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# Functional Status and Health Information in Canada: Proposals and Prospects

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*The primary obstacle to evidence-based health care quality assessment in Canada is reliable data on health encounters and episodes of care. The recent Federal/Provincial Health Accord will enhance health data collection, including standardized functional status information (FSI) for administrative records. Canadian health policy developers also agree that FSI is needed to bridge data gaps since alterations in functional status create the continuity that links all episodes of care and health service utilization. Given Canada's universal, single-payer, health financing structure, the prospects for coherent and systemwide data collection are good. This article describes the Canadian health care from the perspective of health information, and surveys proposals in electronic health technology development, the obstacles that need to be faced, and the prospects of doing so.*

## INTRODUCTION

Health system policymakers and researchers in Canada have long appreciated that the primary obstacle to evidence-based health care quality assessment, cost control, and health system performance assessment is reliable data from health encounters across all episodes of care. Canada is, on the face of it, well situated to deal with this problem. First and foremost, because of the terms of the Canada Health Act (1985), Canada enjoys a highly popular,

universal single-payer health financing structure that can avoid the informational confusions often created by systems that combine private and public financing. Secondly, health data standardization, collection, and analysis are centralized in Canada within the Federal agencies of Statistics Canada and the Canadian Institute for Health Information (CIHI). Finally, the Federal and Provincial agencies responsible for Canada's health care delivery systems have signed a Health Accord, and are currently negotiating an even stronger accord that will enhance health and functional status data collection. In particular, the 2000 Health Accord provided funding for the development of several electronic health information (EHI) initiatives, in particular electronic health records (EHRs), to facilitate data comparability. These initiatives could revolutionize the collection and communication of health data from both administrative and clinical records across the system.

This Federal/Provincial Governments cooperative infrastructure was slow to develop, and indeed remains fragile and subject to review in light of repeated calls to reform the system by injecting elements of privatization. The first task of this article is to review the highlights of how Canada's health care legal and administrative infrastructure have evolved in ways that create a context for optimism about the prospects health information for cost control and quality assessment. This will require a brief description of the terms of the Canada Health Act and the recent Health

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Accord, as well as a chronological survey of the wide-ranging endeavours being pursued in the area of electronic health information collection and dissemination.

An interconnected task of this article is to place these infrastructural developments in the context of the recognition of the importance of information about a person's functional status—the effect of their health condition on their ability to do the actions and tasks of daily living that make it possible for them to participate in all areas of human life. The challenge in health information is to track health encounters across episodes of care, and in particular to bridge gaps between acute-care, inpatient rehabilitative and community-based care. The academic literature has long argued that functional status information is the data needed to bridge these gaps (Üstün et al., 2003). In addition, functional status, especially in the case of chronic disabilities, links the health care system with other health and social services that the individual may utilize. But is it feasible to collect this information, and how can it be integrated into the overall health information system? It is suggested in this article that, because of the cooperative and relatively centralized nature of the Canadian health care system and its approach to health care data collection Canada is well placed to develop and implement administrative and clinical records that incorporate functional status measures. For this purpose, the World Health Organization's (WHO) *International Classification of Functioning, Disability and Health* (ICF) (World Health Organization, 2000) is the most likely tool and has been so recognized within these agencies.

This agenda has been assisted at the population health level by steps taken to include within Canada's major population health and social surveys functional status questions linked to Canada's functioning

and disability survey, the Participation and Activity Limitation Survey. This self-report data needs to be correlated with clinical and administrative record data and this is where the major problems of data collection and comparability have occurred. EHRs, smart cards, and other technological innovations are practical responses to this problem. Unfortunately, these collection modes have not as yet been extended to include functional status data.

There are various reasons why. It is well known that there are substantial practical, technical, and policy problems in putting into place an integrated health care information system. Although standardization is an essential first step, other steps are required to resolve issues of data validity and reliability, as well as, the comparability of functional status data between commonly used assessment instruments. This range of issues is discussed in the last section of this article. Finally, even as innovations for clinical data collection become available, the problem of motivating clinical data collection and lightening its burden looms large. Because of all these identified, but so far unresolved issues, this article speaks of Canadian prospects rather than successes.

