



Health Outcomes of Care:
An Idea Whose Time Has Come



Our Vision

Better data. Better decisions.
Healthier Canadians.

Our Mandate

To lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care.

Our Values

Respect, Integrity, Collaboration,
Excellence, Innovation

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About Statistics Canada

Statistics Canada is authorized under the *Statistics Act* to collect, compile, analyze, abstract and publish statistics related to the health and well-being of Canadians. It conducts surveys of Canadians and collects administrative data to understand the status of the nation's health, interactions of Canadians with the health system, direct measures of health, dynamics of health over time and health outcomes.

It informs Canadians through the analysis and dissemination of its data holdings. Statistics Canada publishes *Health Reports* monthly, a peer-reviewed and indexed journal of population health and health services research.

For more information, visit Statistics Canada's website at www.statcan.gc.ca.

About the Canadian Institute for Health Information

The Canadian Institute for Health Information (CIHI) collects and analyzes information on health and health care in Canada and makes it publicly available. Canada's federal, provincial and territorial governments created CIHI as a not-for-profit, independent organization dedicated to forging a common approach to Canadian health information. CIHI's goal: to provide timely, accurate and comparable information. CIHI's data and reports inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health.

For more information, visit our website at www.cihi.ca. As of April 1, 2012, the following individuals were members of CIHI's Board of Directors:

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Acknowledgements

Statistics Canada and CIHI would like to acknowledge and thank the many individuals who contributed to the development of this report. Particularly, we would like to express our appreciation to the members of the Expert Advisory Committee, who provided invaluable advice:

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Claudia Sanmartin of Statistics Canada was the primary author of this report and provided scientific leadership on the framework and case studies. Other researchers who also provided scientific leadership, as well as served on the editorial committee for this report, include Jillian Oderkirk (currently OECD) and Kira Leeb (CIHI).

The editorial committee from CIHI included Kira Leeb, Heather Dawson, Megan Mueller, Maureen Kelly, Patricia Sullivan-Taylor, Margaret Keresteci and Joanne Hader.

“We are only at the threshold of knowing about the usefulness of medical interventions.”

—Barbara Starfield, 2008¹

About This Report

This report is the second in a series focused on health outcomes of care jointly produced by Statistics Canada and the Canadian Institute for Health Information (CIHI). In the first report, *A Framework for Health Outcomes Analysis*, we explored the feasibility of conducting health outcomes analyses using existing data, with a specific focus on diabetes and depression.² The analysis was guided by the Health Outcomes Conceptual Framework, which places health outcomes within the context of the care path experienced by patients as well as important patient and health system factors hypothesized to be associated with health outcomes of care. Among the key highlights of this first report was the recognition that reporting and understanding health outcomes from a population perspective is important to better understand what care works best for whom. Results of the analytical work conducted in the areas of depression and diabetes clearly demonstrated that existing data sources are very limited in their ability to provide information regarding health outcomes of care. Despite best efforts to use existing survey, administrative and clinical registry data in the most extensive ways, clear data gaps continue to exist at the pan-Canadian level. Specifically, there is a lack of standard, comprehensive and repeated measures of health status at the population level as well as of comprehensive information regarding the full spectrum of health care services received that would follow an individual along the continuum of care received and resulting outcomes.

This report represents the next phase of work conducted by Statistics Canada and CIHI and focuses on options for data development/enhancement to fill the information gaps in health outcomes of care. It begins with highlights of existing Canadian and international examples and initiatives currently under way to collect and report on health outcomes of care for a wide range of health care interventions. The case studies, along with learnings from the published literature, are used to identify and inform data development possibilities in Canada. The report concludes with an exploration of issues and options for moving forward with data collection opportunities for health outcomes information in Canada, drawing on key messages and learnings from existing initiatives and the views of experts and participants who attended a conference on health outcomes sponsored by CIHI and Statistics Canada.

Executive Summary

Despite ever-increasing investments in health care, we know very little in Canada about what we are getting in return for these investments—namely, gains in *health status*. After all, the ultimate goal of a health care system is to produce *health*, not just services. While there have been significant information gains in terms of knowing more about the processes of care and selected outcomes (for example, mortality and readmissions), less is known about the health outcomes of care at a population level.

Health Outcomes—The Time Has Come

Now is the right time to start to focus on *health outcomes* of care. With health care systems around the world facing increased demands and limited resources, there has been a growing interest in measuring and monitoring *health outcomes* of care to ensure that resources are focused on areas where maximum health gains can be achieved. This growing interest has been supported in part by developments in several key areas, including an increased focus on the views and experiences of patients regarding their outcomes of care, developments in instrumentation and data collection and the experiences of those who have already started to focus on health outcomes to improve patient care and performance reporting.

There is general agreement that administrative and clinical data does not provide the necessary information required to provide the full picture related to health outcomes and was not developed with that specific purpose in mind. Increasingly, decision-makers are seeking information from patients themselves. The focus on patient-reported outcomes (PROs) and, by extension, patient-reported outcome measures (PROMs) has proliferated over the last few years, particularly in places like England, where the regular collection of PROMs for selected elective surgical procedures was recently initiated. PROs sprung out of clinical trial research, where there was a general recognition of the need to provide more subjective measures of outcomes to complement the more clinical or biological measures. This represents a shift from a biomedical model of research, which emphasizes diagnoses and clinical-specific outcomes, to a health outcomes model approach that emphasizes life expectancy and health-related quality of life based on the use of PROMs. This approach is intended to complement the more clinically oriented outcomes, such as adverse events (for example, complications and readmissions) and survival.

There have been significant developments in the instrumentation and technology used to capture health outcomes information, making it more feasible and efficient to collect this data. Health outcomes are commonly assessed using generic health-related quality-of-life (HRQL) measures, such as the EuroQol EQ-5D™, the 36-Item Short Form Health Survey (SF-36) and the Health Utilities Index (HUI), which capture information in several areas, including physical, social and mental health. There has also been an explosion of disease-specific measures that are more sensitive to changes in the intended domains (such as pain and function). In most cases, collecting information directly from patients is often costly and time-consuming. However, improvements in information technology and the proliferation of ePRO devices—such as

interactive voice response, computer touch screens, hand-held computer devices, tablets, mobile phones and web-based applications—have enhanced our capacity to collect health outcomes information in an efficient and effective manner.

There have been significant advances in the collection and reporting of health outcomes data in key jurisdictions in Canada and internationally. Several case studies are presented in this report that highlight the collection and use of health outcomes information at the clinical, administrative and policy levels. For example, health outcomes information is currently being collected on lung and heart transplant patients in Edmonton, on knee and hip replacement patients in Manitoba and Alberta, and on surgical patients in Saskatchewan. This data is used by clinicians to improve patient care, by administrators to monitor system performance and by policy-makers to monitor health gains and ensure that the most appropriate patients are receiving care. Similarly, health outcomes information is routinely collected on residents in continuing care facilities via CIHI's Continuing Care Reporting System (CCRS). Routine data collected by health care providers using the Resident Assessment Instrument (RAI) system is used to monitor individual patient progress as well as to produce routine reports at the institution and system levels for performance monitoring. There are also several examples of health outcomes reporting from the United States and England. Currently, NHS hospitals in England routinely collect health outcomes information on all patients undergoing four key surgical procedures.

Health Outcomes—Moving Forward in Canada

Issues and options for moving forward with data collection opportunities for health outcomes information in Canada were explored based on international learnings and the views of experts and participants who attended the 2010 Data Users Conference. The conference, sponsored by CIHI and Statistics Canada, focused on health outcomes.

There are several ways in which national organizations such as Statistics Canada and CIHI can engage (or be engaged) to move this agenda forward, including providing support in the selection of health outcomes measures, working with stakeholders to develop standardized data collection approaches and supporting the development of standard performance indicators in the area of health outcomes.

While there are pockets of innovation across this country, there are currently no pan-Canadian initiatives to collect health outcomes information across a broad range of health care sectors. Moving forward requires the collection of data that reflects well-defined, standardized measures of health outcomes useful to a range of stakeholders to influence processes of care at all levels. Through collaborative efforts, the information needs of the health care system in Canada can be assessed and addressed.

Introduction

The goal of a health care delivery system is to improve and maintain the health and well-being of the populations it serves. In Canada, we continue to make ever-increasing investments in the health care system but generally lack adequate information to know whether we are achieving this goal.³ There is now increasing awareness that we need better information to assess the effectiveness of health care interventions; particularly in an era of resource constraints, this information is vital. Limited resources need to be more focused on interventions that have a positive impact on the health and well-being of the maximum number of Canadians possible.^{4–6}

Information on health outcomes provides an evidence base to evaluate the extent to which the system is achieving the ultimate goal of improved population health. Health outcomes—that is, changes in health status as a result of health care interventions—reflect a comprehensive approach that can be applied to all those who receive health care services. While we continue to collect information about and report on inputs to the health care system, there is little information regarding the health outcomes of these investments beyond information about survival or from clinical trial settings.

