ARCC Conference 2012
Conference Program

Canada’s 1st Applied Research in Cancer Control Conference
May 28, 2012
Hilton Montréal Bonaventure Hotel
Montréal, Québec
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Floor Plan
Welcome Message
From the ARCC Co-Directors
ARCC Conference 2012

Welcome to the 2012 Applied Research in Cancer Control Conference!

We are delighted to be hosting Canada’s first conference in applied cancer research featuring health economics, services, policy and ethics. This conference marks another significant milestone for ARCC, an organization with many achievements and successes since its founding in 2009. It is very exciting to have the national leadership gathered today for this event. This conference clearly demonstrates that the time for applied cancer research is now.

The purpose of this conference is to provide a venue to foster connections among academics, researchers, clinicians, students and policy makers. ARCC offers many resources for the applied cancer control research community as it develops and expands in Canada, and as we continue to expand we encourage you to get involved.

There are many ways for you to engage. Stay informed about our programs, webinars, newsletters, and other related opportunities using ARCC’s Network. For more information on how you can benefit, see www.cc-arcc.ca/network/

We want to thank the many people who have helped make today a special event: Kimberly van der Hoek and Sarah Benn who worked with the Face 2 Face event management team to create this event; ARCC program leads, Melissa Brouwers, Craig Earle, Jennifer Gibson, Arminee Kazanjian, Murray Krahn, Christopher Longo, and Mary McBride, who served on the review committee for the abstracts; and, thank you to Claire de Oliveira who provided invaluable support planning the concurrent costing session.

A special thank you to the Canadian Cancer Society (CCS), the Canadian Association for Health Services Policy Research (CAHSPR) and our partner organizations who have contributed time and funding to ensure the success of this conference.

Enjoy the conference!

Dr. Jeffrey Hoch
ARCC Co-Director

Dr. Stuart Peacock
ARCC Co-Director
7:30am - 5:00pm  
**Registration**  

7:30am - 8:30am  
**Breakfast**  

8:30am - 8:40am  
**Welcome Remarks**  
*Dr. Stuart Peacock*, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC);  
*Peter Goodhand*, President and CEO, Canadian Cancer Society  

8:40am - 9:30am  
**Keynote Presentations**  
*Chairled by: Dr. Jeffrey Hoch*, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC)  

- Developing a Health Data Strategy for Research: The Ontario Perspective  
  *Dr. David A. Henry*, President and CEO, Institute for Clinical Evaluative Sciences (ICES)  

- Applied Cancer Research: Population Health Screening  
  *Dr. Andrew Coldman*, Vice President of Population Oncology, BC Cancer Agency  

- Informing the Process: How to Maximize the Impact of Applied Cancer Research  
  *Dr. Carol Sawka*, Vice President, Clinical Programs and Quality Initiatives and Co-Chair, Clinical Council, Cancer Care Ontario  

9:30am - 10:00am  
**Question and Answer Period**  

10:00am - 10:30am  
**Poster Viewing/Nutritional Break**  

10:30am - 12:00pm  
**Concurrent Sessions**  

**Societal Values and Public Engagement**  
*Chairled by: Dr. Melissa Brouwers*, Associate Professor, McMaster University  

- Public Preferences for the Allocation of Healthcare Resources in a Canadian Cancer Context  
- Quantifying Preferences for Bacterial Infection Prophylaxis in Pediatric Oncology  
- Personalized Medicine and Access to Health Care: A Continuum of Genetic Discrimination?  
- The Value of Personalizing Medicine: Medical Oncologists’ and Patients’ Perspectives on Genomic Testing of Breast Tumours in Chemotherapy Decisions  
- Research Ethics and Clinical Obligations: Ethnographic Observation of Expert Panel Deliberations in Trial of Genomic Sequencing in Cancer Patients
Full Program Agenda
ARCC Conference 2012

Patients and Families
Chaired by: Dr. Arminée Kazanjian, School of Population and Public Health, Research Associate, BC Cancer Agency

- The Childhood, Adolescent and Young Adult Cancer Survivors (CAYACS) Research Program of British Columbia
- Cancer Incidence and Survival Among Adolescents and Young Adults in Ontario
- Social Media and Cancer Drug Funding: Implications for Research and Policy
- The Ontario Cancer Study: Initial Demographics and Health Status Report
- From Science to Service: The Ontario Patient Reported Outcomes of Symptoms and Toxicity (On-PROST) Research Unit

Cancer Costing in Canada
Chaired by: Dr. Murray Krahn, University of Toronto/THETA, University Health Network

- Cost of Palliative Care in Alberta
- The Costs of Cancer Care Before and After Diagnosis for the 21 Most Common Cancers in Ontario
- Costing Cancer Care in British Columbia
- Out-of Pocket Costs for Patients with Cancer in Ontario
- The Impact of Out-of-Pocket Costs on use of Cost Savings Strategies and Care Decisions Among Breast and Prostate Cancer Patients in Newfoundland and Labrador
- Using Canadian Partnership Against Cancer’s Cancer Risk Management Model to Undertake Costing Analyses
- Medical Costs of Care for Childhood Cancer in British Columbia and Ontario

12:00pm - 12:45pm Networking Lunch
12:45pm - 1:30pm Poster Viewing
Concurrent Sessions

Health Technology Assessment and Health Systems Services and Policy  
Salon Fontaine C

Chair: Dr. Christopher Longo, Associate Professor, McMaster University

- A Theoretical Framework for Exploring System-Level Accountability in Ontario’s Cancer Services System
- The Evaluation of Cancer Control Interventions in Lung Cancer Using a Canadian Cancer Risk Management Model
- Does the Healthcare Resource Utilization of Patients with Metastatic Gastric Cancer Vary Between Local Health Integration Networks in Ontario?
- Simulation of Lung Cancer Control Programs in Canada
- Evaluation Of The Diagnostic Assessment Program And The Electronic Pathway Solution. A Multidimensional Cycle Of Improvement And Assessment

Knowledge Translation  
Mont Royal

Chair: Dr. Jennifer Gibson, Assistant Professor, Director of Partnerships and Strategy, University of Toronto: Institute of Health Policy, Management and Evaluation, Joint Centre for Bioethics

- Clear as Mud: Decision Making in the Face of Uncertainty
- The Modeling the Cost-Effectiveness of Prostate Cancer Screening in British Columbia
- Practice Variation and Consistency in the use of Radiation Therapy between Regional Cancer Centres
- Establishing Evidence-Based Workload and Staffing Reallocation within a Provincial Radiation Therapy Program
- Adherence to Human Epidermal Growth Factor Receptor-2 (HER2) Testing & Adjuvant Trastuzumab Treatment Guidelines in Ontario
Health Systems, Services and Policy

