ADDRESSING HIGH PRIORITY ISSUES IN CANCER CARE

EXAMPLES FROM THE OICR AND CCO HEALTH SERVICES RESEARCH PROGRAM
Addressing high priority issues in cancer care:

The Health Services Research Program is a joint effort of the Ontario Institute for Cancer Research (OICR) and Cancer Care Ontario (CCO). Its goal is to provide the knowledge needed to optimize the delivery of cancer services and to ensure appropriate dissemination of health service innovations and well-evaluated technologies.

This report provides brief summaries of results arising from 15 research studies that were conducted between 2010 and 2013. These research studies span the continuum of cancer care, from screening to symptom management in later stages of cancer.

This report is intended for anyone with an interest in health care; for people at risk of developing cancer or for those with cancer. A scientific background is not needed.

For those who would like additional information, links to resources are provided.

We hope you find the report informative,
What was the problem? Colorectal cancer (CRC) is one of the key causes of avoidable cancer-related death. Fecal occult blood testing (FOBT) has been shown to decrease death from CRC in randomized controlled trials. FOBT rates are poor compared to uptake of screening for other preventable cancers such as cervix and breast. Given these data, organized colorectal cancer screening programs are being implemented worldwide. In 2008, Ontario launched Canada’s first organized province-wide CRC screening program, ColonCancerCheck (CCC). A central principle of organized screening programs is that all persons in the target population be invited to participate. In order to test whether large scale, centralized mailed invitations to Ontario’s target population were feasible in promoting FOBT, CCC conducted a large pilot project, called the Primary Care Invitation Pilot.

How was it addressed? The investigators evaluated the Primary Care Invitation Pilot including the proposed mailed invitations by holding focus groups with lay participants who were eligible for screening and with family doctors. They also determined how many people responded to the invitation and received an FOBT.

What were the results? Lay participants said that it was important to receive the invitation from one’s own family physician. Most people preferred the brief letter that emphasized key points, as opposed to a longer letter. Family doctors strongly supported the CRC screening program generally but preferred colonoscopy as a screening test. The team found that 22 per cent of the 11,000 persons who received the mailed invitation through the Primary Care Invitation Pilot had an FOBT in the six months following compared to just 8 per cent of 11,000 persons who did not receive the invitation.

Lessons learned: This work has informed CRC screening health policy in Ontario and is highly applicable to CRC screening efforts in other provinces. These findings have the potential to enhance participation in not only CRC screening, but also in other organized screening programs.
What was the problem? In 2005 Cancer Care Ontario (CCO) published evidence-based standards for lung and esophageal cancer surgery. The standards mandated that surgery for lung and esophageal cancer only take place in high-volume hospitals by high-volume surgeons. The team led by Dr. David Urbach evaluated the effects of this policy on lung cancer surgery outcomes including mortality, readmission to hospital, emergency room visits after discharge from hospital and length of hospital stay.

How was it addressed? To conduct the evaluation, the team analyzed information from health care databases for lung cancer surgeries in Ontario from 2004 to 2010. They examined outcomes in hospitals that were already high-volume and in those that became high-volume because of the policy.

What were the results? The team found that the majority of patients were already receiving their care in high-volume hospitals. They found that higher hospital volumes were associated with improvements in mortality and length of stay but not readmission to hospital or emergency room visits. The improvements seen were mostly due to patients going to hospitals that were already high-volume. Hospitals that became high-volume because of the CCO policy did not have a similar improvement in outcomes except for shorter lengths of stay.

Lessons learned: The results of this study showed several improvements in lung cancer surgery across already high-volume hospitals. But the CCO policy change did not seem to have much impact in hospitals that became high-volume, other than shortening lengths of hospital stay.
A Women’s Cancer Survivorship Team: Late effects of cancer drug therapy

What was the problem? As a result of improved screening and treatment, the five-year survival rate for women diagnosed with breast cancer is about 90 per cent and many will remain cancer free for the rest of their lives. However, many women face health problems caused by their cancer treatment. More information is needed about the long-term effects of breast cancer therapy and about how to identify those at the highest risk of these effects.