In Canada, we have relatively good information regarding key inputs to the system, including how much we spend and in which sectors. Health care spending in Canada is estimated to have been \$200.5 billion, or 11.6% of gross domestic product (GDP), in 2011; this represents an estimated 4.0% growth over expenditures in 2010. While hospitals represented the largest component of health care expenditures, at 29.1%, the second-largest segment continued to be pharmaceuticals, whose share of expenditures was estimated to be a stable 16.2% in 2011.⁷ Population health surveys in Canada provide useful information on the health of the overall population, but we cannot link this information to health expenditures. Hence, at this time, we cannot measure how much *health* we are buying. This severely limits what we can say about the value we are getting for monies spent on health care.³

We also have relatively good information on the supply of providers and services. From professional registries, we know the supply of physicians, nurses and allied health professionals.^{8–10} From administrative data, we know hospitalization and emergency department visit rates and the number of various health care procedures and interventions provided on an annual basis in acute and ambulatory care settings. For some procedures, we know what the rates are at the national, provincial and health region levels.¹¹

We are starting to develop better information on the processes of care and, in some instances, outcomes of care. CIHI, for example, has developed longitudinal clinical and administrative databases in the areas of rehabilitation, home and continuing care, and specialized services such as organ transplant. These databases were designed to track not only the processes of care at the patient level but also a range of health outcomes measures related to their specific populations.

Information from hospital and physician administrative data and survey data provides insights regarding individuals receiving care and whether or not they are experiencing difficulties in accessing that care. In various provinces, disease-specific registries are being developed to

identify and track the care of individuals with selected chronic conditions. Data from diabetes care registries, for example, provides information regarding the proportion of patients who are receiving recommended care, such as glucose tests.¹²

We continue to develop good information on a few key indicators of specific outcomes of care, such as hospital readmission and death. The Health Indicators project, developed jointly by Statistics Canada and CIHI, for example, provides valuable information regarding selected outcomes of care, including readmission and 30-day mortality for heart attack and stroke patients admitted to hospital. While this type of information is critical to our understanding of the outcomes of care, these measures tend to focus on the most serious event—death—reflecting the *poorest* of health outcomes, which often affects a minority of patients. The data, therefore, is limited, since it does not address the outcomes of the majority of the patient population.

While there is little information regarding health outcomes for the *majority* of patients, we know, from small-scale clinical studies, that not all patients are restored to optimal levels of health.^{13–16} However, this evidence is not always generalizable to the larger patient population. In some cases, for example, we do not know whether the intended impact of the treatment was achieved from either the provider's or, more importantly, the patient's perspective. Nor do we know the percentage of patients who were restored to expected levels of health. We need population-based information on health outcomes of care using meaningful metrics and indicators to address these information gaps.

Now is the right time to consider options for data development for health outcomes, for several reasons. First, there is general agreement that administrative and clinical data does not yield the necessary information required to provide the full picture related to health outcomes and was not developed with that specific purpose in mind. Comprehensive information about health outcomes is not likely to be generated from the majority of existing data sources, as these require more extensive information from patient assessments that is currently not captured, with the exception of a few specific data sources (such as CIHI's Continuing Care and Home Care reporting systems). Increasingly, decision-makers are seeking information from patients themselves.¹⁷

Second, there have been significant developments and improvements in the instrumentation of health status measures required to collect health outcomes information across a diverse patient population. There has been a proliferation of health status measures applicable to a broad range of conditions and interventions. Third, there have been significant advancements in information technology to facilitate the collection of health outcomes information. Furthermore, since other countries—like the United Kingdom—are more advanced in the collection and reporting of health outcomes, Canada can learn from their experiences.

In this report, we briefly explore current trends that have contributed to the momentum, making this a good time to discuss the data gaps related to health outcomes of care. We then highlight various initiatives currently under way in Canada and abroad—initiatives that focus on the collection and use of health outcomes information. Finally, the report concludes with an exploration of issues and options for moving forward with data collection opportunities for health outcomes information in Canada.

Health Outcomes—Now Is the Right Time

“Outcomes management is a technology of patient experience designed to help patients, payers and providers make rational medical care-related choices . . . ”

—Paul Ellwood, 1988¹⁸

In the past, focus was on providing the necessary care. Few stopped to ask, “Did that intervention actually improve the health of the patient?” Recent interest in health outcomes of care is partially the result of a shift in thinking. This shift reflects an increased awareness of the need for better information on the effectiveness of care, the role of health outcomes and the unique contributions that patients can make in providing this information. In addition, significant improvements in data collection instruments and technologies have greatly enhanced our ability to obtain this information at the population level.

Outcomes Movement

The increasing recognition of the value of health outcomes information is an extension of a broader movement in health care. This movement was largely driven by the need to know, not just the volume of services delivered, but the quality of care received. This is coupled with a growing need to control escalating health care costs and a desire to focus health care resources on the most effective treatments. In an era of cost constraints, can we really afford to dispense variably expensive therapies without evidence of their effectiveness at the population level?

Concerns about outcomes of care were further magnified following groundbreaking work on small-area variations in the use of health care services in the United States. Many believed that once adjustments were made for differences—such as age and gender—across populations, rates of health care utilization should be relatively uniform across geographic regions. However, this was not the case for many common surgical procedures, such as hysterectomies and hernia repairs, which exhibited significant variation across geographic areas with no appreciable differences in the health of these populations; this led most to conclude that more care is not necessarily better.^{19–21} Variations in health care services have also been noted in Canada. For example, large variations across health regions have been reported for heart attack treatment, joint replacement and Caesarean sections.^{11, 22}

Defining Health Outcomes of Care

Health outcomes are defined as changes in health status that occur as a result of a health care intervention. In most cases, these are patient-reported measures, often referred to as patient-reported outcomes or PROMs.

Health outcomes represent one of many outcomes of care for patients, which can be categorized as follows:

- Health outcomes—change in health status;
- Health-related outcomes—proxy measures of post-intervention health status such as adverse events (for example, readmission and infection rates); and
- Non-health related outcomes—information collected from patients, such as on satisfaction.

Source

Statistics Canada and Canadian Institute for Health Information. *A Framework for Health Outcomes Analysis*. Ottawa, ON: CIHI; 2008.

Patient-Reported Outcomes and Measures

Interest in health outcomes is partially a result of a larger, more specific movement toward patient-reported outcomes (PROs) and the use of patient-reported outcome measures (PROMs). PROs are defined as “. . . direct subjective assessment(s) by the patient of elements of their health including: symptoms, function, well-being, health related quality of life, perceptions of treatment, [and] satisfaction with care received . . .”²³ Simply stated, PROs are measures of any aspect of health that come directly from patients²⁴ and reflect a growing acknowledgement of the need to capture the patient’s perspective. There are a broad range of PROMs available to capture the patient’s experience with care.

PROs sprung out of clinical trial research, where there was a general recognition of the need to provide more subjective measures of outcomes to complement the more clinical or biological measures. This represents a shift from a biomedical model of research, which emphasizes diagnoses and clinical-specific outcomes, to a health outcomes model approach that emphasizes life expectancy and health-related quality of life based on the use of PROMs. This approach is intended to complement the more clinically oriented outcomes, such as adverse events and survival.^{25, 26}

The rise of PROs and use of PROMs in clinical trials was partially accelerated as a result of regulatory requirements for evidence of patient-reported outcomes for new therapeutics.²⁵ The United States provides an interesting example: in the U.S., the Food and Drug Administration requires evidence to support any claims made on drug and medical product labels.²⁷ Necessary evidence includes the patient’s perspective of treatment benefits, such as symptom relief, the ability to carry out daily activities and improvements in quality of life.

Increasingly, decision-makers are turning to PROMs to provide evidence of the effects of health care interventions administered to a wide range of patients and delivered in diverse and complex real-world environments. In the U.K., a review of the National Health Service (NHS) led to the expansion of performance indicators focusing on PROMs to collect information on health outcomes of care, which is part of a larger effort toward continuous quality improvement at the system level.^{28, 29} In the U.S., population-based data is being linked in innovative ways to bring together health status and clinical information to assess the health outcomes of patients enrolled in various health care plans (see the section Evaluating Cancer Care—Surveillance, Epidemiology and End Results).

Advances in Measurement and Technology

The collection of health outcomes information has been enhanced by advancements in PROMs, including health status measures, and technologies for data collection.³⁰ To elaborate, health outcomes are commonly assessed using generic health-related quality of life (HRQL) measures that capture information in several areas, including physical, social and mental health, as well as disease-specific measures, which are more sensitive to changes in the intended domains (such as pain and function).

Several HRQL tools have been developed, including the HUI,^{31, 32} the SF-36 and the 12-Item Short Form Health Survey (SF-12),^{33–35} and the EuroQol EQ-5D.³⁶ These tools have been used with a broad range of patients, including those with chronic diseases such as diabetes,³⁷ chronic obstructive pulmonary disease,^{38, 39} multiple sclerosis^{40, 41} and arthritis,⁴² as well as among various surgical groups.^{43–45} The same instruments can be administered to different patient populations, and information can be provided by patients at several points in the care path (such as before and after treatment) to detect changes in health status over time.