Chaired by: Mary L McBride, Distinguished Scientist, BC Cancer Agency

- Algorithms to Identify Significant Adverse Events (AEs) for Colorectal Cancer Screening Program Population
- Incidence of Endoscopy-Related Adverse Events in a Screening Program Population: Results From Algorithms Based on Medico-Administrative Databases
- Do Patient Reported Symptoms Predict for Emergency Department Visits? A Population Based Analysis
- Family Physician Continuity of Care in End-of-Life Homecare Cancer Patients and its Association with Acute Care Services Use
- How Effective is Population-Based Cancer Screening? Regression Discontinuity Estimates from Across Canadian Provinces

3:00pm - 3:30pm

Poster Viewing Session

3:30pm - 4:25pm

Keynote Presentations

Chaired by: Dr. Stuart Peacock, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC)

Deliberative Engagement: From Biobanks to Personalized Medicine
Dr. Michael Burgess, Professor and Research Chair, Biomedical Ethics, W. Maurice Young Centre for Applied Ethics, Department of Medical Genetics, University of British Columbia

Incorporating the Public: Ontario’s Citizen Council
Diane McArthur, Assistant Deputy Minister and Executive Officer of Ontario Public Drug Programs, Province of Ontario

Transparency and Collaboration: the pan-Canadian Oncology Drug Review
Dr. Mona Sabharwal, Executive Director, Pan-Canadian Oncology Drug Review (pCODR)

4:25pm - 4:50pm

Question and Answer Period

4:50pm - 5:00pm

Closing Remarks

Dr. Jeffrey Hoch, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC)
Speaker Biographies
ARCC Conference 2012

Using Applied Research in Cancer Control

**Dr. David A Henry, MB, ChB, MRCP, FRCP** is President and CEO of the Institute for Clinical Evaluative Sciences (ICES) in Toronto and Professor in the Department of Medicine at the University of Toronto. Dr. Henry is a physician with training in internal medicine, gastroenterology and clinical pharmacology. Currently, Dr. Henry’s interests include the use of controlled observational designs using linked population health data-sets to evaluate the benefits and harms of drugs, health systems performance, health services research and health technology evaluation. Dr. Henry has extensive experience of pharmaco-epidemiology and systematic review methodology. Dr. Henry has also worked in the field of pharmaco-economics and is the past chair of the Economics subcommittee of the Australian Pharmaceutical Benefits Advisory Committee. Dr. Henry was Director of the WHO Collaborating Centre for Training in Pharmacology and Rational Drug Use in Australia and still advises on the regulation and pricing of drugs in low and middle income countries.

**Dr. Andrew Coldman, Ph.D** is the Vice President of Population Oncology at the BC Cancer Agency. Dr. Coldman has worked as a statistician/epidemiologist with the BC Cancer Agency since 1980 and holds joint-appointments as Adjunct Professor in the Departments of Statistics and Health Care and Epidemiology at the University of British Columbia. Dr. Coldman’s research has focused on two principal areas. Firstly the measurement of the effectiveness of screening using population data modelling of screening processes and secondly the development and use of statistical indicators for use in cancer control measurement at the population level. In the last decade his research has concentrated on screening and he is currently a PI for the HPV Focal trial which is a randomized trial of HPV testing as a primary screening modality for cervical cancer. Dr. Coldman continues to work in modeling cancer outcomes. Dr. Coldman is Chair of the technical subcommittee for the CPAC Risk Management Project and principal for the Collaborative stage implementation in the BC Cancer registry.

**Dr. Carol Sawka, MD, FRCPC** is Vice President, Clinical Programs & Quality Initiatives and Co-Chair, Clinical Council, Cancer Care Ontario. In that role, she works with clinical leaders across the province to improve the quality and coordination of the full spectrum of cancer care. Dr. Sawka is a medical oncologist with a special interest in the management of breast cancer. Dr. Sawka is a Professor in the Departments of Medicine, Public Health Sciences, and Health Policy, Management and Evaluation at the University of Toronto. Her research is focused on health services and policy research related to the cancer system.

The use of Applied Cancer Research Supporting Innovation

**Dr. Michael Burgess, Ph.D** is Professor and Research Chair in Biomedical Ethics at the W. Maurice Young Centre for Applied Ethics and the Department of Medical Genetics at the University of British Columbia. Dr. Burgess’ research has focused on health, science and technology policy and public engagement based on theories of deliberative democracy. With co-lead Kieran O’Doherty, the research team developed an approach to deliberative engagement on biotechnology policy, with eight events in BC, the Mayo Clinic and in Western Australia across topics of biobanks, salmon genomics and environmental remediation. Recently, Dr. Burgess has begun to emphasize the wider social effects and policy implications of genomic and computational technologies often characterized as personalized medicine.

**Diane McArthur, MBA** is Assistant Deputy Minister and Executive Officer of Ontario Public Drug Programs for the Province of Ontario. Prior to her appointment in June 2010, Diane was the Assistant Deputy Minister responsible for seniors’ issues within the Government of Ontario. Diane has held progressively more senior positions in several ministries since joining the Government of Ontario as a Management Intern in 1989. Diane has extensive experience in health human resource policy and planning for health provider training, education, supply and distribution initiatives, data and health information planning and analysis, health care provider negotiations, rural health policy, labour relations, and service delivery restructuring.

**Dr. Mona Sabharwal, BScPhm, R.Ph** is the inaugural executive director of the pan-Canadian Oncology Drug Review (pCODR). Dr. Sabharwal has worked in drug technology assessment and formulary management, in both British Columbia and Ontario, for more than 15 years. Before joining pCODR, Dr. Sabharwal was the Senior Manager for Drug Programs Management with the Ontario Ministry of Health and Long-Term Care. In this role, Dr. Sabharwal had operational oversight of the drug submission and evaluation process for Ontario’s seven public drug programs. Ms. Sabharwal was a key participant in the early development of pCODR and led operations for its precursor, the interim Joint Oncology Drug Review (iJODR). She was also instrumental in Ontario’s development of a new and innovative evaluation framework for Drugs for Rare Diseases, which was implemented in 2008. In 2010, Dr. Sabharwal spear-headed and launched Ontario’s patient-evidence submission process, a formal process to systematically solicit patient-centred perspectives on new drug therapies.
### Morning Concurrent Sessions
10:30am – 12:00pm

