several successful national standardization activities.

For instance, CIHI has developed several data content standards which are now in use across the country. These include tools such as Case Mix Groups and Day Procedure Groups (methodologies which group service recipients with similar anticipated resource requirements); the *MIS*

*Guidelines* (providing a common framework to collect and analyze data about a health care facility’s costs and performance); and the discharge abstract (a standardized format for reporting data on acute care discharges). In addition, CIHI has coordinated the development of new standards for reporting data on ambulatory care, continuing care, and rehabilitation services.

Many of these data content standards include information about diagnoses and interventions. Currently, a mix of standards are in use for this type of data. In general, the *International Statistical Classification of Diseases, Injuries, and Causes of Death, Ninth Revision* (ICD-9) and the *ICD-9-Clinical Modification* (ICD-9-CM) are used for diagnosis classification. The *Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedures* (CCP) and the procedure component of the ICD-9-CM are commonly used for acute care procedure classification. CCP and locally developed provincial schedules are generally used in physician claims. The transition to the *International Classification of Diseases and Related Health Problems, Tenth Revision* (ICD-10) for diagnosis coding will begin in 2001. At the same time, the *Canadian Classification of Health Interventions* (CCI) will be introduced.

Significant activity is also underway on technical standards. For example, CIHI formed the Partnership for Health Informatics/Telematics in 1996. The goal was to bring together key players from both the public and private sectors to develop universal and efficient standards for managing and exchanging electronic health data. The Partnership has been active in many areas, including the development of the Canadian Health Information Framework and Health Data Model.

With the advent of the International Organization for Standardization (ISO)’s Technical Committee on Health Informatics (TC 215) and other developments, a Canadian Advisory Committee to provide input to TC 215 has also been established.

### *Privacy and Security*

Today, a variety of legislative protection exists across the country. Most provinces and territories now have comprehensive freedom of information and protection of privacy legislation in place, at least for the public sector. Broad-based national legislation based on the Organization for Economic Cooperation and Development (OECD)’s principles and a privacy code adopted by the Canadian Standards Association, is now being considered.

In addition, many provinces have clauses in health legislation (e.g. the Vital Statistics Act) that provide targeted privacy protection. Several have also recently introduced or are considering sector-specific health information protection legislation.

ENGLAND

### Background

Health care in the United Kingdom is provided mostly by the National Health Service (NHS). Its founding principles of equity, comprehensiveness, and no charge at point of delivery have remained relatively stable since the NHS was founded in 1948. In the past decade, the NHS has introduced significant structural reforms, including the establishment of 'internal markets' for health services. Outside the NHS, a broad range of health services are delivered by the private sector.

### Health Information Strategy, Organization, & Recent Directions

*Information for Health*, a new information strategy for the NHS, was published in September 1998. The strategy is a central feature of the Government's wider program of renewal and reform for the NHS. Over seven years, the strategy aims to put in place the people, resources, culture and processes necessary to ensure that NHS clinicians and managers have the information needed to support the core purpose of the NHS, including caring for individuals and improving public health. The strategy focuses on the needs of the public, patients and clinicians for information and communications tools to deliver improved healthcare, rather than on management or administrative functions. In total, the Government has pledged £1billion of new money over the next 7 years to implement *Information for Health*.

The strategy aims to deliver a life-long electronic health record for everyone in the country, 24 hour access to on-line health records and information about best clinical practice for NHS clinicians, as well as the infrastructure to enable access for every general practice and hospital to *NHSnet*, the NHS information highway. Other plans include using on-line and telephone-based program to increase public access to information and health services and enhancing telemedicine and telecare services. In addition, a National Electronic Library for Heatlh is being created to contain information on evidence-based practice, clinical guidelines, and patient literature. It will be available to both the NHS and the public.

The strategy also includes the establishment of a new NHS Information Authority. The new Authority will be responsible for developing national products and standards to support local implementation of the strategy and ensuring the NHS has high quality information to improve services to patients.

### National Health Data Collections

The Government Statistical Service (GSS) is the main provider of official statistics in the UK. It includes the Statistics Division of the Department of Health and the Office for National Statistics (ONS).

The Statistics Division within the Department of Health covers a wide range of information. Areas of interest include health-related behaviour, morbidity, fertility, primary and community care, community health and prevention, hospitals, ambulance services, mental health and learning disability, social care, health workforce, and health expenditure statistics.

Other types of health information are collected and published by the Office for National Statistics (ONS). The ONS was formed in April 1996 from a merger of the Central Statistical Office and the Office of Population Censuses and Surveys. It produces and disseminates social, health, economic, demographic, labour market, and business statistics. The ONS also conducts census and social surveys and is responsible for the registration of births, marriages, and deaths and the National Health Service Register. The ONS only covers England and Wales. Data for Scotland and Northern Ireland are held by other agencies.

### *Standards*

Standards activities primarily fall under the responsibility of the new NHS Information Authority. A number of activities are underway, including:

- The NHS Data Dictionary, which contains the nationally agreed data standards;
- The NHS Data Model, which is extensively used as a reference document for data collection (soon to be published as an intergrated electronic document with the data dictionary); and
- The NHS Healthcare Modelling Programme (HcMP) which provides business models of healthcare and modelling expertise for use by and on behalf of the NHS.

In addition, as part of the NHS Information Strategy, the Government will set up a new Clinical Information Management Programme which will have sole responsibility for developing national clinical data standards. A Clinical Data Standards Board will be set up to mandate professionally agreed clinical standards throughout the NHS. Already, ICD-10 has been implemented for morbidity purposes. During the life of the new strategy and dependent on the outcome of the evaluation recommended by the Public Accounts Committee, Clinical Terms Version 3 (Read Codes) will be introduced as the standard for operational clinical systems and a common coded drug dictionary for the NHS will be developed. Already, over 75% of general practices in England and Wales use Read Codes. The NHS and the SNOMED Board have agreed to collaborate to create a unified product by the end of 2001. It is intended that this will then become the NHS standard.

Data interchange and other technical standards are also a strong component of the Information Strategy.

### *Privacy and Security*

A number of pieces of data protection and related legislation currently exist, including:

- The *Data Protection Act 1984* has provided overall protection based on core principles for over a decade. Updated legislation received Royal Assent in July 1998 (provisions come into force over the following decade);
- The *Computer Misuse Act 1990* that provides criminal sanctions against unauthorized access or damage to computerized information;
- The *Access to Health Records Act 1990* ensures that individuals generally have a right to what information is held on them in medical records;
- The *Access to Medical Reports Act* outlines the rights of employers and insurance companies to access medical reports; and
- Other health legislation and regulations, such as the *Abortion Act 1991 and the NHS (venereal diseases) Regulations 1974 and 1991*, also include clauses that limit the disclosure of information.

The NHS has also been active in developing strategies and advice related to data security and encryption. For example, the *NHS Information Management and Technology Security Manual* (1996) provides guidance on the administrative and technical measures that the NHS is expected to implement to preserve the confidentiality, integrity, and availability of personal health data. Part of the Information Strategy includes the implementation of the recommendations of the Caldicott Report related to inter-organizational flows of personal data.

In addition, in line with all European Union Countries, England is introducing legislation to implement Directive 95/26/EC of the European Parliament and of the Council of Europe on the protection of individuals with regard to the processing of personal data and on the free movement of such data. One major effect will be to extend data protection legislation to paper systems and another will be to prohibit, in many circumstances, transmission of personal data to other countries unless there are equivalent data protection provisions.