The proliferation of health status measures has led to the development of various databases. For example, the Patient-Reported Outcome and Quality of Life Instruments Database was established by the MAPI Research Trust in France to provide information on HRQL instruments available via the web.^{46, 47} Similarly, the Patient-Reported Outcomes Measurement Information System was developed by researchers at the National Institutes of Health in the U.S. to serve as a comprehensive bank of PRO items in five key areas: physical function, fatigue, pain, emotional distress and social/role participation.^{48, 49} This project was not simply a research exercise but was supported and funded by a significant investment made by the U.S. Department of Health and Human Services, reflecting the department's commitment to collect and use health outcomes information.⁵⁰

In many cases, health outcomes information is not routinely collected due to a lack of time, information infrastructure, personnel and resources.⁵¹ However, improvements in information technology and availability of ePRO devices—such as interactive voice response, computer touch screens, hand-held computer devices, tablets, mobile phones and web-based applications—have enhanced our capacity to collect health outcomes information in an efficient and effective manner.^{52, 53} The use of tablet computers, for example, has been shown to be a valid, feasible and acceptable method of collecting patient-reported outcomes data in oncology clinics.⁵⁴

Collecting Health Outcomes Information— Exploring Current Initiatives

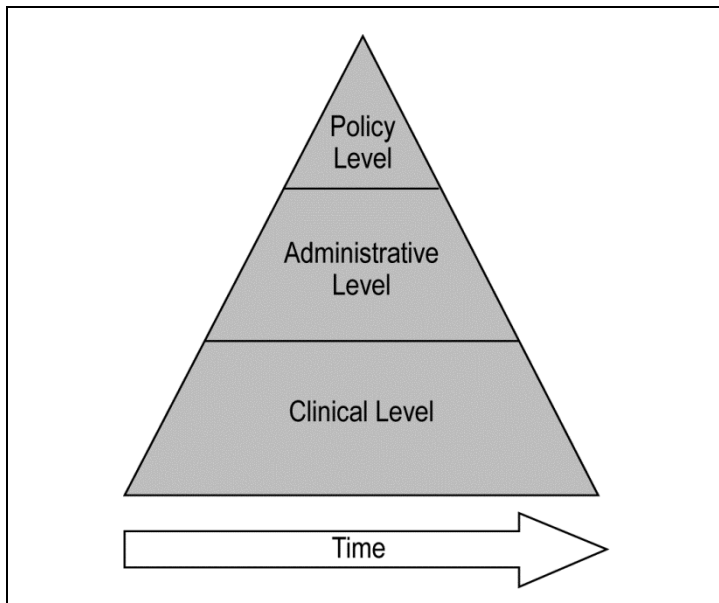
“An outcomes approach requires more than simply collecting data on the outcomes of care. It should be thought of in terms of an outcomes information system.”⁵⁵

Conceptual Framework

Health outcomes information can be collected at various levels for a range of different purposes, from clinical to policy-making. As such, the notion of an integrated health information system is worth exploring as a framework for discussing current and future health outcomes data collection strategies. This approach helps bridge the gap between the needs of clinicians to better manage patient care and the needs of managers and policy-makers to better inform decision-making at all levels of care.^{56, 57}

The information pyramid is commonly used to illustrate the hierarchical nature of an integrated information system (Figure 1). It is based on the notion that the proper kinds of health information systems can function to improve patient care, to support effective management of service delivery and to provide the foundation for effective performance monitoring.^{56, 57} The model applies to the collection of various types of information needed to inform and improve a range of dimensions of care delivery, including effectiveness of care.

Figure 1: Information Pyramid—Integrated Health Outcomes Information



Sources

Adapted from
Wolfson M, Alvarez R. Towards integrated and coherent health information systems for performance monitoring: the Canadian experience. In: Smith PC, ed. *Measuring Up: Improving Health System Performance in OECD Countries*. Paris, France: Organisation for Economic Co-operation and Development; 2002.
Dr. Cy Frank, personal communication, 2008.

The pyramid underscores the need for health outcomes information at several levels, including the clinical, administrative and policy levels. In an ideal information system, health outcomes data would be routinely collected at the clinical level and used by health care providers to manage individual patient care. This data could then be aggregated to create key performance indicators to support decision-making at the administrative level and to create composite performance indicators at the policy level.^{56, 57}

Time is a factor; the effects of health interventions on health status can be detected only over time. These effects may be observable over a short period of time among patients—changes, for example, in health status of patients soon after surgery. Alternatively, changes may be detected over the longer term. For example, improvements in overall health status may be detected in patient populations with chronic conditions following the introduction of integrated chronic disease management programs.⁵⁷

The information pyramid applies to the full spectrum of health care services and incorporates health outcomes measures at all points during patients' care. The information is grounded in the use of clinically validated measures of health status. The points of measurement should reflect anticipated changes in health status. In the case of elective surgical procedures, for example, pre- and post-operative measures of health status may suffice to determine the health outcomes of care. However, ongoing monitoring may be required to detect changes in health outcomes among those with chronic conditions, such as diabetes.

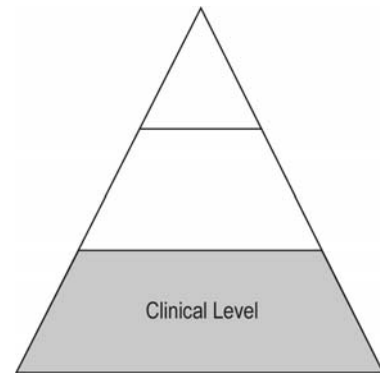
Health outcomes information must be linked to details regarding the care path as well as to the broader determinants of health, such as lifestyle and socio-economic status. This comprehensive approach is reflected in the Health Outcomes Conceptual Framework developed by Statistics Canada and CIHI.² While information may not be required in all areas of health care delivery, the collection of health outcomes information should focus, at a minimum, on high-volume interventions.

In the following section, we use the information pyramid to organize information on existing initiatives for health outcomes data collection, from both Canada and abroad. These cases illustrate the routine collection of health outcomes information; they show how this leads to quality improvement at the clinical level, performance reporting at the institutional and program levels, and planning at the policy level.

Clinical Level

Patient Care

There are several ways in which patients and providers benefit from collecting health outcomes information. At the clinical level, the availability of outcomes data enhances clinicians' capacity to monitor the effectiveness of the care provided. Recent reviews of the role of PROs in clinical practice found that the use of an HRQL measure by patients prior to the clinical encounter had positive effects, including on clinicians' ability to diagnose poor mental health.^{58–60}



Repeated measures of health status, using general HRQL and disease-specific measures before and after treatment, can provide clinicians with a patient-focused outcomes assessment. The use of HRQL measures also provides health care professionals with a more comprehensive assessment of the health benefits of care. General HRQL measures capture information on multiple dimensions of health, including physical, mental and social dimensions. This information can serve to detect physical and/or mental problems that might otherwise have been missed or to detect health benefits of treatment not otherwise anticipated.^{59–61} For example, joint replacement surgery is performed to alleviate pain and improve function; there may also be mental health and social benefits to these outcomes that could be detected using a general HRQL measure. Information derived from health outcomes measures can be used to guide management decisions and, ultimately, to better predict and treat chronic disease.⁶²

The use of health outcomes measures can also foster communication between patients and providers and, as a result, facilitate shared decision-making. The use of HRQL measures in routine clinical oncology practices, for example, was found to improve patient–physician communication. It also improved providers' awareness of their patients' overall health status. Providers who routinely used HRQL measures were more aware of their patients' health problems and were more likely to discuss these problems with their patients. Both patients and providers agreed that the use of routinely collected health outcomes information improved communication.^{63, 64}

Health Outcomes to Improve Patient Care—Three Canadian Examples

There are three Canadian success stories where using health outcomes information improved clinical practices. In **Edmonton**, a pilot project that incorporated health outcomes information sought specifically to improve the care of heart and lung transplant patients (see Box 1). Similarly, orthopedic surgeons in **Manitoba** use pre- and post-operative measures of HRQL and disease-specific measures developed for hip and joint replacement patients to assess the outcomes of their patients. The measures are used to detect changes in overall health and, specifically, functional health and pain (see Box 2).

Box 1: Health Outcomes Information to Improve Patient Care: Heart and Lung Transplant Patients, Edmonton, Alberta

In the outpatient Heart and Lung Transplant Clinic at Edmonton's University of Alberta Hospital, Dr. Maria Santana led a pilot project to introduce health outcomes information to the care of transplant patients. The goal of the project was to collect and use HRQL information for the care of patients, before and after surgery. Dr. Santana observed that while HRQL measures were widely used in clinical trials, this information was not used for the routine care of patients following transplant. The primary objective of the pilot project was to assess the feasibility of including HRQL measures in routine patient care and training clinicians to use this information.

Collection of Information

Pre-operative health information was collected when a patient was placed on the transplant list. Post-operative information was collected each time the patient attended the clinic. At every visit, the patient completed the Health Utility Index Mark 2 (HUI2) and Mark 3 (HUI3) using a touch screen while he or she waited to see the clinical team. Once the information was entered, the HUI score was graphically presented, printed, added to the patient's medical file; the clinical team then reviewed the information before examining the patient. The patient's medical file contained all previous HUI data, so clinicians could readily assess the patient's health outcomes over time.