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<th>Societal Values and Public Engagement</th>
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<td><strong>Public Preferences for the Allocation of Healthcare Resources in a Canadian Cancer Context</strong>&lt;br&gt;Chris Skedgel, PhD Candidate, The University of Sheffield</td>
<td><strong>The Childhood, Adolescent and Young Adult Cancer Survivors (CAVACS) Research Program of British Columbia</strong>&lt;br&gt;Dr. Paul Rogers, Clinical Professor, BC Children's Hospital</td>
<td><strong>Cost of Palliative Care in Alberta</strong>&lt;br&gt;Dr. Konrad Fassbender, Assistant Professor, University of Alberta</td>
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<td><strong>Quantifying Preferences for Bacterial Infection Prophylaxis in Pediatric Oncology</strong>&lt;br&gt;Dr. Dean Regier, Senior Health Economist, Canadian Centre for Applied Research in Cancer Control (ARCC), BC Cancer Agency Research Centre</td>
<td><strong>Cancer Incidence and Survival Among Adolescents and Young Adults in Ontario</strong>&lt;br&gt;Dr. Ronald Barr, Professor, McMaster University, McMaster Children's Hospital</td>
<td><strong>The Costs of Cancer Care Before and After Diagnosis for the 21 Most Common Cancers in Ontario</strong>&lt;br&gt;Claire de Oliveira, Post-Doctoral Research Associate, University Health Network, Toronto Health Economics and Technology Assessment Collaborative</td>
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<td><strong>Personalized Medicine and Access to Health Care: A Continuum of Genetic Discrimination?</strong>&lt;br&gt;Dr. Kelly McClellan, Post-Doctoral Fellow, Centre of Genomics and Policy, McGill University</td>
<td><strong>Social Media and Cancer Drug Funding: Implications for Research and Policy</strong>&lt;br&gt;Dr. Jennifer Gibson, Assistant Professor, Director of Partnerships and Strategy, University of Toronto: Institute of Health Policy, Management and Evaluation, Joint Centre for Bioethics</td>
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<td><strong>The Value of Personalizing Medicine: Medical Oncologists’ and Patients’ Perspectives on Genomic Testing of Breast Tumours in Chemotherapy Decisions</strong>&lt;br&gt;Dr. Yvonne Bombard, Postdoctoral Fellow, Yale University and Memorial Sloan-Kettering Cancer Center</td>
<td><strong>The Ontario Cancer Study: Initial Demographics and Health Status Report</strong>&lt;br&gt;Dr. Craig Earle, Director, Health Services Research, Cancer Care Ontario and the Ontario Institute for Cancer Research</td>
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<td><strong>Using Canadian Partnership Against Cancer’s Cancer Risk Management Model to Undertake Costing Analyses</strong>&lt;br&gt;Fei-Fei Liu, Researcher, Canadian Partnership against Cancer</td>
<td><strong>Medical Costs of Care for Childhood Cancer in British Columbia and Ontario</strong>&lt;br&gt;Mary McBride, Distinguished Scientist, BC Cancer Agency</td>
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### Afternoon Concurrent Sessions

**1:30pm – 3:00pm**

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<th>Health Technology Assessment and Health Systems Services and Policy</th>
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| **A Theoretical Framework for Exploring System-Level Accountability in Ontario’s Cancer Services System**  
Jessica Bytautas, Graduate Student and Research Officer, University of Toronto | **Clear as Mud: Decision Making in the Face of Uncertainty**  
Dr. Melissa Brouwers, Associate Professor, Department of Oncology, McMaster University | **Algorithms to Identify Significant Adverse Events (AEs) for Colorectal Cancer Screening Program Population**  
Pascale Levesque, Research Professional, Institut national de santé publique du Québec; Sophie Pouliot, Project Manager, Institut national de santé publique du Québec |
| **The Evaluation of Cancer Control Interventions in Lung Cancer Using a Canadian Cancer Risk Management Model**  
Dr. William K. Evans, President, Juravinski Hospital and Cancer Centre | **Modeling the Cost-Effectiveness of Prostate Cancer Screening in British Columbia**  
Reka Pataky, Data Linkage Coordinator, Canadian Centre for Applied Research in Cancer Control (ARCC), BC Cancer Agency | **Incidence of Endoscopy-Related Adverse Events in a Screening Program Population: Results From Algorithms Based on Medico-Administrative Databases**  
Sophie Pouliot, Project Manager, Institut national de santé publique du Québec; Pascale Levesque, Research Professional, Institut national de santé publique |
| **Does the Healthcare Resource Utilization of Patients with Metastatic Gastric Cancer Vary Between Local Health Integration Networks in Ontario?**  
Alyson Mahar, Graduate Student, Queen's University | **Practice Variation and Consistency in the use of Radiation Therapy between Regional Cancer Centres**  
Dr. Ivo Olivotto, VP Radiation Therapy and Functional Imaging, BC Cancer Agency | **Do Patient Reported Symptoms Predict for Emergency Department Visits? A Population Based Analysis**  
Dr. Lisa Barbera, Clinician Scientist, Odette Cancer Centre |
| **Simulation of Lung Cancer Control Programs in Canada**  
Dr. Sonya Cressman, The Canadian Centre for Applied Research in Cancer Control (ARCC) | **Establishing Evidence-Based Workload and Staffing Reallocation within a Provincial Radiation Therapy Program**  
John French, Senior Director, Operations, Business and Strategic Planning, BC Cancer Agency | **Family Physician Continuity of Care in End-of-Life Homecare Cancer Patients and its Association with Acute Care Services Use**  
Dr. Hsien Seow, Assistant Professor, McMaster University, Juravinski Cancer Centre, Escarpment Cancer Research Institute |
| **Evaluation Of The Diagnostic Assessment Program And The Electronic Pathway Solution. A Multidimensional Cycle Of Improvement And Assessment**  
Dr. Julie Gilbert, Manager, Research and Evaluation, Cancer Care Ontario | **Adherence to Human Epidermal Growth Factor Receptor-2 (HER2) Testing & Adjuvant Trastuzumab Treatment Guidelines in Ontario**  
Dr. Craig Earle, Ontario Institute for Cancer Research | **How Effective is Population-Based Cancer Screening? Regression Discontinuity Estimates from Across Canadian Provinces**  
Dr. Erin Strumpf, Assistant Professor, McGill University, Department of Economics and Department of Epidemiology, Biostatistics and Occupational Health |
Integration Between Family Physicians and Regional Cancer Systems in Ontario: Opportunities and Obstructions
Presented by: Dr. Daryl Bannbridge, Senior Research Coordinator, McMaster University

The Cost-Effectiveness of Rituximab in Advanced Follicular Lymphoma
Presented by: Corneliu Bolbocean, Ph.D. Candidate, The University of British Columbia

SAGE Directory of Cancer Guidelines
Presented by: Dr. Melissa Brouwers, Associate Professor, Department of Oncology, McMaster University