## CANADIAN HEALTH SYSTEM

Although the present Canadian health care system is governed by the Canada Health Act of 1984, the story begins earlier. The trend in Canada towards a universal, publicly financed pan-Canadian health care system began in 1947 when the Province of Saskatchewan introduced a universal public insurance plan for hospital services. It was both a fiscal and political success, and a decade later the Federal Government introduced the Hospital Insurance and Diagnostic Services Act to encourage the development of hospital insurance plans in

all provinces. The inducement was financial: the Federal Government offered to use general tax revenue to share the costs of eligible hospital and diagnostic services with the provinces on a roughly 50-50 basis. The condition for receiving Federal money was a provincial agreement to make insured services available to all their residents, under uniform terms.

By 1961, all provinces had signed on. Leading the way again, Saskatchewan in 1962 extended its public health care insurance to cover physician services provided outside of hospitals. In 1964 a Royal Commission on Health Services, chaired by Justice Emmett Hall, recommended that the Federal Government establish a public medical care insurance plan similar to Saskatchewan's. The recommendation was taken up, and the Medical Care Act was passed in 1966, requiring the Federal Government to pay one-half the costs of eligible physician services. What followed was a predictable political battle between the two levels of government over the mode of funding, the principal provincial worry being loss of control over health care delivery and administration. The result—not the solution since it remains a hotly contested issue—was a block funding transfer mechanism. The Canada Health and Social Transfer have governed this mechanism since 1995.

Underpinning the political debate was the ideological battle between a multi-payer and multi-tiered system requiring Canadians to pay out-of-pocket or purchase private insurance, while providing public coverage for the poor, and a single-payer system with universal coverage to everyone on the same basis, funded through taxes. Although it was understood that the funding issue would continue to pit the provinces against the Federal Government, it was agreed that the virtues of the single-payer approach were worth the trouble.

The Canada Health Act was enacted in response to provincial attempts to contain costs through extra billing (a practice that creates a multi-payer system by charging patients in excess of the rates covered by public insurance). In exchange for fair and consistent Federal funding, the Canada Health Act requires the provinces to abide by five principles or program criteria:

- **Public Administration**—the provincial insurance plan must be administered and operated on a non-profit basis by a public authority appointed or designated by the government of the province.
- **Comprehensiveness**—the provincial insurance plan must insure all insured health services provided by hospitals, medical practitioners, or dentists, and where the law of the province so permits, similar or additional services rendered by other health care practitioners.
- **Universality**—the provincial insurance plan must entitle 100 percent of the insured persons of the province to the insured health services provided for by the plan on uniform terms and conditions.
- **Portability**—the provincial insurance plan must provide coverage for insured services when an insured person moves or travels within Canada or travels outside the country.
- **Accessibility**—the provincial insurance plan must provide for insured health services on uniform terms and conditions and on a basis that does not impede or preclude reasonable access to those services by insured persons.

Taken together, these principles provide the rationale for a universal, single-payer public health care system. The rationale is supported by the argument that health care is different from other goods and services and not congenial to a free market approach. Since health care consumers cannot determine the health care services

they require, demand must be left to licensed providers. Health care needs are not always predictable, and their costs can be catastrophically high—which argues for risk and resource pooling by an insurance mechanism. Yet private insurance in the health area is subject to a collection of market failures—namely, moral hazard and adverse selection. The first driving individuals to purchase only as much insurance as they think they need, and second driving insurers to avoid individuals (or medical conditions) that are likely to cost them money.

The effect of these two forces, especially in an unregulated free market, is the perverse situation where people with high medical needs face reduced coverage or prohibitively high premiums, and poor people assume a relatively higher proportion of health care costs for an equivalent premium while wealthy and healthy people have superb coverage.

On the other hand, public health care insurance, which guarantees access to insurance to all, avoids market failures and inequities of coverage, and can benefit from economies of scale provided by more predictability and control over costs and expenditures. To reap these benefits, of course, coverage must remain universal and comprehensive, portable and accessible; otherwise unmet health care needs will naturally create a market for supplementary or additional coverage or services. The role of the five principles has therefore been viewed, not without reason, as the means for preserving Canada's public health care system (Kirby Commission, 2002).

