

The Conference
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Understanding the Use of Patient Reported Outcomes in Colorectal Cancer

Experience of a Canadian Hospital



Coalition
Priorité Cancer
au Québec



Hôpital général juif
Jewish General Hospital

Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'Île-de-Montréal
Québec 

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Key Findings

- Patient-reported outcomes (PROs) are direct reports from patients about their own health, quality of life, and/or functional status. They relate to healthcare services (routine or specialized) or treatments patients have received on their care trajectory.
- When care teams use PROs, they facilitate patient-centred care and foster better engagement between patients and their healthcare team. On an organizational and system level, aggregation of PROs can support decision-making on services and patient trajectories or pathways.
- The implementation of PROs, a primary pillar of value-based healthcare (VBHC), is a significant organizational undertaking involving care teams, patients or population representatives, integrated information technology, and support services.
- As part of a quality improvement initiative focused on the use of PROs in patients with colorectal cancer, we collaborated with the Segal Cancer Centre at the Jewish General Hospital (JGH) of the Centre intégré universitaire de santé et de services sociaux (CIUSSS) du Centre-Ouest-de-l'Île-de-Montréal to explore opportunities to improve the systematic collection and use of PROs to support patient care and clinical excellence.
- PROs and other clinically relevant and internationally recognized measures for patients with colorectal cancer are currently being collected and aggregated at the JGH.
- While some colorectal cancer PROs and most of the clinically relevant measures are compiled for documentation and/or aggregation in more than one database, others—mostly PROs—are not currently being aggregated in any of the databases we examined.
- With respect to the use of colorectal cancer PROs, healthcare providers in our study report using all of the internationally recommended ones in their practice.
- Healthcare providers' attitudes toward PROs and their measurement using standardized tools are very positive, indicating an openness to using these PROs to enhance practice.
- Value-realization from the routine collection and aggregation of PROs to advance clinical excellence and patient engagement will require resources, clinical and administrative leadership, patient engagement, and more sophisticated and integrated/interoperable information technology systems.

Introduction

Measurement of patient-reported outcomes (PROs) in clinical practice is growing in importance.

A robust and transparent culture of measurement, inclusive of PROs, clinical outcomes and patient experience, is a primary pillar of operationalizing value-based healthcare (VBHC) approaches and a learning health system. They offer timely information on patients' experiences with perception of the care they received and their current health status (during and following care encounters). As such, PROs provide actionable information to inform therapeutic intervention by clinical teams. They are pivotal to a person-centred value-based approach to improving the quality and safety of patient care. In the context of cancer care, administration and use of PROs with patient cohorts have been associated with improved survival and quality of life.^{1,2}

However, systematic collection of PROs as a standard component to patient encounters with the healthcare system, using scientifically validated patient-reported outcome measures (PROMs) via survey tools/instruments, is still relatively new in the Canadian context.³ Therefore, questions remain about the types of PROs being measured by different institutions, the best and most appropriate and efficient means of collecting them, and then establishing best practices in their collection, use, and systematic reporting.

- 1 Doolin and others, "Why Focus on Patient-Reported Outcome Measures in Older Colorectal Cancer Patients?"
- 2 Besson and others, "Understanding Patient-Reported Outcome Measures in Colorectal Cancer."
- 3 Ahmed and others, "A Catalyst for Transforming Health Systems and Person-Centred Care."

Patient Outcomes: Clarification of Terms

In this impact paper:

Clinical outcomes: Measurable changes in health, function, or quality of life that result from clinical care (e.g., related to their direct medical treatment or testing). Their collection is performed by a healthcare professional.

Patient-reported outcomes (PROs): Reports from patients about their own health, quality of life, or functional status associated with the healthcare or treatment they have received. They come directly from the patient, without interpretation of the patient's response by a healthcare provider or caregiver.

Patient-reported outcome measures (PROMs): A set of validated measurement tools used for the collection of PROs. Examples include validated surveys to evaluate symptoms, functionality, and physical, mental, and social health.



We have previously shown that hospitals in Ontario and Quebec were not consistent in measuring PROs in the care journey for patients diagnosed with colorectal cancer.⁴ In this impact paper, we describe one institution's experience with the collection of PROs and other clinically relevant outcomes in colorectal cancer.

The objectives of this quality improvement initiative undertaken by the Jewish General Hospital (JGH) of the Centre intégré universitaire de santé et de services sociaux (CIUSSS du Centre-Ouest-de-l'Île -de-Montréal), Quebec, were as follows:

- to identify the specific PROs and clinical outcomes being collected for patients with colorectal cancer at the JGH as well as the health record and/or hospital information systems where these data are compiled
- to learn about healthcare providers' awareness of which colorectal cancer PROs and clinical outcomes are being collected at the hospital level and to determine whether providers use PROs to inform their clinical practice.

For the purpose of this impact paper, a distinction needs to be made between “collection” and “aggregation” of patient data. (See Appendix A for more definitions.) We use collection to refer to the act of gathering information.⁵ For example, the interaction of the patient with a healthcare provider will result in the collection of specific health information from that patient with the goal to provide the best possible treatment and care to the patient. This information will be recorded in the patient chart. Aggregation of data, on the other hand, refers to a process where the individual data (e.g., from the patient chart) are compiled together and expressed in summary form, which enables its use on a larger scale (e.g., for statistical analysis on a large number of cases).⁶ Since aggregated data are not limited to one patient, but include numerous patients, they can be used by hospitals to gain a better understanding of the quality of care their patients are receiving, and thus serve to improve patient safety, treatment effectiveness, and overall experience of care.⁷ Analysis of aggregated data is essential for quality improvement.

4 Moroz, Moroz, and Slovinec D'Angelo, “Care Pathways in Oncology.”

5 Hjollund and others, “Health Data Processes.”

6 Ibid.

7 Ryan and Thompson, “The Use of Aggregate Data for Measuring Practice Improvement.”

Data Processing: Clarification of Terms

In this impact paper:

Collection of data: The act of gathering information, such as a healthcare provider asking a patient questions and recording answers in a patient chart, thereby creating “raw” patient data.

Compilation of data: The act or process of collating patient data from various sources into a specific database or information management system where it can be securely stored for documentation purposes and in a format that allows it to be manipulated or extracted appropriately for analysis.

Aggregation of data: The process of integrating single or multiple sources of raw data and expressing defined data elements in summary form for statistical analysis and interpretation.



In the sections to follow, we start by defining health outcomes, describing the importance of their measurement, and identify which outcomes are recommended for routine collection and measurement for patients with colorectal cancer. We then describe the quality improvement initiative undertaken by the JGH, the lessons learned, and the path forward. The insights gleaned from this project are relevant to other Canadian institutions interested in starting or improving their collection and use of patient-reported outcomes to advance VBHC approaches and deliver high-quality care to their patients.