Chemotherapy Waste: Implications for Value in Health
Presented by: EK. Shawn Bugden, Associate Professor, Faculty of Pharmacy, University of Manitoba

Why Do Provinces Make Different Coverage Decisions for the Same Cancer Drugs?
Presented by: Dr. Roger Chafe, Assistant Professor, Memorial University

Health Economic Analysis of a Multi-Centre Pan-Canadian Clinical Trial for the Treatment of Oral Cancer (the COOLS Trial)
Presented by: Ian Croomwell, Health Economist, Canadian Centre for Applied Research in Cancer Control (ARCC)

Developing a Canadian Research Network for Adolescent and Young Adult Oncology
Presented by: Sonja De Pauw, Research Coordinator, McMaster University

Cost-Effectiveness of Hormone Therapies for ER+ Women with Early Breast Cancer in Canada: Exploring the Potential for the CYP2D6 Genetic Test
Presented by: Sandjar Djalalov, Post-Doctoral Fellow, St. Michael's Hospital, Li Ka Shing Knowledge Institute, Health Economics, Canadian Centre for Applied Research in Cancer Control (ARCC)

Closing the Personalized Medicine Information Gap in Breast Cancer: Central HER2 Test Documentation Practice in Ontario
Presented by: Ilia Ferrusi, McMaster University

Does Cost Drive Adherence? The Designer Drug Phenomenon
Presented by: Jalal Elbahn, St. Michael's Hospital

Variation in Treatment Patterns for Breast Cancer Patients in Alberta
Presented by: He Gan, Department of Public Health Sciences, University of Alberta; Dr. Marcy Winget, Leader, Research and Evaluation, Community Oncology, Alberta Health Services - Cancer Care

Monitoring Emerging Scientific Evidence to Guide Colorectal Cancer Screening Programs and Policies: A Prospective Multiple Case Study
Presented by: Hannah Geddie, Research Associate, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC)

Patient Navigation Tools and Resources: a Systematic Scoping Review
Presented by: Hannah Geddie, Research Associate, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC)

The Cost of Public Cancer Prevention in Alberta
Presented by: Dr. Philip Jacobs, Department of Medicine, University of Alberta and Institute of Knowledge and Improves Cancer Outcomes in First Nations Communities

Investigating the Effectiveness of Predictive Genetic Testing for Colorectal Cancer in Modifying Health Outcomes and Health Behaviours
Presented by: Joanne Kim, PhD Candidate, Institute of Health Policy, Management and Evaluation, University of Toronto, Cancer Centre for Applied Research in Cancer Control (ARCC)

Building on Existing Programs and Partnerships to Better Respond To the Needs of a Diverse Cancer Survivors’ Population
Presented by: Dr. Anne Le, Professor and Dr. Louis Schuman Cancer Research Chair, Department of Community Health and Epidemiology

Geomaps to Assess Regional Variation in Prevalence and Health Service Utilization Among Breast Cancer Survivors in British Columbia, Canada
Presented by: Dongdong Li, Statistician, BC Cancer Agency

Dynamic Case Studies in Cancer Control: Creating a Platform for Sharing Contextual Evidence
Presented by: Jacqueline Liberty, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC)

A Pilot Study Evaluating Canadian Cancer Patients’ Treatment Related Out-of-Pocket Costs
Presented by: Dr. Christopher Longo, Associate Professor, McMaster University

The Need for a New Model of Young Adult Cancer Follow-up Care in Canada
Presented by: Dr. Bauqje (Bo) Muersma, Director of Research, Dalhousie University

KT-Net: Improving Cancer Control in Ontario Through Knowledge Translation
Presented by: Dr. Mary Ann O’Brien, Post Doctoral Fellow, University of Toronto

Surgeons’ Views of Facilitators and Barriers to Optimal Breast Cancer Surgery Quality Indicators
Presented by: Dr. Mary Ann O’Brien, Post Doctoral Fellow, University of Toronto

Quantification of the Amount of Data Collected and Reported in Cancer Clinical Trials
Presented by: Eric Pelletier, Institut national de santé publique du Québec (INSHPQ)

Using Prognostic Indices to Guide Clinical Care in Elderly Cancer Patients
Presented by: Mayris Rebeira, Doctoral Candidate, University of Toronto

Funding Academic Oncology Clinical Trials: An Inadvertent Ponzi Scheme
Presented by: Dr. Haen Seow, Assistant Professor, McMaster University; Juravinski Cancer Centre, Escarpment Cancer Research Institute

Assessment of the Non-Medical Costs of Treating Metastatic Colorectal Cancer at the Segal Cancer Centre Using Time and Motion Methodology
Presented by: Gayle A. Shander, Program Coordinator, Department of Oncology, McGill University

Knowledge Sharing in Cancer Control: Online Learning Increases Provider Knowledge and Improves Cancer Outcomes in First Nations Communities
Presented by: Suzanne Stephenson, Engagement Liaison, Saint Elizabeth First Nations, Inuit and Metis Program

Health Services Utilization Among Hepatocellular Carcinoma Patients: A Population-Based Study
Presented by: Dr. Rosie Hla-Hla Thein, University of Toronto Dalla Lana School of Public Health

A Pan-Canadian Perspective of Variations in the Surgical Treatment of Cancer
Presented by: Brandon Wagar, Methodologist, Canadian Institute for Health Information

Developing Consensus-Based Research Priorities for Community-Based Integrative Oncology: A Delphi Survey
Presented by: Dr. Laura Weeks, Research Associate, Ottawa Integrative Cancer Centre

Adherence to Oncology Guidelines in Clinical Practice: A Quality Assurance Study in Early Stage Breast Cancer
Presented by: Audrey Wong, St. Michael's Hospital; Ammar Bookwala, St. Michael's Hospital

Breast Cancer Survivorship Care Tailored to South Asian Women
Presented by: Dr. Frances Wong, British Columbia Cancer Agency- Fraser Valley Centre

The Needs of Users of Health-Economic Evaluations in the Decision Process to Fund Cancer Therapies
Presented by: Dr. Dominika Wranik, Associate Professor, School of Public Administration, Dalhousie University

Value for Money in Cancer - What do we Know?
Presented by: Jean Hae Eun Yong, Lead Analyst, Pharmacoconomics Research Unit, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC)
Public Preferences for the Allocation of Healthcare Resources in a Canadian Cancer Context
Presented by: Chris Skedgel, PhD Candidate, The University of Sheffield