How was it addressed? The goal of the Women’s Cancer Survivorship Team led by Drs. Anderson and Rochon was to bring together women’s health and methods experts based at Women’s College Hospital to create research teams focused on three high priority areas: breast cancer and diabetes, breast cancer treatment and bone health, and breast cancer treatment and cardiovascular health. A key strategy was to build future capacity for survivorship research by attracting experienced researchers who had not worked on cancer before and by providing support to young investigators to develop careers in survivorship research.

What were the results? Each of the three research teams was successful in creating new and important knowledge that will improve understanding of the healthcare issues for breast cancer survivors. The diabetes team has shown that women with breast cancer are at increased risk for diabetes, especially women who had taken a specific type of breast cancer drug. The bone health team published a review of the effects of a common breast cancer therapy on bone health, showed that breast cancer survivors in Ontario often do not get the recommended followup, and found that economic analysis of breast cancer therapy is flawed because it ignores the impact of undesirable side effects. The cardiovascular disease team showed an important association between a common cancer therapy and the risk of heart attack. Each team was able to attract experienced researchers to cancer survivorship research and to win competitive funding to support the careers of new investigators in survivorship research.

Lessons learned: The Women’s Cancer Survivorship Team has created productive research teams focused on topics important to breast cancer survivors. Future challenges include keeping teams together, bringing this model of collaborative survivorship research to other cancers and ensuring that the research has a real and lasting impact on cancer survivors.

Principal Investigators: Geoff Anderson and Paula Rochon
What was the problem? Patients with cancer may have worrisome symptoms such as tiredness, shortness of breath, pain and loss of appetite. Recently, Ontario’s cancer system implemented two patient assessment tools. A research team led by Dr. Lisa Barbera used information captured by these tools to find out the severity and nature of patients’ symptoms and performance status to improve the care they receive.

How was it addressed? The team conducted several studies by linking data from the two patient assessment tools with other data to explore the relationships between symptom burden, function and the health services that patients with cancer received.

What were the results? The studies found that women and those with health problems in addition to cancer had poor symptom scores, with patients suffering from lung cancer having the heaviest burden of symptoms. It was seen that one-third of elderly patients who reported severe pain did not receive prescriptions for effective pain medication. The studies also suggested that as physical symptoms and symptoms related to a sense of well-being worsened, emergency room visits grew in frequency. Shortness of breath, drowsiness, poor well-being, lack of appetite and tiredness were shown to be the symptoms that most worsened as the disease progressed.

Lessons learned: Together, these studies have described patients most likely to have severe symptoms and pointed to several gaps in the care of these patients. The results suggest that an effort to optimize management of cancer-related pain is needed. Patients who report poor well-being may require a detailed assessment in an outpatient clinic, rather than having them seek care in the emergency room. Patients whose function begins to deteriorate may benefit from a referral for palliative care support.

Principal Investigator: Lisa Barbera
What was the problem? While Ontario has a wealth of high-quality health databases, relatively little work has examined how to use them for economic evaluations and determining the costs of cancer care. Consequently, improving the methods and increasing expertise in economic studies is a high priority for the Health Services Research Program.

How was it addressed? A team led by Dr. Nicole Mittmann assessed the availability and quality of cost information in Ontario health databases; tested a method to identify costs to treat different types of cancer at each cancer stage; established different categories of costs; validated the information obtained through linking health databases; and created a report on the cost of cancer in Ontario.

What were the results? Important cancer-related information, including stage of cancer, types of drugs including chemotherapy and other treatments such as radiation and home care were made available to the team for the first time. The team determined management costs for the following types of cancer: breast, non-Hodgkins lymphoma, colorectal, and non-small cell lung. It created a summary table of available cost information by health database.