What Are Patient Outcomes and Why Are They Important?

Health outcomes are defined as “changes in health that result from measures or specific health care investments or interventions.”⁸ They can be clinical- or clinician-reported, or patient-reported. Clinical outcomes reflect assessment of a patient’s health status completed by a healthcare professional according to their clinical judgment or based on observations of the patient’s physical manifestations and/or behaviours.⁹ PROs are direct reports by patients, pertaining to their health, quality of life, or functional status associated with the healthcare or treatment they received.¹⁰

8 Canadian Institute for Health Information, “Outcomes.”

9 Russell, “What Are Clinician-Reported Outcomes (ClinROs)?”

10 Weldring and Smith, “Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs).”

PROs are measured through PROMs, which are a set of validated measurement tools, such as validated surveys to evaluate symptoms, functionality, and physical, mental, and social health.^{11,12} This impact paper focuses on PROs and clinical outcomes (not PROMs).

Systematic collection and use of PROs in routine practice can help ensure that symptoms are identified, acknowledged, and addressed in a timely fashion.¹³ There is evidence showing that considerable numbers of healthcare providers underestimate symptom intensities in their patients with advanced cancers.¹⁴ Symptom underestimation in cancer care has been associated with inadequate symptom control,¹⁵ higher likelihood of poor quality of life, poor compliance with symptom treatment recommendations,¹⁶ and, in patients with metastatic colorectal cancer, with a less favourable 2-year overall survival rate¹⁷.

Systematic monitoring of patients using PROs has been shown to produce numerous benefits to both patients and healthcare professionals. Improved patient–provider communication, increased provider awareness of patient symptoms, and better symptom management are associated with higher patient satisfaction, quality of life, and overall survival.^{18,19} Studies have also demonstrated that it is feasible to integrate PROs into routine cancer care, automate system alerts to trigger care management pathways and positively impact clinical outcomes (including

survival) and system-level outcomes with regard to emergency care utilization for acute events.²⁰

Growing interest in the integration of PROs into routine clinical practice has been motivated, in part, by the growing interest in implementing and benefiting from VBHC approaches.²¹ These approaches are grounded in the attainment of outcomes that matter to patients in relation to costs of achieving these outcomes.²² One major challenge in VBHC is the lack of administration of standardized health outcomes measurements across healthcare providers and institutions. This hinders the ability at the institution, regional, and system levels to monitor the quality of healthcare delivered in different institutions and to compare variations across different settings.²³

Which Patient Outcomes Should Be Collected?

A standardized set of outcomes for patients with colorectal cancer has been co-created with patient representatives, clinicians, registry leaders from around the world, and experts in the field, as part of the work of the International Consortium for Health Outcomes Measurement (ICHOM).²⁴

11 Ibid.

12 Canadian Institute for Health Information, “Patient-Reported Outcome Measures (PROMs).”

13 Basch and others, “Implementation of Patient-Reported Outcomes in Routine Medical Care.”

14 Laugsand and others, “Health Care Providers Underestimate Symptom Intensities of Cancer Patients.”

15 Laugsand and others, “Inadequate symptom control in advanced cancer patients across Europe.”

16 Chandwani and others, “Lack of Patient-Clinician Concordance in Cancer Patients: Its Relation With Patient Variables.”

17 Ooki and others, “Disagreement between patient- and physician-reported outcomes on symptomatic adverse events as poor prognosis in patients treated with first-line cetuximab plus chemotherapy for unresectable metastatic colorectal cancer: Results of Phase II QUACK trial.”

18 Besson and others, “Understanding Patient-Reported Outcome Measures in Colorectal Cancer.”

19 Doolin and others, “Why Focus on Patient-Reported Outcome Measures in Older Colorectal Cancer Patients?”

20 Basch and others, “Implementation of Patient-Reported Outcomes in Routine Medical Care.”

21 Doolin and others, “Why Focus on Patient-Reported Outcome Measures in Older Colorectal Cancer Patients?”

22 Porter, “What Is Value in Health Care?”

23 Porter, “Outcome Measurement.”

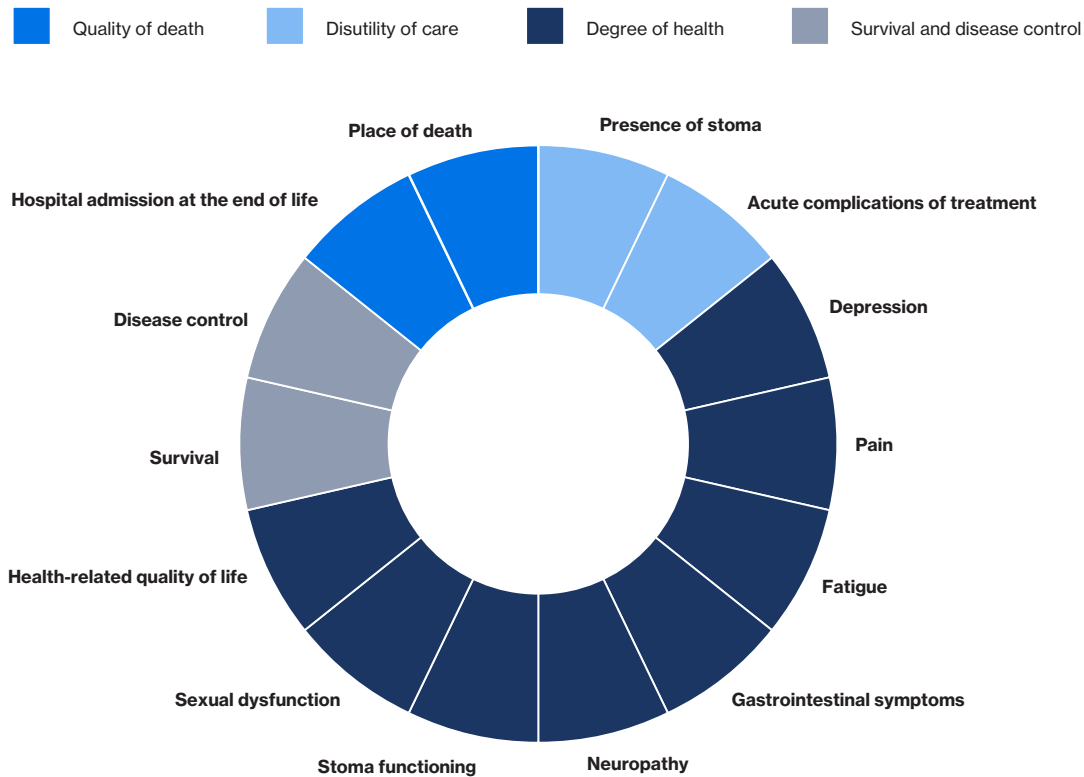
24 Zerillo and others, “An International Collaborative Standardizing a Comprehensive Patient-Centered Outcomes Measurement Set for Colorectal Cancer.”