Public health care systems are always vulnerable to attack from private providers. In several countries with public systems, such as New Zealand and the United Kingdom, rather than fight the trend the private sector is allowed to make in-roads

into the public system, subject to rigorous regulation. Canada has not, as yet, taken this route, although health care services, though financed publicly, are increasingly being delivered privately. The pressure to transform the Canadian health system into a more standard mixed public/private system is considerable and probably irresistible. The Canada Health Act itself opens the door by not requiring that the provinces follow the five principles for services that fall outside hospital and physician services that are medically necessary. These extended services, such as home care, long-term care (LTC), pharmaceuticals, and many ill-health prevention and health promotion activities are open to private enterprise. Indeed, under the terms of the North American Free Trade Agreement, any attempt on the government's part to extend the public system to include these areas (which we now know have substantial public health significance) would be prevented as a form of expropriation.

Overall, Canada's approach to health care financing does well. Although Canada's health care budget is substantial and has increased since the 1970s, as a share of the gross domestic product (GDP), spending has remained relatively stable between 7 to 9 percent, with a public/private payment split of roughly 78/28. (World Health Organization, 2001; Organization for Economic Cooperation and Development, 2001). The U.S., which spends, by a considerable measure, the most per capita on health care than any other country on earth, is creeping up to 15 percent of the GDP expenditure (with a 44/56 payment split between public and private). Canada spends per capita on health care payments (\$2,535 per person) roughly as much as most members of the Organization for Economic Cooperation and Development do, whereas the U.S., spends \$4,631 per person. As for efficiency,

going by the recent WHO calculation of health system performance assessment—a metric combining both health attainment, equality of health attainment, responsiveness, and financing—Canada ranks 30th out of 191 countries in the world, whereas the US, despite its vast overall and per capital expenditure on health, ranks 37th (World Health Organization, 2000).

Still, as is inevitable with such a politically charge policy area, calls are frequently being made to revisit the terms of the Canada Health Act. What has remained utterly uncontroversial about the Canada Health Act, however, is one of the two conditions imposed on the provinces in order to receive full Federal funding, namely that the province provide “such information ... as the Minister [of Health] may reasonably require for the purposes of this Act”. The free exchange of health information—broadly construed to include both clinical and epidemiological data, as well as information about the performance of the health delivery systems—is a precondition to the successful operation of the health system created under the Canada Health Act. This firm legal requirement is the best reason to be optimistic that Canada can solve the problem of coordinating comparable data collection across all episode of care—the precondition for an evidence-based approach to quality assessment, cost control, and health system cost effectiveness.

In practical effect, this seemingly innocuous condition on Federal funding is that the collection of health information, across the country, is centralized. Canada has a single statistical agency, Statistics Canada, responsible for all population statistical data, including health data. Being responsible for census and post-census surveys, Statistics Canada also links health information with the full range of social welfare data, including employment and

educational information. This is an important advantage as it creates a coordinated linkage between clinical health data and functional data concerning, to use the ICF term, participation in areas of human life that, although themselves not health domains, are affected by, or affect, health status. Finally, since 1995, CIHI is responsible for maintaining health administrative databases and for the essential task of standardization of health information. Prominent among the standards promulgated by the CIHI is the ICF.

The legal foundation for a centralized, information-friendly health care infrastructure, created by the Canada Health Act, was further reinforced in September 2000. After a decade of funding cuts, the Federal/Provincial Governments reached a Health Accord that promised a substantial cash transfer to the provinces reeling under the burden of dramatic increases in health care expenditures. The Health Accord also set aside \$2.3 billion to fund developments in three areas: medical equipment, primary care reform, and health information technology. Improvements in health information, the Health Accord made clear, were motivated by the need for improved accountability, and for their part the provinces agreed to provide regular and comprehensive reporting on the health programs and services they delivered.