Lessons learned: The process to obtain permission to use the data was long (more than a year in some cases) and extensive analytical work was needed to ensure that the information was accurate. This work was completed so that future data would remain accurate and new permissions would not be required for future health care planning and decision making.
What was the problem? In the past, analysis of data sets relevant to cancer research, such as the Ontario Cancer Registry (OCR) and Ontario Health Insurance Plan (OHIP) claims, had to be carried out within a handful of secure physical locations and only aggregate data were released beyond the walls of those institutions. While this approach had been successful at preserving patient privacy and confidentiality, it was slow and expensive, and created barriers for researchers not affiliated with one of the specified organizations. It was also unable to accommodate the necessary capacity for research in the province.

How was it addressed? The Ontario Institute for Cancer Research (OICR), Cancer Care Ontario (CCO) and the Institute for Clinical Evaluative Sciences (ICES) began work on a joint initiative to create a new data release mechanism called ‘cd-link’. With this program, data sets are linked, de-identified, and, with the protections of a comprehensive Data Use Agreement (DUA), provided directly to investigators following a comprehensive review and approval process.

What were the results? The first cd-link data release occurred in March 2010. To date, the program has received and approved over 40 requests from academic researchers, clinician scientists and postdoctoral fellows on topics such as: the surgical management of renal tumours; transitions in cancer care: healthcare settings and services used by cancer patients in the last year of life; the effect of adjuvant hormonal treatment on bone health in older breast cancer survivors; the impact of adherence to HER2 testing, treatment and monitoring guidelines in early stage breast cancer; phase-specific and lifetime costs of cancer in Ontario; and the epidemiology and burden of illness associated with hepatocellular carcinoma.

Lessons learned: The cd-link program helps facilitate the timely conduct of research, making it possible to carry out large population-based studies to address policy-relevant issues across the cancer control continuum. With further updates, cd-link will make collaboration even easier by making data sets accessible to researchers outside Ontario through VPN, a highly secure network.
What was the problem? The uptake of many cancer-related advancements into clinical practice is variable, with rates that are less than optimal. The identification and analysis of effective strategies to improve the uptake of cancer control options is an important step if the full benefits of advancement in cancer control are to be realized. The team led by Dr. Brouwers conducted a synthesis and overview of the effectiveness of knowledge translation (KT) strategies for cancer control and to use that information i) to inform the Ontario cancer system of effective KT interventions and ii) to guide future provincial research priorities in the area of KT for cancer control.

How was it addressed? Using a multi-method approach, the program of research i) used existing KT resources to identify and analyze systematic reviews in the published literature evaluating the effectiveness of interventions directed to change behaviour across stakeholder groups; ii) used key informant interviews and questionnaire methods to identify through stakeholders best Canadian KT practices aimed at improving cancer control; and iii) used consensus methodology to integrate the findings and to identify gaps and priorities in the KT research field.

What were the results? A total of 34 reviews providing 41 evidence summaries for 19 KT interventions across the cancer care continuum were identified. None of the reviews concluded definitively in favour of or against a specific intervention. A KT for Cancer Control in Canada Casebook, profiling 19 best KT practices (“field initiatives”) from across Canada spanning the cancer care continuum was developed. The results of the review and the Casebook were presented at a meeting of cancer leaders and KT experts from across Canada.

Lessons learned: An overview of evidence related to KT in cancer control was established, which presented opportunities for improvement. The Casebook provided tangible examples of efforts to improve cancer control and included practical direction for others facing similar experiences.
What was the problem? An overall quality agenda to improve patient outcomes and system performance in cancer control requires an understanding of what effective intervention strategies are available that can facilitate uptake of high quality and credible knowledge. While there have been significant advancements to identify effective interventions, information as to how to operationalize and implement them is less understood. This knowledge gap has been particularly well documented with interventions aimed to promote appropriate cancer screening and referral.