Like other ICHOM standard sets developed for different conditions, it is meant to capture those outcomes that matter most to patients through a process of validation with people with lived experience. ICHOM’s colorectal cancer standard set is very comprehensive and encompasses indicators grouped into the following categories:

- disutility of care (short-term treatment complications)
- degree of health (multiple PROs, including quality of life, functional status, and long-term adverse effects)
- survival and disease control
- quality of death.²⁵

See Exhibit 1 and Appendix B for a more detailed table of these key outcomes.

Exhibit 1
Key Categories of Outcomes Within the ICHOM Standard Sets for Colorectal Cancer Patients



Source: Adapted from ICHOM*.

25 International Consortium for Health Outcomes Measurement, *Colorectal Cancer Data Collection Reference Guide*.

* Ibid.

In addition, a selection of clinical case-mix variables (e.g., demographic characteristics, comorbidities, functional status) are recommended to be collected at baseline.²⁶ Case-mix adjustment is important when comparing outcomes between different providers or institutions, to ensure fair comparisons and account for sources of potential bias in hospitals' outcomes data that are beyond their control.

We used the ICHOM-recommended standard set for colorectal cancer²⁷ to assess what indicators were being collected and aggregated at the JGH, and if they were being used by healthcare providers. (See Appendix C for a description of the methodology.) This quality improvement exercise will contribute to the planned development of an outcomes dashboard at the JGH to advance the quality of care for patients with colorectal cancer.

²⁶ Ibid.

²⁷ International Consortium for Health Outcome Measurement, "ICHOM Standard Set for Colorectal Cancer."





A Quality Improvement Initiative for Outcome Measurement in Patients With Colorectal Cancer at the Jewish General Hospital

About Colorectal Cancer

Colorectal cancer is the second-leading cause of mortality due to cancer in Canada,²⁸ despite being preventable, treatable, and often curable if detected early through screening and timely diagnosis.²⁹ In Quebec, colorectal cancer is the second-leading cause of death related to cancer in men and third in women.³⁰ Each year, approximately 6,800 residents of Quebec (approximately 1,500 of whom are residents of the Montréal region³¹) are diagnosed with colorectal cancer.³²

It has been noted that advances in prevention, screening programs, early detection, and treatment have significantly improved survivorship for colorectal cancer.³³ In Canada, survival statistics show that approximately 65 per cent of those who are diagnosed with colorectal cancer will survive for at least five years after their diagnosis.³⁴ These high survival rates underscore the need for routine measurement of PROs to better understand the impacts of the cancer and treatments on survivors' quality of life.³⁵

28 Brenner and others, "National Trends in Colorectal Cancer Incidence Among Older and Younger Adults in Canada."

29 Colorectal Cancer Canada, "Screening."

30 Gouvernement du Québec, "Colorectal Cancer (Colon and Rectum)."

31 Ministère de la santé et des services sociaux, "Statistiques du Registre québécois du cancer."

32 Gouvernement du Québec, "Colorectal Cancer (Colon and Rectum)."

33 Rutherford and others, "Patient-Reported Outcomes and Experiences From the Perspective of Colorectal Cancer Survivors."

34 Canadian Cancer Society, "Survival Statistics for Colorectal Cancer."

35 Rutherford and others, "Patient-Reported Outcomes and Experiences From the Perspective of Colorectal Cancer Survivors."

Segal Cancer Centre at the Jewish General Hospital

The Segal Cancer Centre is considered one of Quebec's leading cancer centers, constantly striving to improve the quality of care it provides.³⁶ This state-of-the-art facility provides patients with a comprehensive approach to care, which combines cancer prevention, diagnosis, treatment, psychosocial support, nutritional support, and access to clinical trials.³⁷ In addition to patient care, the Segal Cancer Centre is also recognized for its thriving cancer research program, which encompasses fundamental, translational, clinical, nursing, psychosocial, and palliative care research.³⁸

The Colorectal Cancer Program is delivered by a large interdisciplinary team of providers with expertise in medical and radiation oncology, gastroenterology, nursing, cancer genetics, cancer prevention, psychosocial support, and palliative care medicine.³⁹ Allied health professionals, including physiotherapists, dietitians, psychologists, social workers, pharmacists—along with support staff and volunteers from community organizations including Hope & Cope—also play a central role in guiding and supporting patients with colorectal cancer and their families.⁴⁰

The JGH is a member of the CIUSSS du Centre-Ouest-de-l'Île-de-Montréal. This regional network consists of more than 30 member institutions and facilities and provides care to nearly 400,000 residents, enabling and facilitating timely access to a seamless continuum of care that focuses on individuals' needs.⁴¹ The JGH and CIUSSS du Centre-Ouest-de-l'Île-de-Montréal aim to deliver data-driven care for patients.⁴² As a result, the JGH places high importance on patient outcomes collection for delivery of high-quality care.

The JGH was the first hospital in Montreal to implement fully digitized patient records (the ChartMaxx system).⁴³ To enable comprehensive data collection, various databases are used to track specific aspects of patient care. Some of these databases are used for documentation purposes (e.g., ARIA Oncology, Centro, EndoVault, e-Rendez-Vous, Opera, OACIS [Open Architecture Clinical Information System]), others for data aggregation (e.g., SARDO [Système d'archivage de données oncologiques], EIAS [ERAS Interactive Audit System], NSQIP [National Surgical Quality Improvement Program, Med Echo]) though this distinction is not always clear and some databases can be used for both functions (e.g., Centricity Opera). This means that outcome information for the same patient can be stored in different hospital information management systems and used by various professionals for different purposes, based on their permissions, mandates, and goals. (See Table 1.)

36 Jewish General Hospital, "Segal Cancer Centre."

37 Ibid.

38 Ibid.

39 Jewish General Hospital, "Colorectal Cancer Program."

40 Ibid.

41 Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal, "Notre CIUSSS."