Results

The project received positive responses from both patients and providers. Patients felt that they received more attention and had more material to discuss with the clinicians. Clinicians, in turn, felt that the availability of HRQL information allowed them to identify health problems that may not have been a result of the transplant but were still relevant.

In one case, a patient who seemed distant and non-responsive following surgery was believed to have suffered cognitively as a result of the transplant. A low score in the hearing component of the HUI alerted clinicians to the fact that this reaction was, in fact, due to a severe hearing impairment.

Following the pilot project, routine collection of health outcomes information was subsequently incorporated in the clinic on a routine basis.

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Santana, MJ. Using the Health Utilities Index in routine clinical care: process, feasibility, and acceptability: a randomized controlled trial. *The Patient: Patient-Centered Outcomes Research*. 2009;2(3):159–167.

Personal communication with Dr. Maria Santana.

Box 2: Health Outcomes Information to Improve Patient Care: Hip and Knee Replacements in Manitoba

Dr. Eric Bohm is an orthopedic surgeon in Winnipeg, Manitoba. He is a clinician, chair of the Regional Orthopedic Standards Committee and co-chair of the Canadian Joint Replacement Registry (CJRR). Health outcomes information is vital to his job.

Most joint replacement patients in Manitoba are asked to complete both a general HRQL measure (SF-12) and joint-specific measures (WOMAC and Oxford scores). This happens twice: before surgery at the pre-admission clinic, and one year after surgery as part of the post-op consultation. Health outcomes information represents only one of several outcome measures collected for each patient; others include complications, dislocations, pulmonary embolisms and infections.

At the clinical level, HRQL information is used to both manage patient care prior to surgery and assess health outcomes following surgery. Pre-operative HRQL information is summarized and added to the patient's medical file prior to the patient encounter. To better manage patient care, this information is used by surgeons like Dr. Bohm during the pre-operative consultation process to supplement information from both the patient interview and physical exam. It is also used by the pre-habilitation team to determine what (if any) pre-operative interventions are required to optimize patients for surgery. Following surgery, HRQL information is utilized to assess overall health outcomes and to better understand the specific outcomes of surgery from the patient's perspective.

At the regional level, the data is rolled up and aggregated across surgeons to generate regular reports for the Standards Committee and the Manitoba Orthopedic Society. Summary reports provide information on the general characteristics of the patient population and a suite of surgical outcomes, including changes in health status. The data is also used to generate surgeon-specific reports for comparative purposes. The provision of information at the surgeon level has revealed significant variations in outcomes of care. This information serves as an education tool; less-experienced physicians can learn from more-experienced, higher-performing physicians. Dr. Bohm firmly believes that this type of information will lead to better outcomes for all patients.

Source

Personal communication with Dr. Eric Bohm.

In **Toronto**, rheumatology patients use their in-office wait time to enter information about their general health status on computers located in the waiting room. This Electronic Rheumatology (eRheum) Initiatives Research Program integrates the electronic capture and reporting of patient self-reported data into rheumatology care delivery. Patients complete an HRQL measure (such as the SF-36 questionnaire) and a rheumatology-specific tool, the Health Assessment Questionnaire, which focuses on activities of daily living. A printout of the results is provided to the clinician prior to the clinical encounter. This vital information, which includes both the current health status as well as historical measures, is used by the rheumatologists to guide the clinical encounter to improve the quality of patient care.⁶⁵

Patients involved in this initiative can also provide health status information prior to arrival and between visits. Patients are sent emails prior to their rheumatology appointments reminding them to complete the health measures. Patients can access the system in a protected and secure

manner using assigned identification numbers and passwords. A joint project initiated by the clinic with a private-sector medical alert company resulted in the development of a web-based application that allows rheumatology patients to complete the health status measures online.⁶⁵

This Toronto initiative is unique in that it is all-inclusive: it provides health outcomes information for all patients, not just those who experience bad or adverse outcomes (such as adverse drug reactions), which are traditionally collected.

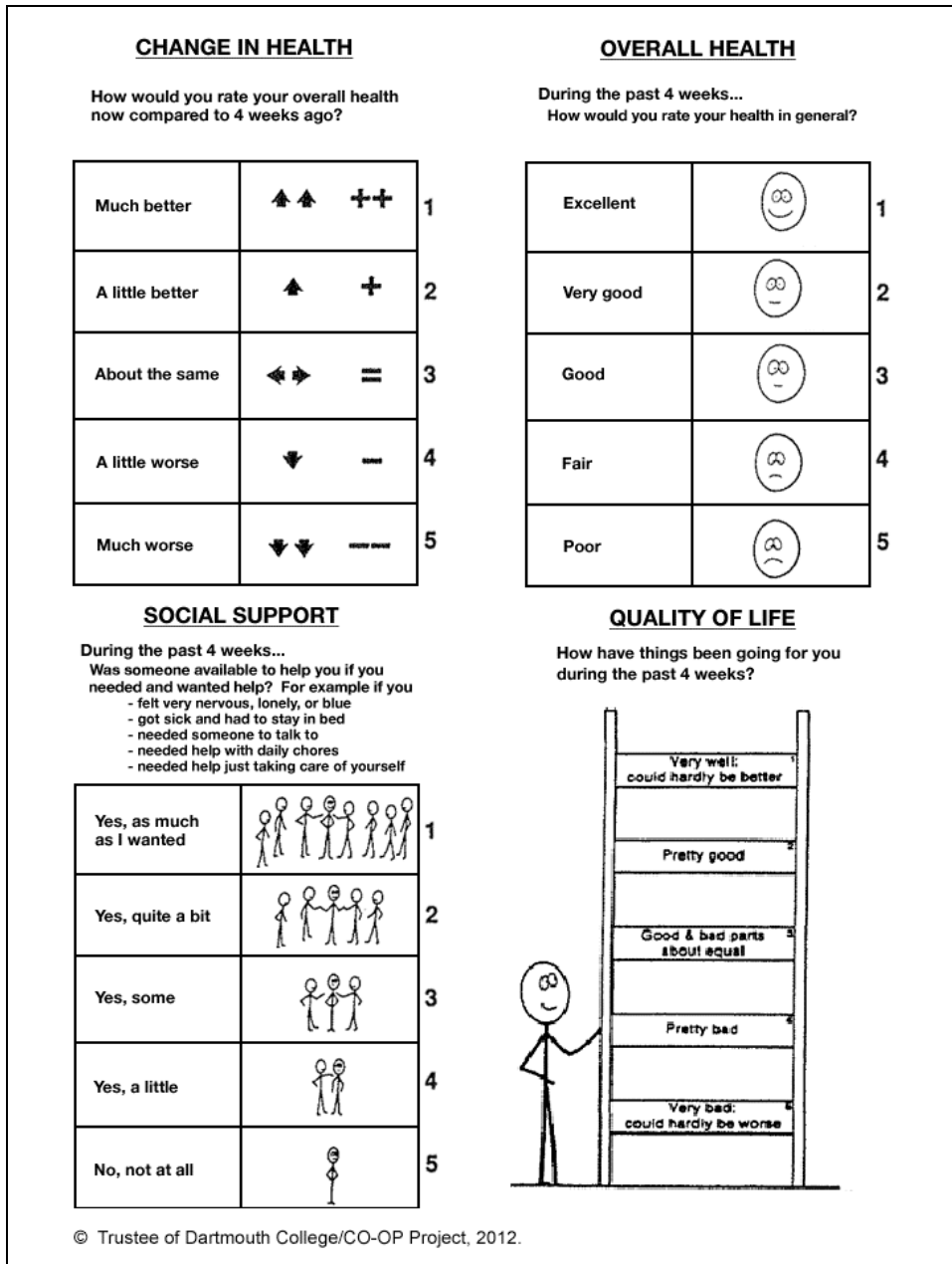
The electronic collection of health outcomes information also provides an opportunity to collect population-level information for the post-market surveillance of pharmaceuticals and biologics. Through the Ontario Biologics Research Initiative (OBRI), researchers can link patient-reported health outcomes information with administrative and clinical data to monitor patients over time, for a maximum of 60 months. The OBRI can also provide comprehensive post-marketing information on biologics used to treat rheumatology patients. This initiative is supported, in part, by the Ontario Ministry of Health and Long-Term Care's Drug Innovation Fund.⁶⁶

Clinical Practice

At the clinical level, health outcomes information can be used to assess and improve the overall quality of care provided at the unit level. Information derived from health outcomes measures can be used to guide management decisions and, ultimately, to better predict and treat conditions such as chronic disease.⁶²

In the Dartmouth CO-OP Project at the Geisel School of Medicine at Dartmouth (Hanover, New Hampshire, U.S.), for example, primary care practitioners use the CO-OP Functional Health Assessment Charts to monitor health status changes in their patients. The CO-OP charts provide a practical, user-friendly way for patients to assess multiple dimensions of health—physical and emotional health, daily and social activities, social support, pain, etc. (see Figure 2)⁶⁷ Information derived from the charts is used in two important ways: to immediately improve patient care during the clinical visit and to improve the overall design and delivery of services for future patients.⁶⁷

Figure 2: Examples of CO-OP Functional Health Assessment Charts



Source

Dartmouth CO-OP Project. <http://www.dartmouthcoopproject.org/>. Accessed March 23, 2012.