How was it addressed? The team conducted a review of the published and grey literatures to identify tools and resources to optimize the successful application of effective knowledge translation (KT) interventions relevant to cancer screening and referral. They focused on interventions of known effectiveness: small media, client reminders and audit and feedback to health care providers. They evaluated the usefulness and feasibility of the resources by stakeholders.

What were the results? Resources were identified describing how to implement and develop the interventions of interest (52.2 per cent involved client reminders, 34.8 per cent small media and 13 per cent were multi-component; no audit and feedback resources were found). Of the 23 resources, 87 per cent described how they developed the resource and 95.7 per cent provided implementation information. From the stakeholder evaluation, the majority of responses were positive regarding layout and usability of the resource summary profiles, with a request for additional information, which was added to the final profile versions.

Lessons learned: While there is a vast literature available on the effectiveness of cancer screening interventions, opportunities exist for improving the translation of their operationalization in practice.

Principal Investigator: Melissa Brouwers
Improving quality of care for pancreatic cancer: Developing evidence-based clinical pathways for patients undergoing pancreatic cancer surgery

Principal Investigator: Alice Wei

What was the problem? Pancreatic cancer is the fourth leading cause of cancer mortality in Canada. Surgical removal in combination with chemotherapy is the best treatment for the disease. However, pancreatectomy is a highly complex surgery that requires specialized expertise to perform safely. Cancer Care Ontario has worked to centralize pancreatic surgery to nine high-volume hepato-pancreatico-biliary (HPB) centres of excellence. Unfortunately, access and quality of surgical care for pancreatic cancer remains variable, leaving room for both increased standardization and quality improvement. Wei and her team believe that advances in quality must include interventions that target the processes of care. Clinical pathways (CPWs) are important quality improvement and knowledge translation tools that target process change to improve the quality of care.

How was it addressed? The goal of this project was to develop an evidence-based CPW for patients undergoing pancreatic cancer surgery in Ontario. The team conducted needs assessment workshops with high-volume HPB centres of excellence and confirmed that there remains variation in the processes of surgical care among institutions. All institutions expressed a desire for a quality improvement instrument, leading to the development of a CPW that incorporated best-evidence recommendations.

What were the results? The CPW was successfully implemented at one pilot site. The next step is to develop an active implementation strategy to introduce the CPW to all institutions performing pancreatic surgery in Ontario.

Lessons learned: Early engagement of health care providers was vital for obtaining input prior to CPW development. Early engagement also promoted uptake and acceptance of the CPW tool. Soliciting feedback and incorporating suggestions from CPW users helped build enthusiasm for the tool and encouraged ownership of the CPW by the entire team.
What was the problem? While pre-operative chemoradiotherapy (preCRT) decreases the risk of cancer returning in the rectum following surgery, preCRT also leads to poorer bowel and sexual function compared with surgery alone. Due to problems with pre-operative staging, patients who are unlikely to benefit from preCRT may not be identified. Currently, MRI is used for pre-operative staging by measuring three distinct elements that would call for preCRT to be used. Previously, this group showed that only 40 per cent of MRI reports in Ontario contain all three MRI criteria necessary to make treatment decisions.

How was it addressed? In order to improve the quality of MRI reporting in Ontario, the team developed and implemented synoptic MRI reports in April 2011 through a Radiology Webinar that was endorsed by Cancer Care Ontario. For the webinar, participating radiologists reviewed five MRIs and completed the synoptic MRI report for each. Physicians discussed the criteria with the radiology expert and asked questions. Data analyses revealed that there was relatively low to moderate agreement for the MRI criteria. The team repeated the Radiology Webinar in 2013 to determine if physician agreement for the MRI criteria has improved.

What were the results? To date, the team has completed the data collection for both the Radiology Webinars in 2011 and 2013 and are analyzing their results. It is expected that the results will show improved agreement (i.e., consistency) among the physician participants for MRI criteria for the Radiology Webinar in 2013 relative to 2011. Feedback from the participants demonstrated that the webinar format and invited expert (Dr. Gina Brown) significantly contributed to the success of the project.