The Health Accord speaks of the need to create a coordinated health infrastructure to improve quality, access, and timeliness of health care for Canadians. It also committed both levels of government to develop EHRs and enhance technologies like telehealth over the next few years. Governments are to continue to work collaboratively to develop common data standards to ensure compatibility of health information networks. This will lead to more integrated delivery of health care services. They will also ensure the strin-

gent protection of privacy, confidentiality, and security of personal health information. (First Ministers' Communiqué on Health, 2000). Drafters of the Health Accord felt confident that the responsible Federal data agencies—Statistics Canada and the CIHI—would be up to the challenge of collecting and analyzing health information, since Canada had already begun the process of creating an informational infrastructure.

## **INITIATIVES IN ELECTRONIC HEALTH INFORMATICS**

For at least a decade, the Canadian Government has invested in the development of an information highway for health and other information. In 1994, the Information Highway Advisory Council (IHAC) was established to study how best to develop and use the Internet and other technology for data collection. The same year the National Forum on Health was established to advise the Federal Government on ways to improve Canada's health system. Their final reports agreed on the need to create a pan-Canadian population health information system (Information Highway Advisory Council, 1995; National Forum on Health, 1997). The Federal Government announced its intention to enter the field of electronic health information, which they did with a somewhat modest financial commitment. Soon thereafter, the Ministry of Health established the Advisory Council on Health Infrastructure (ACHI) and created the Office of Health and the Information Highway (OHIH) to focus future efforts.

ACHI identified five priorities for its ongoing work: (1) strategic planning, (2) telehealth, (3) protection of personal health information, (4) health surveillance, and (5) EHRs. ACHI was a coordinating body linking the ministry with external stake-

holders, including the private sector, and has focused its attention on the use of information and communications technologies (ICTs) in the health sector. The ACHI (1999) report laid out their case for creating a pan-Canadian health information highway "...to strengthen single-payer, publicly funded health care systems guided by Canada Health Act [in order to] provide the information and communications infrastructure that will allow the seamless delivery of patient care across the wide range of diverse institutions composing today's complex health system." The report describes the health infoway as a combination of hardware technology, information, and a legal and administrative infrastructure to manage the information for quality assessment and cost effectiveness.

In addition, the report describes the Canadian health care services as organized by a series of care silos, primary, acute, mental health, ambulatory, home, long term, etc. The flow of health information linked to patients and their encounters, is shaped by these care silos. This causes difficulties when patients, following predictable recovery paths, move through these care settings. Without access to patient information it is nearly impossible to ensure continuity of care, nor is it possible to assess efficacy of treatment, and quality of care in order to make a guess at the cost effectiveness of the health system as a whole.

This creates well known and surprisingly common problems: a patient's medication regime prescribed in a hospital encounter is ignored or reversed when the patient moves back into the community or into a LTC setting; a patient with a chronic condition, which entails a collection of functional decrements that are well known in an ambulatory rehabilitation setting, is inappropriately served in a primary or emergency care situation where this infor-

mation is unavailable. While within each care silo, the vertical care may be exemplary, the horizontal communication between silos may be less so.

The problem of data source fragmentation is not just a concern of the health practitioner and the patient; it is also a concern for those who need to aggregate data across the spectrum of care for health system management or public health purposes. Accountability depends on transparent and evidence-based decisionmaking about health resource allocation and financing. Managers need a detailed and comprehensive picture of resource needs and costs. These data are essential to make determinations of the comparative effectiveness of alternative interventions, and to propose, implement, and monitor plans for coordinating and integrating services across the complete spectrum of health care. The report also revealed that in the present situation no one in Canada can break down the costs of specific health interventions for comparison across provinces and health care providers; nor does anyone have a clear sense of the costs or effectiveness of services performed in different setting—within or outside hospitals and doctors' offices, in clinics, LTC facilities, laboratories, or home care.

The report concludes that what is needed is a health information system that (1) collects and integrates standardized data, across the spectrum of care settings; (2) allows for the expansion of data coverage to link health determinants, interventions and outcomes, and includes the full costs of services; and (3) facilitates timely and accessible data exchange and connectivity. Without such an informational infrastructure, Canadians will not know how the health care system is functioning, and whether health care dollars are allocated in ways that produce the greatest health gains.