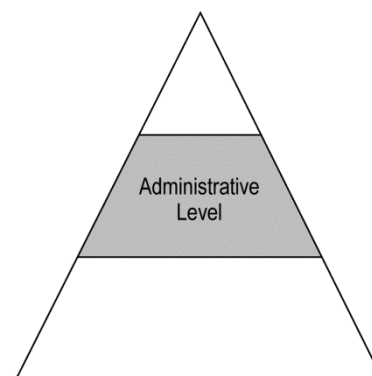
The information in the CO-OP charts plays a critical role in overall quality improvement efforts at the clinical level. The larger goal is to deliver services and to use measures that match local customers' needs. This approach places measurement of patient values, clinical improvement strategies and research objectives into day-to-day health care delivery. The health outcomes information derived from the CO-OP tool is used to measure and monitor patient needs and

to detect positive (or negative) changes as a result of improvements made to the delivery of clinical services.⁶⁷

At the Duke University Medical Center, electronic patient-reported outcomes (ePROs) are an integral part of the rapid-learning health care approach adopted by oncology units. Rapid-learning health care models represent a new infrastructure to support comparative effectiveness research. This approach involves integrating various databases (clinical, administrative and research) through health information technology and using sophisticated iterative analysis to assess the real-time impact of medical interventions and apply the most up-to-date evidence for individual patient care. ePROs are collected from cancer patients prior to the clinical encounter at the site of care using electronic tablets. The ePRO is linked with other patient-level information provided in medical records and administrative data. While still new, this approach has been shown to address key issues facing cancer patients, such as the high rate of depression and the need for psychological support and care. Researchers and clinicians plan to continue the development of the rapid-learning oncology unit to ensure scalability and portability to other clinical areas.⁶⁸

Administrative Level

At the administrative level, health outcomes information can be used to produce key performance measures and indicators to support decision-making. Data collected at the clinic level may be aggregated to provide institution-level information to populate performance indicators, such as on effectiveness of care. Alternatively, data may be collected outside the clinic setting. For example, patient surveys can be used to collect health status and related information before and after medical interventions. This is possible in the case of elective surgical procedures, where patients are surveyed pre- and post-operatively to determine post-operative health outcomes.



In British Columbia, one of the first population-based studies of health outcomes of care was conducted among patients undergoing high-volume surgical procedures in several Vancouver hospitals in early 2000. Patients reported their HRQL before and after surgery using the SF-36 as well as disease-specific health status measures. The results of the study revealed that while most patients experienced markedly improved HRQL following the surgical procedures, between 2% and 26% of patients experienced no changes or declines in their HRQL following treatment. (One interesting note is that this study demonstrated that while collecting outcome information was feasible, it was not popular with all surgeons.)¹³

Additional examples include a pilot project carried out at the Alberta Bone and Joint Health Institute in 2007 to evaluate effectiveness of care using health status information collected before and after surgery (see Box 3), as well as the Saskatchewan Ministry of Health's work on mapping care pathways for surgical patients (see Box 4).

Box 3: Health Outcomes Information at the Administrative Level: Alberta Bone and Joint Health Institute

In 2007, Dr. Cy Frank led the Hip and Knee Replacement Pilot Project to improve the delivery of joint replacement surgery in Alberta. Health outcomes information was collected to evaluate one of the key domains of quality care—effectiveness.

The information strategy was designed based on a Measurement Framework, which focuses on the evaluation of health care services along the continuum of care and is based on the collection of key data elements in a consistent and standardized manner.

Health outcomes information was used to assess the effectiveness of the new continuum of care model versus the more conventional approach. Both a general HRQL measure (SF-36) and a disease-specific measure (WOMAC) were used to collect health status information from patients before and after surgery. Comprehensive patient information—including demographic, socio-economic, risk factor and comorbidity information—was also collected to ensure adequate risk adjustment.

Results indicated that, overall, patients who underwent joint replacement surgery in the new model experienced “even greater increase in physical and social function and pain reduction” compared with patients who underwent care using the traditional delivery model.

Source

Alberta Bone and Joint Health Institute. *Alberta Hip and Knee Replacement Pilot Project—Scientific Evaluation Report*. Edmonton, AB: Alberta Bone and Joint Health Institute; 2007.

Box 4: Health Outcomes Information at the Administrative Level: Surgical Care in Saskatchewan

In an effort to streamline access to care, the Ministry of Health in Saskatchewan has worked with specialty groups to map out the care pathway for patients undergoing a range of elective surgical procedures, including joint replacement and bariatric surgery. Ministry officials have determined that while it is important to understand and standardize the patient's care path, information is also required to better understand the changes in patients' health status along this path. In particular, it is important to determine whether or not patients' health status has improved as a result of the health care services they have received.

In Saskatchewan, all patients undergoing elective surgery will be required to complete the EQ-5D, a general HRQL measure, at the following four key points in the care path:

- 1) At the initial admission to the clinic;
- 2) At the pre-operative assessment in the clinic;
- 3) At three months after surgery; and
- 4) At one year after surgery.

The EQ-5D provides a simple generic measure of health for clinical and economic appraisal and is used for benchmarking pre- and post-operative measures of health status.

Health outcomes data derived from the EQ-5D is used to track patient progress during the care path to assess effective change in health over time. Ministry officials are using the data to identify patients who do and do not improve in terms of health status during the course of care, and they plan to explore these findings by linking results with other patient variables to help better understand patient outcomes.

Source

Saskatchewan Ministry of Health. *Measuring Patient Outcomes*. Paper presented at: Data Users Conference; September 2010; Ottawa, ON.

Health Outcomes Survey (United States)

In the U.S., health outcomes information is routinely collected to evaluate the performance of managed care programs for Medicare enrollees. The Health Outcomes Survey (HOS) was established in 1996 by the Centers for Medicare and Medicaid Services (CMS). The aim of this survey is to provide outcomes data to monitor the performance of programs that provide services to Medicare enrollees. The ultimate goal is to examine the overall effectiveness of programs. This represents the first—and currently only—national survey to collect patient-reported outcomes from Medicare beneficiaries.⁶⁹

While there have been several versions of the HOS over the years, the most recent version comprises several key components, including the Veterans RAND 12 Item Health Surveyⁱ (VR-12)⁷⁰ and patient characteristics for case-mix risk-adjustment.⁷¹ The HOS is conducted annually on a different baseline cohort of Medicare enrollees. These individuals are randomly selected from participating managed care programs that have a minimum enrollment of 500 individuals. Information is collected via a mailed survey administered at baseline and again after two years. Telephone contacts are made to increase the response rate.^{71, 72}

Table 1: Sample Report of Health Outcomes Across Managed Care Programs

Physical Health Performance Measurement Results for all MAOs in the State, StateXX, and HOS Total				
	Percent Better*	Percent Same*	Percent Worse*	Performance Results**
HXXXXA	15.1%	49.9%	35.0%	↓
HXXXXB	16.9%	48.0%	35.0%	↔
HXXXXC	17.3%	48.8%	33.9%	↔
HXXXXD	16.5%	49.3%	34.3%	↔
HXXXXE	17.1%	49.0%	33.9%	↔
StateXX	17.1%	49.3%	33.5%	
HOS Total	17.2%	49.5%	33.3%	

Notes

* The percent better, same, or worse refers to beneficiary health status within an MAO.

** The statistical significance of the performance result for the MAO is indicated by one of the following symbols:

↑ MAO performed significantly better than expected (higher than the national average)

↓ MAO performed significantly worse than expected (lower than the national average)

↔ MAO performed as expected (the same as the national average)

Source

Centers for Medicare and Medicaid Services and Health Services Advisory Group. *Medicare Health Outcomes Survey Sample MAO Report*. Baltimore, U.S.: Centers for Medicare and Medicaid Services; 2010. <http://www.hosonline.org/>. Accessed March 23, 2012.

Currently, health outcomes information is used to populate key Health Plan Employer Data and Information Set effectiveness indicators. At the federal level, the CMS—the primary payer for services for Medicare enrollees—uses the HOS data to monitor planned performance, reward top-performing plans and inform agency programs and priorities. Regular reports, such as those

i. The VR-12, formerly known as the Veterans SF-12, was developed from the RAND-36, developed at the RAND Corporation and the Medical Outcomes Society.