42 Ibid.

43 Jewish General Hospital Foundation, "Reimagining the Future of Healthcare."

Table 1

Databases Used for Health Information Management at the Jewish General Hospital Examined for Colorectal Cancer Outcomes

Database	Brief Description
ARIA Oncology	An oncology-specific information management system used in radiation and medical oncology. ARIA allows the creation and editing treatment plans, supports a wide range of multi-modality images (e.g., conventional computed tomography [CT], cone-beam computed tomography [CBCT], magnetic resonance imaging [MRI], and positron emission tomography [PET]), and also to track patients' health throughout the course of treatment and beyond.
Centro	An electronic medical record documentation program for new consults and progress notes.
EndoVault Oncology	An oncology-specific information management system that manages patient health records at the Segal Cancer Centre.
MediVisit and E-Rendez-Vous	Patient-scheduling systems.
OACIS	A clinical information system which is part of the Jewish General Hospital's Electronic Medical Record (EMR).
Opera	An information system consisting of a set of tools designed to enhance planning and efficient management of surgeries in the operating rooms. The information provided by the system allows for better planning and scheduling of surgery by achieving optimum allocation of resources.
EIAS	A clinical management information system for tracking indicators and standards associated with implementation of ERAS [Enhanced Recovery After Surgery] protocols, developed by Encare, in co-operation with the ERAS Society. ERAS involves a multidisciplinary team and a multimodal care pathway designed to streamline and standardize patient care before, during, and after surgery. It aims to achieve early mobility and recovery while improving outcomes and patients' overall experiences.
Med Echo	An information system that contains data on hospital stays in Quebec hospitals (general and specialized). These data, compiled by hospitals, relate to acute care (physical and psychiatric) and day surgeries. These data are produced by the public payer, the Régie de l'assurance maladie du Québec (RAMQ), and cover all of Quebec.
NSQIP	An information management system of the American College of Surgeons (ACS), National Surgical Quality Improvement (NSQIP) quality verification program. This standards-based program is designed to help participating sites improve quality of care across surgical departments using their NSQIP risk-adjusted data.
SARDO	A specialized application in oncology that allows for maintaining a structured and comprehensive local cancer registry for all types of cancer and for the entire care trajectory. Some of this information is transferred to the Quebec Cancer Registry, in accordance with the ministerial normative framework, for public health purposes.

Notes: At the time of research, MediVisit was being replaced by E-Rendez-Vous.

Source: The Conference Board of Canada.

From a quality improvement perspective, it was important for the JGH to identify which of the ICHOM-recommended clinical- and patient-reported outcome colorectal cancer indicators were being collected at the institution level and in which databases they were compiled.

Objective 1

What Clinical- and Patient-Reported Outcomes Are Collected For Patients With Colorectal Cancer at the JGH and in Which Databases are They Compiled?

To answer these questions, a few key medical archivists and registrars with knowledge and practical experience with data entry into the JGH databases were asked to go through the list of the ICHOM-recommended PROs and clinical/administrative indicators for colorectal cancer. We asked them to verify which ones were being collected and specify in which databases they were compiled. Detailed responses are presented in Appendix D.

We found that **50 of the 67 (75 per cent)** ICHOM-recommended indicators for patients with colorectal cancer are being aggregated at the JGH. However, these indicators reside in several different (non-integrated) databases. (See Table 2.)

While most are compiled in multiple databases, other PROs: degree of health and quality of death—are not. Within these two outcome categories, only **8 out of 19 (42 per cent)** of PROs and **1 of 3 (33 per cent)** of quality of death indicators are aggregated. (See Table 3.)

Most indicators are aggregated in SARDO (**34 of 50, 68 per cent**), followed by EIAS (**21 of 50, 42 per cent**), NSQIP (**19 of 50, 38 per cent**), and Med Echo (**13 of 50, 26 per cent**), and Opera (**6 of 50, 12 per cent**). (See Appendix D for more detail). EIAS and NSQIP are international programs designed to help participating sites improve quality across surgical departments. They also audit process compliance at participating institutions, with EIAS auditing patient-reported outcomes.⁴⁴ EIAS was the only database where the degree of health outcomes (multiple PROs, including quality of life, functional status, and long-term adverse effects) were being aggregated. The other databases we assessed (Aria, Centro, EndoVault, MediVisit/e-Rendez-Vous, and OACIS) are not used for aggregation of any of the ICHOM-recommended indicators. Rather, they are used for documenting various aspects of patient care at the point of care in the form of consultation notes, or scheduling information, and, with exception of Opera, in a format that does not render itself to manipulation for statistical analyses.

Table 2
Databases at the JGH, Where ICHOM-recommended Colorectal Cancer Indicators are Compiled for Aggregation

Key categories of ICHOM-recommended indicators	Opera	EIAS	Med Echo	NSQIP	SARDO
Demographic factors	✓	✓	✓		✓
Baseline clinical factors	✓	✓	✓	✓	✓
Baseline tumour factors		✓	✓	✓	✓
Baseline treatment factors	✓			✓	✓
Treatment variables	✓	✓	✓	✓	✓
Disutility of care	✓	✓	✓	✓	✓
Degree of health PROs		✓			
Survival and disease control			✓	✓	✓
Quality of death					✓

Note: Only indicator categories are shown; breakdown per indicator category shown in Appendix D.
Source: The Conference Board of Canada.

44 Ljungqvist, Scott, and Fearon, "Enhanced Recovery After Surgery."

Table 3
 Current Status of Aggregated Versus Non-aggregated ICHOM-recommended Colorectal Cancer Outcome Indicators at JGH

Outcome indicators categories	Number (per cent) of indicators being aggregated	Indicators not being aggregated
Disutility of care (adverse events and complications)	3 of 3 (100 per cent)	
Degree of health (PROs)	8 of 19 (42 per cent)	emotional functioning social functioning depression sexual functioning fatigue dietary restrictions fecal leakage stool frequency erectile dysfunction vaginal symptoms neuropathy
Survival and disease control	4 of 5 (80 per cent)	progression free survival
Quality of death	1 of 3 (33 per cent)	preference for place of death hospital admission at the end of life (admission to the hospital > 1 time in last 30 days of life)

Source: The Conference Board of Canada.

Interpretation

It is notable that while certain outcomes are compiled for aggregation in more than one database, indicating some duplication of effort, others are not. PROs pertaining to the degree of health, for example, in aggregate format, can serve as a valuable indicator of the quality of healthcare provided by the hospital. Survival and disease control are two primary endpoints often used in clinical trials to demonstrate treatment efficacy, and therefore would greatly benefit clinicians if aggregated, analyzed, and reported back to clinical teams. Aggregation of information pertaining to targeted therapies would be equally valuable and indicates a potential gap in assessment of the impacts of innovative treatments on patients.

It is also notable that several different databases are used at the JGH to either document or aggregate outcome indicators relevant to colorectal cancer. There may be others, but this information is not readily available. Our findings indicate that the databases with the highest number of ICHOM-recommended PROs and clinical/administrative indicators are those linked to larger-scale programs, either local (e.g., Quebec Cancer Registry) or international (e.g., ERAS Society program, or NSQIP). Some of the ICHOM-recommended PROs and clinical/administrative indicators, although not aggregated, are typically collected by clinicians and charted in the patient’s electronic medical records. However, the objective of this quality improvement initiative was not to perform a chart audit to identify PROs being documented by individual providers, but to assess what PROs and clinical/administrative indicators are being compiled and aggregated at the institutional level.