ACHI's report persuaded Canada Health who, bolstered by the results of stakeholder workshops (Canadian Medical Association and Office of Health and the Information Highway, 2000), declared that the key to the information gap was ICTs. As a direct result, in the Health Accord the Federal Government announced it would immediately "...invest \$500 million in an independent corporation mandated to accelerate the development and adoption of modern systems of information technology, such as electronic patient records, so as to provide better health care." Within a year, an independent, not-for-profit corporation, Canada Health Infoway Inc. was created and mandated to identify investment opportunities that will accelerate the development and adoption of EHI systems with compatible standards and technologies across the country.

The parameters of this vast enterprise have recently been outlined by the two major players on the Canadian health information scene, CIHI and Statistics Canada. The CIHI (2001) plan creates information resources to support both accountability and continuous feedback on factors affecting the health of Canadians. Subject to stringent privacy safeguards, confidentiality requirements and data security arrangements, the plan provides for the integration of standardized health data, expanded data coverage for health services, medical interventions, health determinants and the costs of services, data exchange and connectivity, and increased analytic expertise and the dissemination of results. CIHI's role in health information in Canada is central since, under the Health Accord, it is now mandated to maintain all clinical and population health databases.

Health Canada waited another year before releasing its report on the information products and technologies that will dominate the Canadian health information

scene for the next decade. The OHIH reports (2001a,b) focused primarily on the EHR. As the ACHI argued in 2001 "...the electronic health record (EHR) [is] of pivotal importance to an integrated health care delivery system. It is the means by which patient centered health care delivery can be achieved. As such, the EHR is a key priority for Health Canada as a key element of a Canadian health infostructure." (OHIH, 2001a,b.) The OHIH maintains that privacy is protected and has insisted that patient-based EHRs are the precondition to the health infostructure. In its interim report on the state of Canada's health system, also released in 2001, the Standing Senate Committee on Social Affairs, Science and Technology singled ERH as the "...cornerstone of an efficient and responsive health care delivery system that is able to improve both quality and accountability" (Kirby Report, 2001).

The reasoning behind all these claims is straightforward. The quality of an informational system is only as good as the quality of its data sources and modes of data intake it utilizes. All health information, even population health data generated statistically, flows ultimately from individuals, either through self-report, clinical observation or diagnostic test. Once mechanisms for patient data intake in each of the care silos is implemented, then the electronic technology can deal with information gaps created by the care silos and ensure conductivity between data users across all care settings. Indeed, with an EHR it is relatively easy for patients themselves to ensure that physicians, other professionals, and providers in every silo of the health care system had timely access to relevant portions of their medical records. Such EHRs can therefore help to integrate and coordinate health care services delivery around patients and their needs.

The data components for an EHR would include person, health setting or facility, and provider identifiers; administrative information; and health data in a standardized format collected over time (for a longitudinal picture). The sources of these data, besides the patient and his or her family, would include physicians, nurses, community health workers, laboratory, hospital encounters, pharmacy prescriptions, therapists, dental visits, podiatrists, psychologists, social workers, optometrists, nurse practitioners, physiotherapists, midwives dietitians, radiology technologists, chaplains, etc. In theory, there are no limits to the person, institution, or location that can be a source of data, and as it is an electronic media, the data take any form, from text, images, audio, video and any combination of these. In practice, EHR would focus on minimum data sets of longitudinal health data, across the continuum of care, with the built-in capacity for incremental additions to the core data set so ensure completeness across the system (Advisory Council on Health Infostructure, 2000).

The virtues of electronic data collection and storage are well known: any form of data can be included; the data exists only in virtual form; can be instantaneously, and infinitely transmitted without loss or degradation; it is recordable, infinitely expandable, and malleable to any organizational, statistical, or analytic structure that may be required by the user, in discrete or aggregate form. In fact, it is difficult for some commentators not to exaggerate the virtues of the EHR, even when the focus is exclusively clinical. The Institute of Medicine (1997) report on computer-based patient records, for example, suggests that, merely by virtue of basic features of electronic retrieval, the EHR enhances diagnoses and provides the clinical rationale for

the management of patient care, promotes routine assessment of outcomes by supporting the systematic measurement and recording of the patient's health status and functional level, and can guide the process of clinical problem solving by providing clinicians with decision analysis tools, clinical reminders, prognostic risk assessment, and other clinical aids.