To estimate the societal value of different aspects of healthcare by eliciting allocative preferences from a representative sample of the Canadian public, using conjoint methods. Such estimates could inform a Communitarian allocation of resources, which holds that societal value can be enhanced by allocating resources according to societal preferences. An online panel of 1000 respondents was asked to prioritize one group from each of 11 pairs of hypothetical, unlabelled cancer patient groups. Groups were described in terms of age, quality-of-life and life expectancy with/without treatment, total patients and total quality-adjusted life years (QALYs) gained. Attitudes toward healthcare rationing and societal decision making were also elicited. Panel data were analyzed using a fixed effects mixed logit model (MXL). Attribute importance was calculated as the relative contribution of each attribute to the overall change in societal value associated with a move from the least preferred to the most preferred attribute levels. The MXL model showed that all factors except life expectancy without treatment were significant to people’s choices. Final quality-of-life, patient age, and life years gained had the greatest impact on societal value, with each accounting for approximately 25% of the net change in overall societal value. The total number of patients had the least impact, accounting for 10% of overall change. 1% of respondents maximized QALYs in every choice task. 75% of respondents ‘strongly’ or ‘somewhat strongly’ agreed that healthcare rationing would always be necessary, and 52% supported a public role in healthcare prioritizing decisions. 53% were ‘extremely’ or ‘somewhat’ comfortable having their preferences used in such decisions, and a respondent’s support for a public role was not correlated with their own preference comfort. Respondents consistently sacrificed efficiency in maximizing QALYs in order to prioritize patients based on equity factors such as quality-of-life and age. A majority also supported an explicit public role in healthcare decision-making. These results question QALY maximization as a decision rule and may be consistent with a more Communitarian approach.

Co-Authors: Dr. Allan Waileo, Professor, The University of Sheffield; Dr. Ron Akehurst, Professor, The University of Sheffield

Quantifying Preferences for Bacterial Infection Prophylaxis in Pediatric Oncology
Presented by: Dr. Dean Regier, Senior Health Economist, Canadian Centre for Applied Research in Cancer Control (ARCC), BC Cancer Agency Research Centre

Bacterial infection in pediatric oncology causes morbidity and mortality. The clinical utility of antimicrobial prophylaxis in children is uncertain and the personal utility of these agents is disputed. A discrete choice experiment was used to estimate the personal utility and willingness to pay for bacterial infection prophylaxis in pediatric oncology. Respondents included children with cancer receiving chemotherapy, parents of children receiving chemotherapy, and healthcare professionals at The Hospital for Sick Children, Toronto. Two alternatives in each of 16 choice questions differed on 5 attributes: risk of death, risk of infection, risk of side effects, drug administration, and treatment cost. Each question included an opt-out option to allow for non-demanders. A latent class model was used to estimate personal utility and to investigate preference heterogeneity. Respondents’ willingness to pay given a profile of benefits and risks with prophylaxis versus usual care was estimated; confidence intervals were constructed using Monte Carlo techniques. 11 children receiving chemotherapy, 52 parents of children, and 31 healthcare professionals completed 16 choice questions. The Bayesian Information Criterion suggested the optimal number of latent classes was 3. The demographic characteristics between the latent classes demonstrated no clear trend, suggesting respondents’ latent utility cannot be sufficiently characterized using pre-defined, deterministic group characteristics. Respondents’ utility part-worths for the attributes differed between the latent classes; notably, respondents in class 1 preferred, on average, to opt-out of prophylaxis treatment. Respondents’ mean WTP for bacterial prophylaxis was $426 (95% CI 272,1240) in latent class 1, $846 (95% CI 524,1366) in class 2, and $1,169 (95% CI 648,2900) for class 3. Average WTP across all latent classes was $855 (95% CI 505-1374). Across the 3 latent classes respondents were, on average, willing to pay $855 (95% CI 505-1374) per month for infection prophylaxis. Given the respondents value bacterial infection prophylaxis, our study suggests that further clinical research into the risk and benefits of bacterial infection prophylaxis in children is warranted.

Co-Authors: Caroline Diorio, MD Candidate, University of Toronto; Marie-Chantal Ethier, Clinical Research Manager, Child Health Evaluative Sciences, The Hospital for Sick Children; Lillian Sung, Scientist, Division of Haematology/Oncology, The Hospital for Sick Children

Personalized Medicine and Access to Health Care: A Continuum of Genetic Discrimination?
Presented by: Dr. Kelly McClellan, Post-Doctoral Fellow, Centre of Genomics and Policy, McGill University

The advent of personalized medicine promises that an individual’s genetic information will be increasingly used both in the prescription of medical interventions and to prioritize access to health care. The use of an individual’s genetic information to inform medical decision making, however, raises the question as to whether such use could be inequitable. This question is addressed using a concrete example of a genetic based clinical tool currently in use: breast cancer genetic risk prediction models. We examine the features and clinical use of these models that could give rise to inequities in gaining access to health care. This is followed by a discussion of the legislative, policy, and case law frameworks surrounding equitable access to health care in Canada. Two distinct normative regimes exist in Canada which together have the purpose of promoting equitable access to health care, through equal benefit of the law free from discrimination. Yet, as a result of the additional criteria imposed by the Supreme Court of Canada on medical benefits and emerging technologies in the evaluation of equitable access, it is doubtful inequitable use of genetic information would be recognized as discriminatory under the law. Yet our analysis raises the possibility that increasingly these legislative tools will not be able to meet their purpose of ensuring equitable access to universal health care. Given the increasing role personalized medicine is forecast to play in the provision of health care, this question is addressed using a concrete example of a genetic based clinical tool currently in use: breast cancer genetic risk prediction models. We examine the features and clinical use of these models that could give rise to inequities in gaining access to health care. This is followed by a discussion of the legislative, policy, and case law frameworks surrounding equitable access to health care in Canada. Two distinct normative regimes exist in Canada which together have the purpose of promoting equitable access to health care, through equal benefit of the law free from discrimination. Yet, as a result of the additional criteria imposed by the Supreme Court of Canada on medical benefits and emerging technologies in the evaluation of equitable access, it is doubtful inequitable use of genetic information would be recognized as discriminatory under the law. Yet our analysis raises the possibility that increasingly these legislative tools will not be able to meet their purpose of ensuring equitable access to universal health care. Given the increasing role personalized medicine is forecast to play in the provision of health care, addressing a broader view of genetic discrimination, one that occurs along a continuum, will be needed during the implementation of new medical applications based on individual genetic profiles. This raises the question as to how challenges related to maintaining equitable access can be addressed? And which stakeholders bear the responsibility for addressing equitable access? With the 2014 revision of the Canada Health Accord approaching, it is timely to consider these questions.