Lessons learned: There is a high level of physician interest in using synoptic MRI reporting for rectal cancer. The study should improve the completeness of the reporting and agreement between physicians on each of the three essential elements in the synoptic report that are used for pre-operative staging.
What was the problem? Primary care physicians and cancer specialists are not well integrated and have differing views of how to communicate. This results in confusion about what role each provider plays, especially once cancer treatment is complete. This project seeks to determine opportunities to improve the communication between primary care physicians and specialists through the use of multidisciplinary case conferences (MCC). At MCCs, individual cancer patients are reviewed by medical, radiation and surgical oncologists, pathologists, radiologists and nurses and recommendations on best management are made. MCCs are already being used in the cancer system but do not include primary care physicians, an addition that could benefit knowledge translation between the two parties and enhance patient care.

How was it addressed? This project is testing the feasibility of bringing primary care physicians into MCCs using the Ontario Telemedicine Network platform and if possible, to determine what types of knowledge are exchanged between providers when this happens. Feasibility will be assessed by determining the percentage of invited primary care physicians who attend the MCCs. In addition, semi-structured interviews will be held with the primary care physicians and oncologists to understand the experience of participating in the MCC, as well as perceived benefits and barriers to participation.

What were the results? The study is ongoing. To date, 18 primary care physicians have been approached to participate in an MCC, with three having been completed. Once complete, the results may smooth the transition between providers as patients move through their cancer journey, impacting the way providers work together to care for patients.

Lessons learned: Scheduling has been a challenge for many primary care physicians and is the major reason for the lack of participation at this point. Based on feedback to date, strategies to address this barrier are under development to be tested in the fall of 2013.
What was the problem? Knowledge exchange (KEX) involves interaction between researchers and research users. KEX increases the relevance and use of research, and improves health care delivery and outcomes, but it is not widely practiced due to multiple challenges that may differ by context. This study was conducted to examine whether and how context influences KEX and to issue recommendations for strategies to support KEX.

How was it addressed? Ethnography was used to examine contextual factors that influenced whether and how KEX occurred, and its impact. This was studied in three contexts: colorectal cancer screening, prostate cancer diagnosis and pancreatic cancer management. Data were collected from content analysis of documents, observation of meetings and interviews with researchers and research users between September 1, 2012 and May 15, 2013.

What were the results? KEX was greater in the colorectal context, which featured the following factors: socio-political (clear goals, consensus on goals), economic (dedicated funding), capacity (space, forums, leadership, administrative support), specified researcher roles (affiliated, embedded) and diversity of engaged disciplines. KEX included interaction at meetings and joint production of research and guidelines. Researchers contributed to decision-making by summarizing, presenting, interpreting and commenting on the quantity, quality and relevance of evidence, and whether and how it could inform decisions. KEX largely involved physician-researchers and research users. There was only one instance of interaction between a researcher and patients, and no mention of interactions with policy-makers. Social and research outcomes were achieved, but health system outcomes were not apparent. There was no difference across the three contexts in reported factors that challenged KEX. Researchers and decision-makers lacked awareness and knowledge of how to undertake or achieve KEX. Managers preferred published research over KEX.

Lessons learned: Social, political and economic support influenced the capacity for, prevalence of, and outcomes associated with KEX. Numerous factors challenged KEX, but several possible strategies were identified to address these challenges.
What was the problem? Lung cancer is the most common and deadly cancer in Canada. The standard treatment approach should include molecular testing of a person’s lung cancer and then personalized therapy to improve quality of life, decrease side effects and slow cancer growth. Although this approach significantly improves outcomes, it is used only in a minority of people diagnosed with lung cancer in Ontario.

How was it addressed? Dr. Leighl’s team studied whether molecular testing rates and processes could be improved through educating specialists involved in diagnosing lung cancer, and identified barriers and potential solutions to be presented to Cancer Care Ontario and the provincial government.