Yet, clinical and research applications notwithstanding, it is cross-system accountability that adherents of EHR emphasize the most. Longitudinal health record information at the point of care that can be used for managing and evaluating quality and cost of care is output of EHR that has and will continue to endear this technology to health administrators, planners, and politicians. As previously mentioned, political accountability for the operation of the health system looms particularly large in Canada since it is a universal, single payer, State-administrated system. It is an article of faith that market forces will cleanse the overall system of ineffective and inefficient private health insurers and providers. But such forces are not, at least directly, engaged in the Canadian system, and as a result accountability for performance indicators is a high priority political issue.

Much depends, however, on technological developments and implementation decisions—how the data can be collected and by whom. The microchip embedded smart card has the capacity to store patient information, but though once lauded as a technological fix, it has recently fallen onto hard times, given studies suggesting considerable reluctance on the part of practitioners to use or rely on the card (Aubert and Hamel, 2001). Undoubtedly, the lynchpin of any successful EHR is technology that enables health care practitioners, across health care settings, in and outside of hospitals, to input point-of-care and real

time data from examination or consultation, history-taking, diagnostic testing, treatment or other relevant context. A recently reported technological and clinical model for collecting clinical health data (in this case involving pain management) demonstrates what is possible given the merging of sophisticated technology and clinical expertise (Goldstein, VanDenKerkhof, and Rimmer, 2002).

The Queen's University Anesthesiology Informatics Laboratory (QUAIL) (2002) has combined a hand-held computer with bar codings and wireless network technology with software that allows patients' real time health records to travel with them as they proceed through a hospital's cycle of referral, assessment, pre-operative consultation, surgery, post-anesthetic care, recovery ward, and home followup. Each of the hand-held computers is connected to the hospital's main computer by means of infrared access points so that as new data about a patient is entered in (either at the bedside or in an office) the data is immediately available to other health professionals (who have security identification). The hand-held computer displays a patient's name and identifier on each screen and the clinician can easily flipped between numeric rating scales for pain, medication (with a pull down menu listing that can be scanned and clicked on), dose, frequency, start dates and times, side effects, etc. The system also has limited feedback capacities and can be configured to alert physicians of specific medical problems (e.g. bradycardia or tachycardia) as they develop. The health data collected in the QUAIL project, although sufficient to the acute-pain management area is somewhat limited. However, it is easy to envision other modules tailored to specific clinical areas, all similarly linked via a central repository that can be accessed by other health care practitioners.

The next step, which the QUAIL researchers are already preparing for, is to link these modules via a wireless connection to a secured Internet site.

## **FUNCTIONAL STATUS AND HEALTH INFORMATION INFRASTRUCTURE**

The value of health information in improving the quality of care and the health of Canadians is as much a function of what kind of data are collected, as is the technological tool used to collect it, or infrastructure in place to store, analyze, and disseminate the data. In Canada, as elsewhere, the academic arguments and growing empirical evidence favoring the collection and use of FSI has not gone unheard. In a recent report by the Commission on the Future of Health Care in Canada, (Romanov Commission, 2002), a strong case was made for the development of "...common indicators to measure performance from the national system level to the individual clinic..." and it was noted that these health outcome indicators must look beyond measurements of illness and treatment to functional status and the experience of the patient.

What the Romanov Commission (2002) acknowledges is the growing evidence that functional status data is vital, not only clinically, but to form the informational basis for quality assessment and health system performance. Several studies have shown that diagnostic and illness and treatment information alone is insufficient to predict health service needs, length of hospitalization, level of care required, or to assess effectiveness of interventions and other indicators relevant to health policy and health system quality control and cost effectiveness (Üstün et al., 2003).

We have had for decades highly reliable tools for collecting data on causes of death and ways of estimating population mortality.