Co-Authors: Dr. Denise Avard, Associate Professor, and Research Directot, Centre of Genomics and Policy, McGill University; Dr. Jacques Simard, Professor, and Director of the CIHR Team in Fertility Risks of Breast Cancer, Université Laval; Dr. Bartha Maria Knoppers, Professor, Director, Centre of Genomics and Policy, McGill University
The Value of Personalizing Medicine: Medical Oncologists’ and Patients’ Perspectives on Genomic Testing of Breast Tumours in Chemotherapy Decisions

Presented by: Dr. Yvonne Bombard, Postdoctoral Fellow, Yale University and Memorial Sloan-Kettering Cancer Center

The benefit of adjuvant chemotherapy for early-stage breast cancer patients depends on baseline recurrence risk. Gene expression profiling (GEP) of tumours informs baseline risk prediction, potentially reducing unnecessary treatment and healthcare costs. Limited evidence exists on its clinical utility; we explored patients’ and oncologists’ perspectives on GEP in chemotherapy decisions. We used a qualitative design, comprised of individual interviews with medical oncologists (n=10) plus focus groups and individual interviews with breast cancer patients (n) from Ontario, Canada. Patients treated for breast cancer, who underwent genomic testing of their tumours ('OncotypeDX'), were recruited through oncology clinics from two academic hospitals in the Greater Toronto Area. Medical oncologists were recruited through participating oncology clinics, professional advertisements and referrals from the research team. Qualitative data were analyzed using interpretative qualitative methods, including content analysis, qualitative description and constant comparison techniques. Patients and oncologists valued GEP as an additional decision-support tool, complementing existing clinical indicators, though its perceived utility varied between patients and oncologists. Patients valued the test highly, suggesting it was one of the primary determinants of their treatment decision. All patients followed the course of action their results suggested. Patients with intermediate scores often used the results to reinforce their pre-existing treatment preferences. Oncologists were mixed about the test's utility. Some considered it another tool supporting their approach to risk assessments, while others used it more definitively to resolve their uncertainty. Oncologists explained the test's contribution to decision-making but remained uncertain about patients’ understanding and expectations of the test. Some raised concerns about the variability of its use and interpretation within their medical community. Patients and oncologists valued the test, often using it as a primary determinant in their treatment decision, despite oncologists’ concerns about its technical limitations and patients’ limited understanding. Results identify a need for informational decision aids and practice guidelines to support patient understanding and standardized application of the test.

Co-Authors: Dr. Linda Rozmovits, Independent Qualitative Researcher, Consultant; Dr. Maureen Trudeau, Associate Scientist, Sunnybrook Health Science Centre and University of Toronto; Dr. Natasha Leighl, Medical Oncologist and Assistant Professor, Princess Margaret Hospital and University of Toronto; Dr. Ken Deal, Associate Professor, McMaster University

Research Ethics and Clinical Obligations: Ethnographic Observation of Expert Panel Deliberations in Trial of Genomic Sequencing in Cancer Patients

Presented by: Jessica Bytautas, Graduate Student and Research Officer, University of Toronto

Trials to assess the clinical feasibility and utility of next generation sequencing technologies in cancer care identify somatic variants of uncertain clinical significance and unanticipated inherited health risks. Whether such individually-relevant research findings should be reported for clinical use is a much-debated topic in research ethics. As part of a multicenter trial evaluating the feasibility and clinical value of high throughput sequencing in the care of patients with advanced metastatic disease, we conducted non-participant observation of the Expert Panel (EP) that assessed the functional and clinical relevance of identified variants, to assess which were actionable and should be reported to physicians, with accompanying evidence assessments. The EP met weekly for 11-months. With ethics approval from OCREB, and the informed consent of EP members, we collected data at EP meetings and through brief ethnographic interviews. Adopting an interpretive descriptive approach, field notes were analyzed through constant comparison. 37 EP meetings have been observed (data collection on-going through March 2012). EP decisions about result disclosure evolved over the course of sequential deliberation, propelled by difficult cases. As the EP worked to formalize its judgments, scientific uncertainty was in tension with felt obligations of various sorts. The felt obligation of hope encouraged the EP to err on the side of permitting rather than excluding a treatment option by reporting uncertain information. The felt obligation of deference to clinical discretion and judgment encouraged the EP to defer scientific uncertainties to treating physicians. The felt obligation of clinical relevance encouraged the EP to emphasize clinical over study timelines. The felt obligation of clinical leadership encouraged the EP to use their research to motivate clinical practice. We report preliminary findings from an ethnographic study embedded within a targeted genome sequencing study in patients with metastatic disease. Our findings highlight the importance of felt clinical obligations in expert judgments about result 'actionability' and disposition. Whether these obligations are appropriate in the experimental oncology context warrants careful reflection.

Co-Authors: Robin Hayeems, Postdoctoral Fellow, University of Toronto; Dr. Fiona Miller, Associate Professor, University of Toronto
Patients and Families
10:30am – 12:00pm

The Childhood, Adolescent and Young Adult Cancer Survivors (CAYACS) Research Program of British Columbia
Presented by: Dr. Paul Rogers, Clinical Professor, BC Children’s Hospital

The Childhood, Adolescent and Young Adult Cancer Survivors (CAYACS) research program, funded by Canadian Cancer Society, examines late effects and long-term care issues among survivors of cancer diagnosed in British Columbia before age 25 years from 1970 who have survived at least five years. A retrospective cohort of 3,483 survivors, and representative comparison groups, were identified from population-based registries and linked with administrative databases of risk factors (including treatment) and outcomes to create a research database. Survivors of childhood and adolescent cancer had over nine times the mortality rate of the general population, five times the risk of a second cancer, and almost four times the risk of severe late morbidity. Survivors had similar educational achievement to their peers (except survivors of brain tumours). Survivors utilize more health care than their peers. They had three times the odds of being hospitalized, and were approximately twice as likely to visit a general practitioner and specialist over a 3-year period. Analysis of primary provider continuity of care suggested a slight decrease in continuity among survivors transitioning from pediatric to adult care. Adherence for most recommended follow-up tests was low (below 50% for eligible survivors). This program of data linkage identifies long term risks, health care utilization, and quality of care among long-term cancer survivors. This research will not only inform future health care policy and practice, but also generate hypotheses for further research.