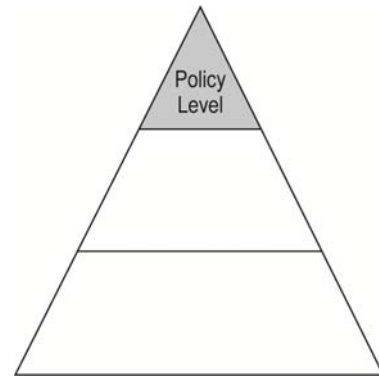
presented in Table 1, are used to rank programs based on the proportion of patients who became better (that is, showed improvements in HRQL) versus those who remained at the same level of health or were in worse health following treatment.⁷³

At the state level, quality improvement organizations receive state-specific baseline and performance measurement reports for all managed care programs. At the individual plan level, the HOS data is used for quality improvement.⁷⁴ Every year, a baseline report and a performance measurement report are disseminated to each participating program. Micro-data files are also available to participating programs after each cohort is completed so they can conduct plan-specific analyses. State-level HOS data is also available to researchers to advance the science of functional health outcomes measurement and quality improvement interventions and strategies.^{73, 75} Public-use data files are available on the HOS website.⁷⁶

Policy Level

“The NHS will be the first health care system in the world to measure what it produces in terms of health, rather than in terms of the production of health care.”⁷⁷

At the policy level, health outcomes information can be used to assess the effectiveness and performance of health care programs and delivery systems to answer the ultimate question—how much health are we buying for resources invested in the health care system? This data can be obtained by aggregating health outcomes information collected at the clinical or institution level. Alternatively, data linkage techniques can be used to bring together data on patient health status (found in population-based surveys) with data on medical interventions (found in clinical and administrative data) to create an enriched source of data to more effectively assess health outcomes of care.⁷⁸



Of particular interest at the policy level is the possibility of using health outcomes information to assess and compare the cost-effectiveness of health care services. Several HRQL tools include patient- or population-based utility or preference scores for a range of health states that represent different levels of morbidity and function. The scores are combined with estimates of the amount of time patients spend in these health states to calculate quality-adjusted life years (QALYs) of individuals at various points in time. QALY information can then be combined with information on cost of treatment to determine the overall cost-effectiveness of the health care service in terms of health gained.⁷⁹

The following examples provide illustrations of the use of health outcomes information in performance reporting at the program and policy levels.

Patient-Reported Outcomes—A New Initiative in the National Health Service (England)

“While a surgeon may deem a hip replacement successful because the procedure has been performed perfectly on the day, the patient will rightly disagree if they are still in pain and continue to have a poor quality of life some months down the line.”

—Health Minister Lord Darzi, 2009⁸⁰

In England, the collection and reporting of health outcomes information has become a priority. This practice began in a small number of private hospitals where information was collected via patient surveys that were administered before and after surgery. The data is used to report on the health gains of patients undergoing key, high-volume procedures, such as joint replacements and varicose vein surgery. This effectiveness measure represents one of a suite of indicators routinely reported to provide patients and clinicians with comparative information regarding the overall performance of each institution (see Box 5).

Box 5: Health Outcomes Information at the Policy Level: The Case of Spire Hospitals, United Kingdom

Spire Healthcare is one of the leading private hospital providers in the U.K. It maintains approximately 37 hospitals and more than 1,900 beds. It was the first private hospital provider to publish health outcomes data on the internet. These efforts earned Spire Healthcare the Independent Sector Award for Healthcare Outcomes in 2008.

Health improvement, measured as the change in health status before and after surgery, is one of a broad range of performance indicators routinely reported by Spire for each hospital on its website. Other performance indicators include patient satisfaction, *C. difficile* rates and unplanned re-admissions.

Health outcomes information is collected and reported for patients undergoing hip replacement, knee replacement, cataract surgery, hernia repair, gall bladder surgery and hysterectomy. The information is collected from all patients via surveys administered at the time of admission (pre-op) and mail-back surveys four to six months following surgery (post-op). Patients are asked to complete either a general HRQL measure (SF-36) or a disease-specific measure (such as the Oxford Hip Score or Visual Functioning 14).

The health outcomes data is used to generate the Health Improvement Indicator, which is routinely reported on Spire's website for each hospital. The information is publicly available on Spire's website at www.spirehealthcare.com. Patients undergoing care can use the Health Improvement Indicator to better understand the expected health gains associated with their procedure. They can also use the hospital-specific indicators to compare quality across hospitals.

Health outcomes information, along with other key performance indicators, is also used to generate institution-level reports for hospitals seeking overall quality improvement. The reports provide patient-level information to identify outlier outcomes as well as to compare institutions with their peer organizations. Provider-level information is also available, although it should be noted that these reports are not publicly available.

Source

Spire Healthcare. Website. www.spirehealthcare.com. Accessed March 23, 2012.

The Office of Health Economics Commission on NHS Outcomes, Performance and Productivity conducted a comprehensive study on the feasibility of collecting health outcomes information for all NHS patients.⁸¹ The commission firmly believed that being aware of health outcomes is critical to achieving the greatest benefit from resources spent in the health sector. While the NHS and Department of Health have an extensive history of routine performance reporting for quality improvement, the time had come to consider the establishment of health outcomes measures as a matter of routine practice at the national level.

The study focused on evidence and examples that highlighted the effective use of general HRQL and disease-specific measures for key tracer conditions, including elective surgery, mental health, chronic obstructive pulmonary disease and colorectal cancer.⁸¹ In elective surgery, the results of a national pilot project led commissioners to recommend the use of both a generic HRQL measure (EQ-5D) and disease-specific measures to collect health outcomes information for all patients undergoing one of several high-volume surgical procedures, including hip and knee replacements, cataract surgery, hernia surgery and varicose vein surgery.⁸² The commission also recommended modifications to existing national population surveys, such as the Health Survey for England, as a way of assessing the wider impacts of the health delivery system on the health of the population.⁸¹

The commission set a target: within five years, routine measures of patient outcomes should be collected for the majority of NHS activities. Within 10 years, the commission expected this to be the rule, rather than the exception.

This message was heard by policy-makers: in 2008, the Department of Health announced that collection of pre- and post-operative health status would begin in 2009. Today, NHS hospitals routinely collect health outcomes information on patients undergoing four key surgical procedures. On June 2, 2009, the Department of Health announced that the contract to collect PROMs had been awarded to the Royal College of Surgeons of England in association with researchers at the London School of Hygiene and Tropical Medicine.⁸⁰ This consortium has focused on new ways to analyze and report on health outcomes, the goal being to improve overall quality of care and cost-effectiveness.

In the 2010 White Paper *Equity and Excellence: Liberating the NHS*, the government established improvement in quality and health care outcomes as the primary purpose of all NHS-funded care. This approach requires a shift from existing top-down performance targets, such as waiting time targets, toward targets that focus on patient outcomes—reducing mortality and morbidity and ensuring patient safety. This approach is guided by a new NHS Outcomes Framework that provides direction for the NHS. The framework includes three domains of quality, one of which is “effectiveness of the treatment and care provided to patients”; this is measured by both clinical outcomes and patient-reported outcomes. Effectiveness of health care services is defined in three areas: 1) preventing people from dying prematurely; 2) enhancing the quality of life for people with long-term conditions; and 3) helping people recover from episodes of ill health or following injury. The framework also includes a set of national outcome goals determined by the Secretary of State and guides the commissioning of care within the NHS.^{83, 84}

Continuing Care Reporting System and Home Care Reporting System (Canada)

CIHI's Continuing Care Reporting System (CCRS) and Home Care Reporting System (HCRS) are active, pan-Canadian initiatives to collect health information. They provide outcomes data to guide patient care at the clinical level, to steer quality improvement at the organization level and to affect policy direction at the policy level.

There are currently more than 2 million resident-level assessments from seven jurisdictions in CCRS and more than 1 million client-level assessments from five jurisdictions in HCRS. This represents significant progress in two important and growing health care sectors.

CCRS and HCRS were designed to capture *both* processes and outcomes of care. They have *extensive* information on health outcomes—functional, cognitive, medical, social and psychological—through a large number of validated outcome scales, as well as large sets of risk-adjusted quality indicators.

CCRS is a longitudinal reporting system, allowing for the monitoring of continuing care services and residents over time. It captures standardized information on residents in continuing care facilities, including hospitals and residential care facilities with 24-hour nursing care. CCRS accepts detailed clinical, functional and health service use information collected through the RAI-MDS 2.0© clinical assessment instrument. The tool is a multi-dimensional instrument that provides a common language for assessing the health status and care needs of patients.⁸⁵ The assessment is used to collect information on multiple dimensions of health status, including physical functioning, psychological well-being, vision and activities of daily living. Demographic and comorbidity information is also collected, as is information about the use of health care services.⁸⁶

The RAI-MDS 2.0 can be administered at different points in the resident's journey to measure and monitor outcomes of care. This includes improvements in health and in functional and cognitive status. Ideally, this data is captured once (electronically), thereby providing real-time feedback to clinicians.

Outcomes information is available to clinicians and decision-makers at all levels. At the clinical level, resident information is critical for the planning and delivery of high-quality care. At the point of care, the comprehensive clinical assessment reveals the needs, strengths and preferences of the client/resident as well as the services used (see Box 6).

This data can then be aggregated to provide information for decision-making at multiple levels. At the organizational level, decision-makers can use CCRS information to support planning and quality improvement. At the system level, CCRS information can be used for system-wide planning, management and accountability. This information can also assess the role of key health care providers.