The importance of knowing which databases are used to aggregate which type of outcome data is important for institution-level quality improvement efforts and for advancing clinical practice. Aggregated data can be used by the hospital and individual providers to monitor trends and proactively take action as needed. Despite these benefits, there are challenges associated with data aggregation and integration. While the latter may be limited by information technology (IT) systems interoperability, the collection and entry of data from one system to another for the purpose of aggregation requires resources, as does the interpretation and analysis of this information. In a clinical setting, allocation of clinical resources to data aggregation may have direct impact on patient care and hence requires careful consideration. Progressive IT solutions and artificial intelligence applications for data management, such as Power BI used at the JGH, can synchronize data stored in some databases and import them into an interactive dashboard. This can provide actionable data insights to physicians, care teams, and hospital administrators.

Objective 2a

Healthcare Providers' Awareness of Outcomes Being Collected at the Hospital Level

We surveyed eight healthcare providers at the JGH. Even though it was a small sample, it was representative of a multidisciplinary team for colorectal cancer at the JGH—these providers included a medical oncologist, surgeon, nurses, and allied health professionals (dietitians).

Healthcare Providers' Perception of Outcomes Being Collected at JGH Differs From What Is Actually Being Aggregated

We asked the participating providers which of the ICHOM-recommended PROs and clinical/administrative indicators for colorectal cancer are being collected at the JGH (hospital level). They indicated that all of the ICHOM-recommended indicators for colorectal cancer were being collected. Their responses did vary between indicators, but this was likely due to their role in patient care (e.g., nurse vs. physician/surgeon vs. allied health provider) and the types of outcomes that were relevant to their practice.

Interpretation

A discrepancy was noted between the outcomes the healthcare providers believed were being collected versus the outcomes that were being aggregated at the JGH. While our findings do not explain the observed discrepancy, several possibilities exist and may require further investigation.

First, we cannot be sure how the word “collect” was interpreted by the respondents to the question: *Which of the following colorectal cancer indicators are being collected at the JGH?* It is possible that to healthcare providers, collect—especially with regards to PROs—meant obtaining these outcomes through a patient assessment, charting them in the patient’s electronic medical record, but not necessarily having these data aggregated at the hospital level for ongoing tracking, monitoring, and quality improvement. The latter requires a separate resource to compile the data from patient records to another software.

It is also possible that the providers are collecting these outcomes during patient assessment but not charting them in a consistent or standardized manner. The accuracy of information recorded in patient charts has been debated in the literature, and various inaccuracies, errors of omission, fragmentation between paper and electronic format, and inconsistencies in scope and kind of charted information have been described.^{45,46,47} Unless the information is clearly recorded in a patient’s chart or electronic record, using consistent wording and common medical language, the archivist or registrar will not be able to transfer it to the appropriate database.

45 Smith and Haque, “Paper Versus Electronic Documentation in Complex Chronic Illness.”

46 Yadav and others, “Comparison of Accuracy of Physical Examination Findings in Initial Progress Notes Between Paper Charts and a Newly Implemented Electronic Health Record.”

47 Strömngren and others, “Does the Medical Record Cover the Symptoms Experienced by Cancer Patients Receiving Palliative Care?”

Another possibility is that the archivist or registrar responsible for data management of specific databases may not be required to compile specific types of information under their permissions or mandate. In such cases, even if the information is recorded in a patient's chart, it would not be transferred for aggregation to the database managed by that archivist or registrar.



Objective 2b

Do Healthcare Providers Use PROs in Their Practice?

Our questions in this section assessed providers' use of ICHOM-recommended PROs and clinical/administrative indicators pertaining specifically to a patient's health, including quality of life, functional status, and long-term adverse effects. We also inquired about the providers' attitudes toward measuring these PROs.

Healthcare providers report using PROs in their practice and see them as important. When asked about the frequency of using ICHOM-recommended PROs in their practice, almost all participants indicated that the following PROs were used "always" or "often"—pain, dietary restrictions and diarrhea, overall well-being, physical functioning, mobility, bowel functioning, fatigue, and gastrointestinal (GI) symptoms. The least frequently used PROs included sexual functioning, erectile dysfunction, and vaginal symptoms.

Attitudes Toward Measuring PROs

When asked about the importance of measuring PROs via standardized collection tools, all respondents answered that doing so was "very important" or "important" (6 out of 8 answered very important and the remaining two answered important).

All providers indicated that PROs measurement was very important or important at all points throughout the care process:

- at initial visit (8 out of 8 indicated very important)
- at subsequent visit(s) during active treatment (6 out of 8 indicated very important and 2 indicated important)
- at subsequent visit(s) off active treatment (5 of out 8 indicated very important and 3 indicated important)
- updated annually (5 of out 8 indicated very important and three indicated important)

Interpretation

The JGH healthcare providers' attitudes toward PROs were positive. This is important to support and ensure the success of the JGH's ongoing quality improvement about the collection, compilation, aggregation, reporting, and use of these measures. Some questions still remain, as they were not addressed in the provider survey. For example, why do all providers feel it is very important or important to collect PROs using standardized tools? How exactly do they use PROs in their practice? Have they experienced any challenges with PROs collection or interpretation? These remaining questions may require further investigation to inform a broader PROs implementation strategy at the JGH.

There is limited evidence on provider attitudes toward PROs for colorectal cancer. In one study, clinicians' knowledge and attitudes toward PROs for colorectal cancer were examined via interviews, which revealed rather positive general attitudes toward PROs and their advantages in clinical use.⁴⁸ At the same time, the authors noted some skepticism among the participating clinicians regarding the practical utility of PROs, stemming potentially from lack of experience with using PROs and the uncertainty around possible clinical consequences of PROs results for treatment options and modifications.⁴⁹ The authors of the study highlight the importance of involving clinicians as early as possible when planning a broader implementation of PROs in colorectal cancer and identifying appropriate implementation strategies based on ways clinicians regard PROs as a useful tool for routine cancer care.⁵⁰

In another study, clinics that reported collecting PROs attributed a higher level of importance for doing so than those that were not collecting PROs,⁵¹ suggesting again that familiarity with PROs, their use, and interpretation may be important to overcoming barriers related to the lack of perceived clinical usefulness. Enhancing clinicians' knowledge about PROs and their importance for colorectal cancer care needs to be considered when developing a concrete PROs implementation strategy.⁵²

48 Sibert and others, "Clinicians' Knowledge and Attitudes Towards Patient Reported Outcomes in Colorectal Cancer Care."

49 Ibid.

50 Ibid.

51 Zhang and others, "Use of Patient-Reported Outcome Measures in Quality Oncology Practice Initiative."

52 Sibert and others, "Clinicians' Knowledge and Attitudes Towards Patient Reported Outcomes in Colorectal Cancer Care."

To that end, it is important to highlight that existing evidence indicates that PROs can serve as predictors of survival in patients with colorectal cancer.^{53,54}

When it comes to patient perspectives toward PROs, evidence from patients with various health conditions and from a range of countries reveals various benefits, including gaining a sense of empowerment through self-reflection and playing a more active role in their care planning, individualizing treatments, and sharing in decision-making (among others).⁵⁵ In another study, integrating PROs in clinical care was found to enhance patient involvement and helped patients (and providers) to set priorities for office visit discussions.⁵⁶ Providers also report that integration of PROs in patient care enhances patient engagement and shared decision-making.⁵⁷ There's growing consensus that the provision of patient-centred care is fostered by better engagement between patients and their healthcare team, which can be facilitated through incorporation of PROs into clinical workflows.