Co-Authors: Maria Lorenzi, Biostatistician, BC Cancer Agency; Dr. Sam Sheps, University of British Columbia; Mary McBride, BC Cancer Agency

Cancer Incidence and Survival Among Adolescents and Young Adults in Ontario
Presented by: Dr. Ronald Barr, Professor, McMaster University, McMaster Children’s Hospital

To determine the incidence of cancer among adolescents and young adults (AYA) in Ontario by 3 major study factors: disease category; age-at-diagnosis group; and complexity of care level. To assess the relationship between 5-year survival rates and the study factors. To estimate the clinical trial enrollment rate among AYA cases. Data were collected from Cancer Care Ontario (CCO) and the Ontario Cancer Registry (OCR) for patients diagnosed between the ages of 15 - 29 years during January 1, 1990 through December 31, 2001. Disease categories were defined according to the 10-category AYA system. Age-at-diagnosis groups were: 15-19; 20-24 and 25-29 years. Complexity of care was categorized as: Pediatric Oncology Group of Ontario (POGO) centre; Regional Cancer Centre (RCC); RCC Affiliate/satellite; and remaining. Associations between study factors and incidence and survival proportions were tested using chi-square. 10,075 incident cases were identified. Disease categories with the highest frequencies were carcinomas (32.1%), lymphomas (21.8%) and germ cell tumours (13.0%). By age group, the highest frequency categories were: 15-19, lymphomas (30.0%); 20-24, lymphomas (24.6%) and carcinomas (26.4%); 25-29, carcinomas (40.4%). The majority of cases were treated at RCC (72.1%). Among 15-19 year olds, 24.3% were treated in POGO centres with the majority (60.7%) being treated at an RCC. The 5-year survival rate for the study population was 83%. There was a significant association (p<0.001) between 5-year survival proportions and each of the study factors. Preliminary data suggest about 1% of 15-29 year old patients at RCC are enrolled in clinical trials compared to 16% of adolescents and 55-65% of children at POGO centres. Important variability occurred in incidence and survival rates among AYA by disease category, age-at-diagnosis group, and complexity of care level. Clinical trial accruals of AYA are lower than of children and mature adults. Overall survival rates for AYA in Ontario (83%) are higher than in the USA (77%).

Co-Authors: Charlene Rae, McMaster University; William Furlong, McMaster University; Dr. Mark Greenberg, Pediatric Oncology Group of Ontario

Social Media and Cancer Drug Funding: Implications for Research and Policy
Presented by: Dr. Jennifer Gibson, Assistant Professor, Director of Partnerships and Strategy, University of Toronto: Institute of Health Policy, Management and Evaluation, Joint Centre for Bioethics

Social media is becoming a widespread phenomenon with implications for information exchange and social mobilization. Social media discourse offers a source of policy evidence about public perspectives and values. In this presentation, we report on a pilot study examining social media activity about cancer drug funding in two provinces. We developed a methodology to: i) collect and map Twitter activity, Google Search hits (as a proxy measure of public awareness) about cancer drugs under review over a 12 month period in Ontario and British Columbia, ii) calculate time to funding for each drug, and iii) analyze the nature and content of Tweets, including re-Tweets. Social marketing and data mining tools (e.g., Topsy, Google Insight) were used to collect Twitter and Google hits. Information about drug funding processes was taken from the public websites of each health ministry. The presentation will focus primarily on describing and assessing our study methods, including key challenges and lessons learned for using this technology to understand public perspectives and values and its influence on health policy. The limits of available data mining tools will also be discussed. To illustrate the methodology, we will present the Ontario case of Herceptin for small breast tumours in 2011. Volume of Twitter activity and Google Search hits were found to be closely aligned and often associated with a print media story. Most Tweets were written by individuals (vs. organizations) and expressed appeals for policy action (e.g., letter-writing campaign), including some directed at specific policy actors. These findings are mapped onto a timeline of policy events related to Herceptin funding in Ontario. Social media influence in health policy is not well-understood, and methods for analyzing its influence are not well-developed. Our pilot study takes some early, but promising, steps toward bridging these gaps.

Co-Authors: Michelle Cleghorn, University of Toronto Joint Centre for Bioethics; Laena Maunula, University of Toronto Joint Centre for Bioethics; Dr. Scott Berry, Sunnybrook Health Sciences Centre; Dr. Jeffrey S Hoch, St. Michael's Hospital Keenan Research Centre, Li Ka Shing Knowledge Institute, Canadian Centre for Applied Research in Cancer Control (ARCC); Dr. Stuart Peacock, British Columbia Cancer Research Centre, Canadian Centre for Applied Research in Cancer Control (ARCC)
The Ontario Cancer Study: Initial Demographics and Health Status Report
Presented by: Dr. Craig Earle, Director, Health Services Research, Cancer Care Ontario and the Ontario Institute for Cancer Research

The Ontario Cancer Study (OCS) is an analytic sub-cohort of the Ontario Health Study (OHS). The goal is to take advantage of the OHS infrastructure to enroll incident, prevalent, and former cancer patients, to efficiently create a large cancer cohort for research. People enrolling in the OHS who report a personal history of cancer are automatically part of the OCS. In addition, we are piloting strategies to enrich the OHS with cancer patients through clinic-based recruitment and centralized recruitment using the Ontario Cancer Registry. OHS data are captured through online surveys. To date over 95% of patients give active consent for re-contact (e.g., for surveys or to request biological specimens) and to have their data linked with administrative data. Here we report basic demographics of initial OHS participants. As of January 6th, 2012, 65,276 participants had enrolled and completed the baseline OHS questionnaire. Of these, 5,795 reported a personal history of cancer. Participants with cancer are older than those without (mean 58.4 vs. 44.6 years). The sex distribution is similar (61% vs. 62% female). Skin was the most common cancer site (1913 respondents), followed by breast (635), prostate (516), and colorectal (320). More than one cancer was reported by 662 participants. Respondents with a cancer history were more likely to report a family history of cancer (64% vs. 44%). They were less likely to rate their health as 'Excellent' or 'Very Good' (47% vs. 59%), and were more likely to say they live with pain or discomfort (37% vs. 26%). The OCS is establishing an outstanding resource for cancer research. The abilities to re-contact participants and link data, combined with information collected on medical resource utilization and health and screening behaviors in the OHS, will support future studies ranging across basic biology, health services delivery, economics, and outcomes.

Co-Authors: Kelly McDonald, Ontario Health Study; Dr. Sepideh Kamali, Odette Cancer Centre; Dr. Geoff Anderson, Women’s College Hospital

From Science to Service: The Ontario Patient Reported Outcomes of Symptoms and Toxicity (On-PROST) Research Unit
Presented by: Dr. Geoffrey Liu, University Health Network

Routine collection of Patient Reported Outcome Measures (PROMs) can contribute to clinical decision-making and improve health. Their systematic implementation in Ontario, outside the Edmonton Symptom Assessment (ESAS), has not yet occurred. Reaching consensus on a core set of PROMs is critical to improving health and monitoring the impact of cancer. On-PROST aims to improve the patient experience of cancer and the quality of care through the routine collection of a standardized set of patient-reported outcomes for use in clinical care, and to advance the science of cancer treatment through research across the cancer continuum. Based on initial consensus for the implementation of core PROM data (PROMs-Cancer Core), we will develop a cohesive research agenda and foster the development, standardization and implementation of core PROMs relevant across cancer populations for research use and clinical practice. We aim to collect outcomes that reflect the multidimensional impact of cancer on physical, emotional and social health. On-PROST focuses on five cancer research areas: Health Services Research; Biomarker Research; Radiation Oncology; Palliative and Supportive Care; and the PROMs-Cancer Core items. We plan to develop national and international partnerships, and to foster the development, standardization and implementation of core PROMs relevant across cancer populations and for disease specific purposes for routine clinical care and trials. Our goal is to foster common PROMs with multiple purposes, including performance and impact of cancer reporting, that will help deliver personalized quality care and treatment, and will concretely impact on cancer control and policy over the next five years.