Although the rehabilitative disciplines have produced countless disability assessment tools and quality of life measures (McDowell and Newell, 1996), what has been lacking is a complete classification that could ensure reliable data collection and international comparability. This was the primary motivation behind the ICF (World Health Organization, 2001). The ICF now serves as WHO's framework for health and disability; it is the conceptual basis for the definition, measurement, and policy formulations for all aspects of disability.

The ICF puts the stress on health and levels of functioning. Previously, disability began where health ended; once you were disabled, you were in a separate category; disability was an all or nothing matter. The ICF presents a conception of disability as a continuum, relevant to the lives of all people to different degrees and at different times in their lives. This is a radical shift. Disability is not something that happens only to a minority of people, it is a natural feature of the human condition. From an informational point of view, the ICF is the key to valid and reliable data on functional status. It is suitable as the basis for coding and data collection in population health surveys and other self-report questionnaires.

ICF is available in electronic form, including a CD-ROM format with a multi-language interactive platform that has advance search software built-in. In clinical contexts, the ICF is available as a checklist for a quick functional status profile. The WHO's development assessment tool and Disability Assessment Schedule, are directly linked to the ICF.

Canada, represented by the CIHI, was a major player in the developmental and testing stages of the ICF, so it is known and used here. The existence of an international classification, even one endorsed by government statistical agencies, does not dictate its use throughout the health informa-

tional system, especially at the essential level of individual clinicians. A prior, and more difficult question is whether standardized data will find a permanent place in the developing Canadian health information system, so that such information is regularly collected, analyzed, and used for quality of care and health system performance assessment.

The foregoing certainly gives grounds for optimism, both that an informational system will soon be in place, and that functional data will be part of it. The Canada Health Act establishes a legal framework for centralized health collection, under the control of two well-funded agencies with a clear health data agenda—the CIHI and Statistics Canada. The recent Health Accord reinforces a Federal/Provincial agreement to collect and share health information in a standardized format, and provides initial funding and a corporate vehicle—Canadian Health Infoway, Inc. to begin product development. Finally, in the clearest possible terms, and consistently over the past decade, the Federal Government has given its commitment to electronic health in general, and EHRs in particular as a way of implementing the health information agenda.

There is a well-understood rationale for putting together these infrastructural and legal components for a pan-Canadian and integrated system of health information that includes FSI (Advisory Council on Health Infostructure, 2001). However diverse the sources of health information are, and however complex the interrelations between these data sources and health care settings, in order for an integrated health information system to work, the stakeholders have agreed that it must be centralized and based on a single set of standards. In the Canadian setting, it is arguable that the governing legislation makes health information a public good,

which paves the way for a public, government administered and funded, health information system. Canadian policymakers understand that in a privatized or market-driven environment, health information tends to create segregated, non-overlapping information systems that lack common standards. Yet, if pressures to privatize are not resisted, then a potential conflict will arise between the public interest and the interests of private insurers who will likely insist on proprietary rights over health information they create or control. It is not clear how this conflict will be resolved without undermining the Canadian health system.

There is another reason to think that functional status data will find a place in Canada's developing electronic health enterprise. Statistics Canada—which unlike the National Center for Health Statistics, is a centralized data collection organization mandated to collect population-based health and social data across the country—has long favored the collection of FSI. Canada is a world leader in developing cross-sectional disability and functional status surveys starting with the Health and Activity Limitation Survey, conducted in 1986-1987 and again in 1991-1992, followed by the Participation and Activity Limitation Survey conducted in the latter part of 2001. The Health and Activity Limitation Survey was based on the WHO's (1980, 1993) original disability classification, the *International Classification of Impairments, Disabilities and Handicaps*, and the Participation and Activity Limitation Survey is now fully integrated with the ICF. Moreover, the disability filter or screener questions from the Participation and Activity Limitation Survey have been included in the Census of Population's long form for 2001, as well as the two major population health surveys—the Canada Community Health Survey and the National Population Health Survey.

Finally, these screener questions have now been included in a handful of population social surveys, such as the Survey on Labor and Income Dynamics, the National Survey of Children and Youth, and cycles of the General Social Service.