What were the results? To date, approximately 100 Ontario specialists (respirologists, thoracic surgeons, radiologists and pathologists) have been surveyed about their lung cancer molecular testing knowledge. Following an educational program, specialists had better understanding of the importance of testing, when to order it and for whom, and techniques to get sufficient cancer tissue for testing. Barriers identified include the lack of dedicated government funding for testing, and clear guidance for Ontario pathologists on the importance of routine molecular testing for the expression of certain receptors as part of the diagnostic pathway. These receptors included the epidermal growth factor receptor (EGFR) and anaplastic lymphoma kinase receptors (ALK), which can both lead to the growth of certain lung cancers.

Lessons learned: Educational gaps still exist among Ontario specialists about the importance and requirements for molecular testing in lung cancer. Ensuring that timely molecular testing is integrated into the lung cancer diagnostic pathway, measured as a quality indicator and funded by the province, will help ensure more Ontarians can access personalized medicine.
What was the problem? Gene expression profiling (GEP) of tumours estimates recurrence risk, potentially affecting decisions about chemotherapy for women with early breast cancer, of whom only 15 per cent will experience a recurrence.

How was it addressed? In phase one of the study, the team used interviews and focus groups with breast cancer patients and medical oncologists (MOs) to obtain views on the value of, and challenges with, GEP for chemotherapy treatment decision-making in breast cancer. In phase two they measured the value of GEP information in chemotherapy treatment decisions based on risk-benefit trade-offs using a conjoint analysis survey that included hypothetical scenarios and participants’ cancer experiences.

What were the results? In phase one, through interviews and focus groups with 28 breast cancer patients and 14 MOs, the team found that both groups valued GEP, often using it as a final determinant in treatment decisions, despite MOs concerns about the technical limitations and patients’ limited understanding of GEP. Results from the survey in phase two revealed that more than 75 per cent of respondents knew someone who had chemotherapy for cancer, while less than 10 per cent knew someone who had GEP testing. Across the groups, 300 women with breast cancer, 1004 women from the general population and 50 MOs, it was found that the two most important factors in chemotherapy treatment decisions were GEP score, indicating likely benefit from chemotherapy and doctor’s estimate of risk of cancer returning, based on clinical algorithms.

Lessons learned: GEP is highly valued and influences chemotherapy treatment decisions to a different extent in each group, providing preliminary evidence supporting the clinical value of GEP in breast cancer treatment decisions.

Principal Investigator: Deborah Marshall

Understanding risk benefit trade-offs of genetic testing in chemotherapy treatment decisions for breast cancer
Decisions regarding adjuvant endocrine treatment can be difficult for post-menopausal women with early-stage, hormone-receptor positive breast cancer and their treating physicians. In order to assist both parties in this decision, Feldman-Stewart proposed a decision aid that could be integrated into clinical practice in Ontario.

In order to create the proposed decision aid, Feldman-Stewart developed a research program. The first steps in the program involved a quantitative study identifying the questions women would want answered when deciding among treatment options. It also involved a qualitative study identifying how physicians structure their decisions, how they present the decisions to their patients, what information they consider important and what type of decision aid they’d feel would be helpful in their clinical practice.

In the quantitative study it was found that many patients wanted a lot of information before a decision was made but there were wide differences within the group regarding both the number and which specific questions they would want answered. It was also shown that although most patients wanted to participate in the decision, they varied widely on which specific details they would want to help them make the decision. In the qualitative study, it was found that physicians try to balance the complexity of the decision against patient burden by simplifying the choice. However, simplification differs across physicians.

The wide difference in the information considered important to individual patients means that decision support and education should be tailored to the needs of the individual patient. A decision aid, used within the consultation by both physician and patient or by the patient alone outside the consultation, was found to be a useful tool.

Creating a patient decision aid addressing adjuvant endocrine therapy for post-menopausal women with hormone receptor positive early-stage breast cancer

Principal Investigator: Deb Feldman-Stewart
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