Lessons Learned and the Path Forward

The quality improvement initiative undertaken by the JGH provided important insights into the colorectal cancer PROs and clinical/administrative indicators that are currently being collected, compiled, and aggregated at the hospital level. Approximately two-thirds of ICHOM-recommended PROs and clinical/administrative indicators for colorectal cancer we assessed are being aggregated in different, non-integrated databases at the JGH. Most are aggregated in SARDO, followed by EIAS, NSQIP, Med Echo, and Opera. This example highlights the importance for institutions to understand which specific databases may store the required PROs for a given therapeutic area; and should subsequently be included in data aggregation efforts.

Several PROs and clinical/administrative indicators are recommended by ICHOM that are not being aggregated in any of the databases examined. Most of these are PROs assessing patients' degree of health. The PROs that were identified as not aggregated were related to patients' emotional, social, and sexual functioning, depression, fatigue, dietary restrictions, fecal leakage and stool frequency, and neuropathy. This is important as international evidence shows that many colorectal cancer survivors experience persistent and long-term GI symptoms and functioning impairments that have a negative impact on the patient's physical, social, emotional,

53 Rutherford and others, "Patient-Reported Outcomes as Predictors of Survival in Patients With Bowel Cancer."

54 Hsu and others, "The Utility of Abbreviated Patient-Reported Outcomes for Predicting Survival in Early Stage Colorectal Cancer."

55 Carfora and others, "Patients' Experiences and Perspectives of Patient-Reported Outcome Measures in Clinical Care."

56 Westergaard and others, "Patient Perspectives on Patient-Reported Outcomes in Multiple Sclerosis Treatment Trajectories."

57 Lavalley and others, "Incorporating Patient-Reported Outcomes Into Health Care to Engage Patients and Enhance Care."

and sexual function.⁵⁸ Reports from survivors also indicate that these effects are underestimated by clinicians and that survivors experience and manage these symptoms in isolation.⁵⁹

Healthcare providers' attitudes toward the collection of PROs were very positive. All rated measuring PROs via standardized collection tools as very important or important at all critical points throughout the disease process (initial visit, subsequent visits during active treatment, subsequent visits off active treatment, and updated annually). The high level of importance assigned by healthcare providers to the collection of PROs is an important finding and is likely to lead to better adoption and compliance with their collection, as well as their use at the institutional level, if the JGH decides to implement standardized collection of PROs.



We also found a potential discrepancy between the outcomes the healthcare providers believed were being collected at the hospital level versus the outcomes that were actually being compiled and aggregated. Whatever the reason for this discrepancy (possible interpretations were explored earlier), it highlights several opportunities for improvement.

First, to enhance the quality of care and services provided to patients, it is important for care providers to know exactly what outcomes they and their teams are collecting and the means and methods through which these measures are—or are not—being compiled and aggregated at the hospital level; and how they are used for tracking, monitoring, and improving the quality, safety, and efficiency of care delivered at the hospital. It is also important for high-quality information (e.g., aggregated clinical and PROs) to be brought back to providers to inform and influence clinical excellence.⁶⁰ To influence clinical practice, healthcare providers require the information to be appropriately aggregated and available in a timely manner.

Improvement can be achieved through providing more information about the pertinence of collecting PROs, standardization of how outcome data are tracked (e.g., by implementing checklists and alerts), and raising awareness of the different databases that are used at the JGH. Better outcome tracking at the provider level will not only improve the quality of care for patients but will also make it easier for medical archivists and registrars to track and monitor the outcomes at a hospital level—thus enabling better macro decision-making and benchmarking based on results.

58 Rutherford and others, "Patient-Reported Outcomes and Experiences From the Perspective of Colorectal Cancer Survivors."

59 Ibid.

60 Williams and others, *Patient-Reported Outcome Measures*.

From a patient's perspective, having PROs and clinical data integrated at the patient level (micro level) is important to facilitate individual-level clinical and shared decision-making.

Despite the importance and benefits of the collection of PROs, administrative and technical challenges related to integrating PROs into clinical practice and existing processes have been described in the literature.⁶¹ These include: lack of robust and easily accessible IT infrastructures, inadequate resources and administrative support to facilitate implementation, lack of coordinating structures overseeing the implementation process, and lack of clarity and evidence-based knowledge on what to do (action) with the results.^{62,63,64,65}

For these reasons, it has been recommended that any institution planning to undertake routine collection of PROs does so with consideration of these challenges as well as the key success factors—having centralized staff and resources, ability to provide adequate training, and continuous monitoring and adjustment.⁶⁶ The integration of sophisticated technology (e.g., remote monitoring, electronic PROs (ePROs), artificial intelligence, machine learning) can support the greater integration of various types of outcome measures and feedback loops into routine clinical care.⁶⁷ It requires investments in IT infrastructure but offers the potential to realize benefits of minimizing the burden associated with data collection and tracking on patients and healthcare providers, while helping to optimize patient outcomes.

Final Remarks

This impact paper describes a quality improvement initiative undertaken by the JGH in Montreal, Quebec, Canada, which aimed to characterize and describe its current colorectal cancer outcome measurement practices in relation to the highly regarded ICHOM standard set recommendations. Improving the delivery of care to colorectal cancer patients using PROs can improve patients' quality of life. These initial findings highlight specific areas for improvement towards standardizing the routine collection of PROs within this and other therapeutic areas. They also inform the JGH and other institutions in their approach to planning and monitoring the ongoing implementation of PROs. Other institutions can use a similar approach to identifying their baseline outcomes measurement as they embark on their own quality improvement endeavours to standardize and advance the collection and aggregation of PROs and to maximize their utilization to advance clinical excellence and patient engagement.

61 Basch and others, "Implementation of Patient-Reported Outcomes in Routine Medical Care."

62 Breidenbach and others, "Could Existing Infrastructure for Using Patient-Reported Outcomes as Quality Measures Also Be Used for Individual Care in Patients With Colorectal Cancer?"