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Box 6: Health Outcomes Information Across the Information Pyramid: Continuing Care Reporting System

Clinical Level

Clinical Assessment Protocols (CAPs) are key outputs from the RAI-MDS 2.0 assessment instrument that provide real-time information to clinicians for care planning and monitoring of resident outcomes. When key items in the RAI assessment indicate a risk of decline or failure to improve that may respond to intervention, the issue is flagged and a CAP is triggered. The CAPs, based on research and best practice, provide the clinician with a structured approach to address important care issues. Through subsequent reassessment, progress toward care goals can be measured and adjustments can be made to the resident's care plan.

Administrative Level

An example of how CCRS data has been used to improve outcomes at an organization level is the IC-5 project. The *Hospital Report 2003: Complex Continuing Care* found wide variations in how Ontario's complex continuing care hospitals cared for residents with urinary incontinence. As a result, the Hospital Report Research Collaborative led the IC-5 project, which brought 12 complex continuing care (CCC) facilities from Ontario together to work collaboratively to improve continence care. The facilities met to share current best practices and initiatives regarding continence care and learned about models for quality improvement. Based on this exchange, facilities developed plans to improve continence care and presented results at a quality congress. Facilities initiated multiple projects, including creating standardized, detailed continence assessments and decision trees and working to decrease the number of residents using indwelling catheters. All facilities reported some level of success in their plans to improve processes and outcomes related to continence care.

Policy Level

Ontario has used CCRS information to monitor and report on health outcomes and quality of care for both its hospital-based CCC and long-term care facilities. The Hospital Report series for CCC included indicators that measure change in performance of activities of daily living, increase in signs of depression, communication decline, decrease in bladder continence and incidence of new pressure ulcers and new falls.

The incidence of new pressure ulcers is also used as a performance indicator for the Hospital Annual Planning Submission, which is used by CCC hospitals and local health integration networks (LHINs) for service planning and the measurement and evaluation of hospital services and organization performance within each LHIN.

Ontario long-term care facilities began collecting CCRS data in 2005 (full province-wide implementation was completed in 2009). In 2008, the Ontario Health Quality Council (now called Health Quality Ontario) was mandated by the Ontario Ministry of Health and Long-Term Care to publicly report on the quality of long-term care facilities. Its 2009 report included CCRS indicators on worsening depression and deterioration in functional status. Health Quality Ontario plans to further expand its reporting on outcomes and quality of care in long-term care facilities, using CCRS data as it becomes available.

Sources

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Cross-Sector Reporting System—Health Outcomes for Better Information and Care (Ontario)

Data that provides information on patient outcomes as individuals move across health sectors—such as from acute care to home care to long-term care—allows policy- and decision-makers to determine the quality of care in each sector and the effectiveness of continuity of care across the system. This can lead to decisions regarding resource allocations and different referral mechanisms. As well, the potential exists to be able to predict patients' need for services in various health sectors, based on their admission outcomes in some cases and discharge outcomes in others.

Health Outcomes for Better Information and Care (HOBIC) is an initiative funded by the Ontario Ministry of Health and Long-Term Care. Originally conceived to assess nurses' contribution to quality patient care, it involves the assessment of eight patient health-related factors, including functional ability and pain. Nurses assess patients' status on admission and discharge from acute care and home care and quarterly for long-term care and chronic hospital care. Data can be linked to other administrative databases and patient outcomes can be compared as patients move across sectors.

The HOBIC information system builds on CIHI's CCRS using standardized measures to assess health outcomes of care. The data is collected electronically at the point of patient care when nurses complete patient assessments. In the acute care hospital setting, health measures are collected at the point of admission and discharge. In the long-term and complex continuing care system, the measures are collected at admissions, quarterly or when there have been significant changes in patient health status.

The HOBIC system was designed to benefit patients, decision-makers and researchers. Two databases, one live and accessible only by nurses and nurse administrators in each organization, and a second containing de-identified data for researchers and policy-makers, are housed at the Institute for Clinical Evaluative Sciences.

For patients, HOBIC information is used by nurses to monitor the impact of care and to ensure, for example, that patients are prepared for discharge. For managers and decision-makers, HOBIC data is aggregated at the unit and institution levels to inform quality improvement initiatives, performance monitoring and resource allocation. For researchers, the HOBIC data can be linked to administrative health data for research purposes.

HOBIC has been pilot tested and implemented in more than 150 institutions in Ontario. The program continues to expand across local health integration networks in Ontario.⁸⁷

Health Outcomes for Program Evaluation— Care Support (United States)

In Oregon, health outcomes were used to evaluate a new program, called Care Support, designed to meet the needs of high-risk Medicare enrollees. Care Support was initiated by CareOregon, a not-for-profit Medicare program that provides services to non-insured, low-income enrollees.

Care Support identifies individuals with high levels of morbidity—those who are at high risk of an acute event—and stratifies them for intervention. The program has proven effective in terms of lower utilization of hospital services and costs. However, information was lacking regarding the health outcomes of patients.

As a result, a pilot project was initiated to introduce a general HRQL measure to the screening process between September 2005 and November 2006. After four months, follow-up HRQL measures were obtained for patients who entered the Care Support program and compared with measures for those who did not enter the program. Individuals who entered the program were found to have significantly better emotional health scores. (Differences in overall health status were found to be clinically, but not statistically, significant.)

In addition to providing critical outcomes information, this pilot project served as an opportunity to assess the feasibility of introducing a general HRQL measure in the data collection and information system at the Medicare program. CareOregon management recognized the value of patient-reported health outcomes, “to build Care Support’s evidence base, strengthen CareOregon’s existing case identification algorithm, and provide an important dimension of program assessment.”⁸⁸

Evaluating Cancer Care—Surveillance, Epidemiology and End Results (United States)

At the policy level, health outcomes have also been identified as critical information for the evaluation of nation-wide programs in key disease areas, such as cancer. As survivorship among cancer patients improves and individuals live longer following treatment, it is increasingly important to better understand the effect of the disease and subsequent treatment. In the U.S., one of the key strategic objectives identified by the National Cancer Institute (NCI) is to ensure the best outcomes for all patients, including improving the quality of life for cancer patients, survivors and their families.⁸⁹ The need to focus on health outcomes was echoed by the American Cancer Society in its 2015 goals.^{90, 91}

A joint initiative of NCI and CMS led to the development of linked surveillance data to monitor the health outcomes of cancer survivors among Medicare enrollees. The objective was to create a data set that can be used by researchers to better understand the health outcomes of cancer survivors. To this end, data from the Surveillance, Epidemiology and End Results (SEER) cancer registry program has been linked to health status data from the Medicare HOS.⁹²

The SEER–HOS data set represents the linkage of four cohorts of HOS data collected between 1998 and 2003. The data covers 12 states and approximately 31,000 Medicare cancer patients and 140,000 enrollees who had never been diagnosed with cancer. The SEER data set provides detailed clinical information on the cancer status of enrollees, including histology, stage and grade, as well as information on initial surgical and radiation treatment within 12 months of diagnosis. This information was linked to the HOS data which, as previously described, provided patient-reported HRQL measures at two time points, as well as a wealth of information on enrollees, including demographic, socio-economic and comorbidity information.⁹³ The SEER–HOS data was recently used to detect differences in the impact of cancer on HRQL among enrollees by cancer site, race and socio-economic status,⁹⁴ as well as the impact of comorbidities.⁹⁵

Evaluating Cancer Care Options—Population Health Model (Canada)

Health outcomes information can also be derived by linking health status and health care intervention information in micro-simulation models. Statistics Canada’s Population Health Model (POHEM), for example, is a sophisticated tool that integrates population health data and intervention data to address key policy questions. It does so by conducting what-if analyses to assess the health impacts of intervention options for the care of specific patient populations.⁹⁶

POHEM is currently being used to develop a Cancer Risk Evaluation and Decision-Support Computer Simulation Model to project the health status and cost impacts of key cancers. The model links key evidence regarding the incidence, progression and case fatality of cancers to measure the impacts of major risk factors as well as the effects and effectiveness of cancer prevention, screening and treatments (cancer control) on health outcomes and on costs to the health care system. The model uses HRQL measures to assess health impacts at various stages of disease progression and to develop cost-effectiveness measures based on related utility scores. The project is currently being developed for the Canadian Partnership Against Cancer in support of its Cancer Risk Management Initiative.⁹⁷

Health Outcomes for Cost-Effectiveness—The Case of Pharmaceuticals (Canada)

Cost-effectiveness evaluations of health care interventions and technologies can provide much-needed information on value for money. Measuring the health status gains for money spent provides policy-makers with information to decide how to allocate scarce health care resources. Canada has a notable history in the use of health outcomes and associated utilities data to assess the cost-effectiveness of pharmaceuticals. In the early 1990s, the Ontario government developed guidelines for the economic evaluation of pharmaceutical products and required the submission of cost-utility analyses for any new drugs applying for listing on the provincial formulary.⁹⁸ With slight modifications, these Ontario guidelines became the first-edition Canadian guidelines. These efforts evolved into the Common Drug Review, now conducted at the Canadian Agency for Drugs and Technologies in Health (CADTH).^{99, 100}

A 2009 report released by CADTH focused on the effectiveness of erythropoiesis-stimulating agents (ESAs) in the treatment of anemia related to cancer. This issue arose because ESAs are costly and there has been controversy about their safety. The review of evidence focused on a range of outcomes, including improvements in quality of life and mortality following the use of ESAs. Despite clinically meaningful gains in quality of life, it was revealed that ESAs may pose an increased risk of all-cause mortality. The report also considered the cost-effectiveness of ESAs and concluded that they do not represent good value for money, with estimates of cost per QALY ranging from \$70,000 to more than \$100,000.¹⁰¹

Moving Forward With Health Outcomes Data Collection in Canada

In the final section of this report, we explore issues and options for moving forward with data collection opportunities for health outcomes information in Canada. We draw on key messages and learnings from existing national and international experiences as well as the views of experts and participants who attended a national conference dedicated to the theme of health outcomes. The 2010 Data Users Conference, sponsored by CIHI and Statistics Canada, focused on health outcomes, thus providing the opportunity to both share information regarding the importance of collecting health outcomes information and capture the views of experts and participants on how we might move this data collection agenda forward.