The rationale behind these moves at Statistics Canada is to use functional status data, not merely to expand our information about population health, but also to treat disability as a demographic variable. This variable could then be used to analyze the participation rates of persons with disabilities in the major areas of life that are included in social surveys, such as education, employment, housing, and transportation. In time, these data will inform broad policy decisions that link health system outcomes and expenditures with an array of social service outcomes and expenditures. Research in Canada has long relied on the large databases produced by these surveys to track the influence of work, household structure, and other socio-economic status indicators on gender differences in health (Walters, McDonough, and Strohschein, 2002). Analogous studies connecting functional status, social indicators, and health status are anticipated.

In short, in the Canadian context, where the informational challenge of continuity of care and the need to standardize health information are well understood and where both levels of government are committed to putting into place a technologically sophisticated and pan-Canadian information infrastructure, the prospects of supplementing standard medical health information with FSI are very good. The obstacles standing in the way of adding standardized information about functional status are the same as to those the overall informational system faces and will have to be resolved.

The first obstacle is merely to convince all stakeholders of the need for an integrated health information infrastructure and

the importance of including functional status data to supplement health information. As previously mentioned, in Canada, this task has been primarily taken up by the highest levels of the Federal and Provincial Governments. Canada has no equivalent agency to the National Committee on Vital and Health Statistics. Therefore, we do not have the benefit of such an agency acknowledging the importance to our understanding of health and healthy populations of FSI (National Committee on Vital and Health Statistics, 2001). Yet, Canada's commitment to FSI, and the ICF, is strong in Canada.

An important aspect of this task is to get practitioners to buy into the new technologies that will make the electronic health plan possible, and the accumulation of functional status data practicable. Without their cooperation, an integrated and complete health information system will not be achievable. Practitioners, reasonably enough, will demand ICF-based measurement and assessment tools, which have to be developed. They will also need to be convinced that their clinical practice will benefit from the data collected and analyzed. Finally, they will need access to financial resources and expertise to support data collection. Across the system, the cost of development and implementation of a truly integrated and pan-Canadian EHR will obviously be substantial. Although these are small numbers by U.S. standards, there are still 800 hospitals with some 123,000 inpatient beds across the country, with more than 28,000 general medical practitioners and 27,000 specialists, with at least 15,000 therapists, and 9,000 pharmacists. That is a lot of data source-points.

The complexities of an electronic information system cannot be underestimated, and they present a fundamental challenge to implementation. Even in Canada's single-payer system, there is a multitude of

health care providers and service delivery models across the country that have to be integrated for informational purposes. The problem is complicated when more settings are added to the mix, such as long-term and in-home care settings (both of which are in current negotiations, and being considered for coverage under the Canada Health Act). Also, the location and stewardship of the data is a complex matter, given the geographic vastness of the country.

Many of these obstacles can be effectively eliminated by the coercive tactic of tying reimbursement to data collection, and demanding that health care providers fill in the electronic functional status fields on the patient's health record before being paid. Given the necessity of getting and keeping the cooperation of those individuals whose data input is the primary driver of a successful EHR, the heavy-handed approach may not be the best one. Instead, practitioners who are concerned about providing the best evidence-based care they can, who are interested in the health outcomes of their patients, and the effectiveness of their interventions, can be convinced of the clinical value of this health information. To convince them of this, ironically, may require evidence that, but for their cooperation, will not be easily available or, if available, reliable. But then, the proof of the value of any information system can only proceed from the data that that system will provide, and it can only do so when it is in place.

## CONCLUSION

A case has been made that Canada is well placed to be an innovator in creating and sustaining a pan-Canadian, integrated electronic health information system that connects all episodes of care with stan-

dardized data accessible to clinical and health management users and which incorporates FSI. The problems created by health data that is fragmented, incomplete, not easily shared, not analyzed to the fullest extent, and inaccessible, can only be solved by a centralized, integrative system of collecting and analyzing consistent and comparable health data, that links health determinants, interventions and outcomes. The need for such an informational system is recognized and the process has started to create it. Also recognized, at least in theory, is that FSI is the kind of information that is required to bridge data gaps, created by data fragmentation from the informational silos that discrete health care setting creates. The future for Canadian health information is promising, but the road to be traveled from vision to action, and then to outcome is filled with obstacles, some predicable others less so.

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