63 Horn and others, "Electronic Health Record—Integrated Approach for Collection of Patient-Reported Outcome Measures."

64 Zhang and others, "Use of Patient-Reported Outcome Measures in Quality Oncology Practice."

65 Williams and others, *Patient-Reported Outcome Measures*.

66 Basch and others, "Implementation of Patient-Reported Outcomes in Routine Medical Care."

67 Melstrom and others, "Patient Generated Health Data and Electronic Health Record Integration in Oncologic Surgery."

Appendix A

Definitions

Aggregation of data: A process where the individual data that have been compiled together is expressed in a summary form, which then enables its use on a larger scale (e.g., for statistical analysis on a large number of cases).

Clinical outcomes: Reflect the assessment of a patient's health status completed by a healthcare provider according to their clinical judgment or to interpretation of a patient's observable signs, including physical manifestations and behaviours.

Clinician-reported measures: Measurements that are completed by a healthcare provider.

Collection of data: The act of gathering information, such as the interaction of the patient with a healthcare provider, which results in collection of specific health information from that patient to provide the patient with the best possible treatment. This information will be recorded in the patient chart.

Compilation of data: The act or process of collating of patient data from various sources into a specific database or information management system where it can be securely stored for documentation purposes and in a format that allows it to be manipulated for analysis..

Databases: In healthcare, these are systems into which healthcare providers and/or healthcare administrators routinely enter clinical and/or patient-reported outcome data. Examples include electronic medical records, patient registries, etc.

Health information system: A system designed to manage healthcare data. Such systems can collect, store, analyze, and transmit healthcare data for purposes of documentation, health information management, or performance-monitoring and are used to support clinical and healthcare policy decision-making.

Health outcomes: Refer to changes in health status of an individual that result from specific health care interactions or interventions. They can be clinical- or clinician-reported, or patient-reported.

Health-related quality of life: “[T]he subjective assessment of the impact of disease and treatment across the physical, psychological, social and somatic domains of functioning and well-being.”¹

International Consortium for Health Outcome Measurement (ICHOM): A healthcare improvement organization, which collaborates with patients, providers and life science organizations across the world to define and promote the measurement of patient-reported outcomes in an effort to improve the quality and value of care.

Outcome measure: A tool used to assess a patient's current status (can be clinical or patient-reported).

Patient-reported outcomes (PROs): Reports from patients about their own health, quality of life, or functional status associated with the healthcare or treatment they have received. They come directly from the patient, without interpretation of the patient's response by a healthcare provider or caregiver. These could include disease symptoms or treatment side effects, such as pain, fatigue, or anxiety; functional outcomes such as physical, sexual, social, emotional, or cognitive functioning; or multidimensional constructs such as health-related quality of life.

Patient-reported outcome measures (PROMs): A set of validated measurement tools used for the collection of PROs. Examples include validated self-reported questionnaires to evaluate symptoms, functionality, and physical, mental, and social health.

Quality improvement: In healthcare, refers to a systematic approach that is guided by data or evidence and meant to improve the quality and safety of healthcare delivery.

Quality indicators: Standardized, evidence-based measures of healthcare quality designed to measure and track clinical performance and outcomes (clinical and patient reported) over time.

Standard sets: Condition-specific standardized outcomes, measurement tools and time points, and risk adjustment factors that are co-developed by an international consortium of experts and patients (ex. through ICHOM). The sets focus on outcomes that matter to patients and the shared needs of a specific patient segment.

¹ Revicki and others, “Recommendations on Health-Related Quality of Life Research to Support Labeling and Promotional Claims in the United States.” (p. 888)

Appendix B

ICHOM Standard Set for Patients With Colorectal Cancer

Table 1
ICHOM Standard Set for Patients With Colorectal Cancer

Patient population	Indicator	Frequency of measurement	Suggested data sources
Disutility of care			
Patients with surgery	Stoma status	Updated at least 6 months, 1 and 2 year(s) post-treatment	Clinical
All patients with treatment	Impact of acute complications Type of acute complication	Updated at least 6 months after treatment	
Degree of health			
All patients	Overall well-being Physical functioning Emotional functioning Social functioning Mobility Depression Sexual functioning Bowel functioning Ostomy functioning Pain Fatigue	Baseline, 6 months, 1 year post-treatment, tracked annually up to 10 years	Patient reported, using a standardized questionnaire (the most widely used and generally accepted health-related quality of life in oncology is the questionnaire by the European Organization for Research and Treatment of Cancer, which is supplemented by disease-specific modules, subscales reflecting the functional scores (physical function, emotional function, anxiety, etc.)
Patients with surgery/ radiotherapy	Dietary restrictions Fecal leakage Stool frequency Diarrhea Gastrointestinal symptoms Erectile dysfunction Vaginal symptoms		
Patients with systemic therapy	Neuropathy		
Survival and disease control			

(continued ...)

Table 1 (cont'd)

ICHOM Standard Set for Patients With Colorectal Cancer

Patient population	Indicator	Frequency of measurement	Suggested data sources
All patients	Overall survival	6 months, update at least annually up to 10 years	Administrative/clinical
	Cause of death (death attributed to colorectal cancer)		
Patients with curative intent	Recurrence-free survival	Updated at least 6 months after treatment	Clinical
Patients with advanced disease	Progression-free survival		
Patients with rectal cancer receiving neoadjuvant therapy	Pathologic or clinical complete response (no sign of residual invasive cancer of resected specimen or on diagnostic evaluation)		
Patients with rectal cancer receiving surgery	Margin status (evidence of circumferential margin involvement)		
Quality of death			
Patients with advanced disease	Place of death	6 months, update at least annually	Administrative/clinical
	Preference for place of death		
	Hospital admission at the end of life (more than 1 time in the last 30 days of life)		Clinical

Source: Adapted from ICHOM*.

*International Consortium for Health Outcome Measurement. "Colorectal Cancer Data Collection Reference Guide."

Appendix C

Methodology

We used the ICHOM-recommended standard set for colorectal cancer (see Appendix B) to assess which of the indicators were being collected and aggregated at the Jewish General Hospital (JGH), and if they were being used by healthcare providers.

First, we identified a few people (medical archivists and registrars) with knowledge and practical experience with data entry into JGH databases and asked them to go through a detailed list of 67 ICHOM-recommended indicators for colorectal cancer. We asked them to verify which ones were being collected and for the indicators that are being collected, to specify in which databases they were compiled.

We then surveyed eight healthcare providers at JGH about their knowledge of the colorectal cancer indicators being collected at the hospital and about their own use of PROs (the “degree of health” category of indicators as presented in Appendix B). The sample of providers, even though small, was representative of a multidisciplinary team for colorectal cancer at JGH and included a medical oncologist, surgeon, nurses, and allied health professionals (dietitians).