Health Outcomes Gaining Support in Canada

While countries such as England and the United States have moved forward with collecting and reporting on health outcomes of care, the concept remains relatively new in Canada. To raise awareness, CIHI and Statistics Canada dedicated the 2010 Data Users Conference to the theme *Understanding Health Outcomes*. More than 300 participants, including national and international experts, joined to share ideas on how to further the national agenda for health outcomes data collection. The conference concluded with an interactive panel discussion to facilitate dialogue between experts and conference participants on the impetus to collect health outcomes data and how this data can be put into action to improve the quality of patient care. The views and reactions expressed are summarized in this final section.

Overall, the idea of collecting data on health outcomes of care was met with resounding support from conference speakers and participants. Most recognize that while Canada does a good job of collecting and reporting on the outputs of the system (such as rates of hospitalization) and adverse outcomes (such as readmission and death), there is relatively little information at the national and cross-jurisdictional levels on the health gains of the services provided. Movement toward the collection of health outcomes information will allow us to shift focus away from a simple volume approach to evaluating the intended outcome of health care systems: health. In other words, if it is health we are seeking to achieve with the health care system, why not measure it? Patients are in the best position to provide this type of information—hence, health outcomes promote a patient-centred approach to health care. Health outcomes data can help move the health care system toward dealing with issues of effectiveness and value for money

in a system otherwise focused on volumes of care. Advances in both measurement and data collection technologies make this a good time to move forward. Canada is uniquely positioned to move forward as “. . . we have a data structure which is generally superior to most other(s).”¹⁰²

The Time Has Come—But Proceed With Caution

While there was support for moving forward with collecting information on health outcomes of care, the message was to move forward in a planned and thoughtful way, with attention paid up front to potential challenges. Several key issues were raised for consideration as institutions and jurisdictions consider the next steps:

- **Have a plan for the data:** As outlined in this report, the same data can be used for multiple purposes. Health outcomes data can be collected at multiple levels for various purposes, including guiding patient care, reporting on performance and assessing appropriateness and value for money. Health outcomes data can also be used to provide patient profiles to inform patients of what they can expect following care. It is critical that any initiative begin with a common understanding of health outcomes and agreement regarding the purpose, objectives and anticipated uses of the data. Some mentioned the need for a business case to ensure that resources spent on data collection activities will produce valuable inputs to improve overall system performance and quality. This type of groundwork will allow for early stakeholder buy-in and will also guide data collection options.
- **Engage stakeholders from the start:** Health outcomes data has the potential to inform multiple levels of the health care system, from the clinical encounter to the policy level. It is critical, therefore, that key stakeholders, particularly physicians and health care planners, be engaged and have an incentive from the start to collect and use this data. Much learning is needed on the part of stakeholders to ensure that the data is collected, interpreted and used in the most effective way possible. This is particularly true at the clinical level, where health outcomes information is currently not commonly used to care for patients. As we know, data collection activities can be resource-intensive. Concerns have been raised by clinicians regarding the need for additional time and resources for this type of initiative.
- **Measurement is critical:** The recent explosion of measurement tools in health care has resulted in a wide range of general and disease-specific measures of health. The choice of which measure to use is critically important and should be linked to the need for and eventual use of health outcomes information. In general, most advocated for the use of both a general HRQL measure and a disease-specific measure. Comprehensive HRQL measures are used to capture the full effect of health care services but may not be sensitive enough to capture the intended outcomes. Disease-specific measures can fill that gap, since they are designed to be extremely sensitive to changes in specific domains.^{39, 103} Finally, HRQL measures need to be identified that can capture changes in health status for both episodic care (such as elective surgery) as well as continuing care (such as chronic disease management).

- **Comparability is key:** Health outcomes information provides a powerful tool to assess the effectiveness of health care services and to compare institutions and jurisdictions. Comparability requires a commitment to the use of standardized tools that allow data to be both aggregated and compared across units. This was instrumental in the current health outcomes initiative launched by the Department of Health in England—the use of a standardized HRQL tool (EQ-5D) and disease-specific tools (such as Oxford hip and knee scores) has allowed clinicians, health care planners and policy-makers to obtain a system-wide view of the health gains of patients undergoing selected elective surgical procedures. Furthermore, accurate comparisons require additional information to risk-adjust the data such that differences in the underlying patient population are accounted and controlled for.
- **Where to start:** Most agreed that collecting health outcomes information is simpler in the context of episodic acute care, such as elective surgery, where measures of health status before and after care can be more easily collected. The situation is somewhat more complex, yet equally if not more important, in the context of primary and ongoing care, such as chronic disease management. There was general agreement that data collection initiatives should perhaps start with elective surgery, given the need to focus on performance and value for volume of care. Elective surgery represents a significant portion of overall health care spending, yet there is limited information about this area of health care regarding value for money. This approach would also allow jurisdictions to gain some experience in the collection and use of health outcomes data. However, data collection efforts should also move forward in other settings, such as chronic disease management, where such measures can provide valuable information for better patient care. While the primary care and chronic disease management settings are more complex, it may be necessary to start in units with existing data infrastructure, such as electronic medical records, that would facilitate data collection.
- **Privacy and data ownership:** The collection of health outcomes data raises several issues regarding the need to balance patient privacy and confidentiality while ensuring access to data to inform decision-making. These considerations have an impact on how the data is collected, processed and stored. Several data custodians may be required to maximize the use of the data for decision-making at various levels. Custodial use of health outcomes information, like other health data, would be governed by privacy legislation. Similarly, the ability to share this information across various decision-making levels and groups would be governed by data-sharing agreements and de-identification frameworks that specify the flow, terms of use and particular conditions surrounding disclosure.

Conclusions

Measuring and reporting on health outcomes of care is an idea whose time has come. There is increasing awareness that we need better information to assess the effectiveness and value of health care interventions taking place in real-world settings. While we have made significant gains regarding information on the inputs and *outputs* of the health care system, we lack sufficient information to truly know the *health gained* within the population for the investments made in health care. New drug therapies, surgical procedures, health promotion programs and other investments produce outputs, but whether or not they all lead to improvements in population health is less known.

The increased focus on health outcomes is born from a shift toward a greater emphasis on the need to understand outcomes of care and to include the patient's perspective. The possibility of collecting health outcomes information is supported by the significant gains made in the measurement of health-related quality of life as well as in electronic-based methods that would ease the burden of data collection.

There has been some progress made both within Canada and internationally to move toward a population-based approach to the collection of health outcomes information. This report highlights a framework for data collection at various levels, including the clinical, administrative and policy levels. Using this framework, the experiences of innovators (both national and international) have been highlighted to demonstrate that health outcomes are and can be collected at the population level. We can learn from key initiatives adopted in other countries, such as England and the U.S., as they have moved toward broader data collection strategies in an effort to improve the availability of health outcomes information.

While there are pockets of innovation across this country, there are currently no pan-Canadian initiatives to collect health outcomes information across a broad range of health care sectors. This report ends with the views of experts and participants at a national conference focused on health outcomes regarding how we move this data collection forward to improve the availability of health outcomes information. We recognize that in the best of all worlds, we would want to collect health outcomes information on patients from across the continuum of care. Data collected would reflect well-defined, standardized measures of health outcomes that would be used for effective decision-making at all levels by clinicians, health care managers and policy-makers to influence processes of care. Through collaborative efforts, the information needs of the health care system in Canada can be assessed and addressed.

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Production of this report is made possible by financial contributions from Health Canada and provincial and territorial governments. The views expressed herein do not necessarily represent the views of Health Canada or any provincial or territorial government.

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ISBN 978-1-77109-071-1 (PDF)

© 2012 Canadian Institute for Health Information

How to cite this document:

Canadian Institute for Health Information, *Health Outcomes of Care: An Idea Whose Time Has Come* (Ottawa, Ont.: CIHI, 2012).

Cette publication est aussi disponible en français sous le titre *Les résultats des soins pour la santé — le temps est venu*.

ISBN 978-1-77109-072-8 (PDF)

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