After having identified the collected outcomes, providers were asked additional questions to assess their use of ICHOM-recommended PROs (e.g., which ones they use in their practice and how frequently) as well as the providers’ attitudes toward measuring these PROs (e.g., how important, in their opinion, is measuring patient-reported outcomes via standardized collection tools and how important is patient-reported outcome measurement at different steps throughout the care process).

The answers to all questions were tabulated and descriptive summaries were generated to provide JGH with insights into colorectal outcome collection, compilation, and aggregation, and inform further quality improvement efforts.

Appendix D

List of ICHOM-Recommended Outcomes for Colorectal Cancer and the Databases at JGH Where They Are Compiled for Aggregation

Table 1

	If information collected, where is it compiled for aggregation?									
Baseline (pre-treatment) clinical factors	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Performance status ECOG (Eastern Cooperative Oncology Group)									✓	✓
Comorbidities (e.g., heart disease, lung disease, diabetes, kidney disease)							✓	✓	✓	
Cognitive status/evidence of cognitive disorder								✓	✓	
Familial adenomatosis polyposis (presence of adenomatous polyposis coli [APC] mutation)							✓		✓	
Lynch syndrome/hereditary nonpolyposis colon cancer presence of mismatch repair [MMR] or epithelial cell adhesion molecule [EPCAM] mutation)										
Diagnosis of Inflammatory Bowel Disease						✓		✓	✓	
Baseline (pre-treatment) tumour factors	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Initial date of tumour histological diagnosis										✓
Tumour location (e.g., caecum, appendix, ascending colon, hepatic flexure, transverse colon, splenic flexure, descending colon, sigmoid colon, rectum)							✓	✓	✓	✓
Location of rectum tumour (distance in cm from the anal verge)									✓	
Clinical stage per American Joint Committee on Cancer (AJCC) 5th–7th									✓	

(continued ...)

Table 1 (con't)

If information collected, where is it compiled for aggregation?										
Synchronous primary tumour (presence of more than one primary tumour)									✓	✓
Histological grade of tumour									✓	✓
Presence of BRAF mutation										✓
Presence of Ras mutation										✓
Microsatellite instability (MSI)/DNA mismatch repair, presence of MSI)										✓
Pathological M stage per AJCC 5th–7th										✓
Pathological TNM stage per AJCC 5th–7th									✓	✓
Number of lymph nodes resected									✓	✓
Number of lymph nodes involved										✓
Presence of lymphovascular invasion of the tumour									✓	✓
Presence of perineural invasion in resected tumour										✓
Completeness of surgical resection (presence of residual disease after surgery)										✓
Baseline treatment factors	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Urgency of procedure (as per National Confidential Enquiry into Patient Outcome and Death) classification: elective, scheduled, urgent, emergency						✓			✓	
Presence of perforation of the bowel at site of the tumour									✓	✓
Treatment intent (curative or palliative)										✓
Treatment variables	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Surgery: Whether the patient received surgery during the last year and type (e.g. hemicolectomy right, extended colectomy right, transverse resection, hemicolectomy left, subtotal colectomy, total colectomy, sigmoid resection, anterior resection, low anterior resection (LAR), abdomino-perineal resection (APR), proctectomy with coloanal, other)						✓	✓			✓
Surgery: Method of surgical procedure (e.g., endoscopic [for colon tumours], transabdominal open, transabdominal minimally invasive (laparoscopic/robotic), transanal open, transanal endoscopic microsurgery/transanal minimally invasive surgery, other)						✓	✓	✓	✓	✓
Surgery: Date						✓	✓	✓		✓
Radiotherapy: Whether patient received radiotherapy during the last year (e.g., neoadjuvant, adjuvant, definitive)							✓		✓	✓

(continued ...)

Table 1 (con't)

If information collected, where is it compiled for aggregation?										
Radiotherapy: What type (e.g. short course, long course without chemotherapy, long course chemoradiation, brachytherapy, intraoperative radiation therapy (ORT), or other)										✓
Radiotherapy: Start date and Stop date										✓
Chemotherapy: Whether the patient received chemotherapy during the last year (e.g. neoadjuvant, adjuvant, definitive)							✓		✓	✓
Chemotherapy: What type (e.g. FOLFOX regimen, capecitabine/oxaliplatin, capecitabine, 5-FU/leucovorin, 5-FU, irinotecan, FOLFIRI, FOLFOXIRI, Uracil-tegafur (UFT)/leucovorin, Lonsurf (trifluridine and tipiracil, or other)										✓
Chemotherapy: Start date and Stop date										✓
Targeted therapy: Whether the patient received targeted therapy during the last year										
Targeted therapy: Start date and Stop date										
Disutility of care (adverse events and complications)	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Stoma status (Any stoma (colostomy/ileostomy) received after surgery)						✓	✓	✓	✓	✓
Impact of acute complication as described in the Clavien-Dindo Classification and Common Terminology Criteria for Adverse Events (CTCAE) v4.0								✓		
Type of acute complication (e.g. leakage, breakdown of anastomosis, wound infection, thromboembolic, hematoma, stoma related complications, skin desquamation, dysuria, dehydration, weight loss, febrile neuropathy, neutropenic sepsis, mucositis, skin toxicity, neurotoxicity)							✓	✓	✓	
Degree of health- Patient reported outcomes	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Overall well-being							✓			
Physical functioning							✓			
Emotional functioning										
Social functioning										
Mobility							✓			
Depression										
Sexual functioning										
Bowel functioning							✓			
Ostomy functioning							✓			

(continued ...)

Table 1 (con't)

If information collected, where is it compiled for aggregation?										
Pain									✓	
Fatigue										
Dietary restrictions										
Fecal leakage										
Stool frequency										
Diarrhea									✓	
Gastrointestinal symptoms									✓	
Erectile dysfunction										
Vaginal symptoms										
Neuropathy										
Survival and disease control	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Cause of death indication if death attributed to colorectal cancer								✓	✓	✓
Recurrence-free survival (local, regional, or distant recurrence)										✓
Progression-free survival										
Pathologic or clinical complete response (No sign of residual invasive cancer of resected specimen or on diagnostic evaluation)										✓
Evidence of circumferential margin involvement									✓	✓
Quality of death	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Place of death										✓
Preference for place of death										
Hospital admission at the end of life (Admission to the hospital > 1 time in last 30 days of life)										
Demographic variables	ARIA	Centro	EndoVault	E-Rendez-Vous	OACIS	Opera	EIAS	Med Echo	NSQIP	SARDO
Demographic information: Gender, age, ethnicity, educational level, relationship status							✓			✓

Source: The Conference Board of Canada.

Appendix E

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