Co-Authors: Dr. Doris Howell, University Health Network; Dr. Michael Brundage, Queen’s University; Dr. Andrew Hope, University Health Network; Dr. Gary Rodin, University Health Network; Andrea Perez Cosio, Program Co-ordinator, University Health Network
Cancer Costing in Canada
10:30am – 12:00pm

Cost of Palliative Care in Alberta

Presented by: Dr. Konrad Fassbender, Assistant Professor, University of Alberta

One in three Canadians are diagnosed with cancer at some point in his or her life, and about half of those people die of the disease. There is a paucity of large-scale, comparative costs for care provided to dying Canadians — the net result of which is a small evidence base upon which decision makers can rely. In Canada, end of life care policies continue to be targeted to individuals that are expected to die within six months. The rationale for this fact is based largely on an average 6-month decline in functional status and potential cost-savings from reducing utilization of unnecessary treatments in inappropriate settings for the cancer population. While costs associated with this time period are substantial, there is an emerging consensus that palliative care ought to be provided earlier. The objective of this presentation is to describe, explain and evaluate the economic consequences of introducing comprehensive, co-ordinated and integrated palliative care programs in Alberta, Canada. This evidence is required to address concerns from policy and decision makers as they continue to shift health care resources from institutional to community settings for terminally ill patients. We will examine the cost consequences from a societal viewpoint and also review studies which address personal and caregiving costs.

The Costs of Cancer Care Before and After Diagnosis for the 21 Most Common Cancers in Ontario

Presented by: Dr. Claire de Oliveira, Post-Doctoral Research Associate, University Health Network. Toronto Health Economics and Technology Assessment Collaborative

Cancer is one of the leading causes of death in Canada. The first year after cancer diagnosis is a period of intensive treatment and high cost. Our objective was to estimate costs for the 21 most common cancers in Ontario in the six months before diagnosis, and during the first year after diagnosis. We selected patients 19 years of age or older at diagnosis, with valid ICD-O and histology codes, who survived more than 30 days after diagnosis, and had no second cancer within 90 days of the initial cancer from the Ontario Cancer Registry between the years 1997-2007 (N= 402,399). We linked these patients to health care administrative databases. We examined health care resource use and calculated mean costs for each cancer during the pre- and post-diagnosis periods. Pre-diagnosis costs ranged from $10,000 for liver cancer to $2,000 for testicular cancer for long-term survivors and from $11,000 for breast cancer to about $6,000 for brain cancer for short-term survivors. Diagnostic testing and inpatient hospitalizations contributed the most to the overall cost. For the post-diagnosis period, costs of care were highest for esophageal cancer and multiple myeloma (over $50,000) and lowest for thyroid and testicular cancers (under $15,000) for long-term survivors. For short-term survivors, costs of care ranged from $80,000 for testicular cancer patients to $28,000 for liver cancer patients post-diagnosis. High costs post-diagnosis were mainly due to hospitalizations and, in some cases, chemotherapy. Our research provides cancer-specific cost estimates for the pre- and post-diagnosis phases. These estimates can help inform policy makers’ decisions regarding resource allocation for cancer prevention and control and serve as an important input for economic evaluations.

Co-Author: Karen Bremner, University Health Network, Toronto Health Economics and Technology Assessment Collaborative; Nadia Gunraj, Institute for Clinical Evaluative Sciences, Sunnybrook Health Sciences Centre; Dr. Kelvin Chan, Department of Medicine, University of Toronto, Sunnybrook Health Sciences Centre and Princess Margaret Hospital; Dr. Murray D. Krahn, Department of Medicine and Faculty of Pharmacy, University of Toronto, University Health Network, Toronto Health Economics and Technology Assessment Collaborative

Costing Cancer Care in British Columbia

Presented by: Reka Pataky, Data Linkage Coordinator, Canadian Centre for Applied Research in Cancer Control (ARCC)

The BC Cancer Agency (BCCA) provides population-based cancer control for the province of British Columbia, including screening, diagnosis, treatment, and supportive care. The placement of the BCCA within the structure of the BC healthcare system presents some unique opportunities and challenges for measuring the use of health services and calculating the costs of care. This presentation will focus on the secondary use of data from the BCCA’s Cancer Agency Information System (CAIS) to calculate the costs of cancer care, in particular the costs of chemotherapy, radiotherapy, and other outpatient services. We will also review the relationship between CAIS data and other administrative data sources in the province, and present preliminary cost estimates for a population-based cohort of BC patients.

Out-of Pocket Costs for Patients with Cancer in Ontario

Presented by: Dr. Christopher Longa, Associate Professor, McMaster University

A cancer diagnosis not only impacts the health care system, but also has an impact on patients and their families financially. A review of work published by Longo (2006,2007), Lauzier (2008), Mathews (2009) and others will briefly explain what we understand about the financial impact of a cancer diagnosis for common cancers, including the impact on out-of-pocket costs, travel costs, and lost income to patients and their families.
Previous studies in Canada reported that cancer patients may face substantial out-of-pocket costs related to their care. Studies of patients in Newfoundland and Labrador (NL) suggest that out-of-pocket costs may influence the patients’ treatment decisions and lead to the use of cost-saving strategies that may compromise the quality of their care. We surveyed 170 men with prostate cancer and 131 women with breast cancer in NL to examine the relationship between out-of-pocket costs and their influence on treatment decisions and the use of cost saving strategies. We found that 18.8% of prostate cancer patients and 25.2% of breast cancer patients had out-of-pocket costs greater than $500 in the three month period prior to the survey. These costs consumed more than 7.5% of quarterly household income for 15.9% of prostate and 19.1% of breast cancer patients, respectively. Few patients (8.8% of prostate and 15.3% of breast cancer patients) ever adopted any drug or appointment related cost saving strategies (e.g. rationing drugs, cancelling appointments etc.). Few patients (7.2% prostate and 9.6% breast) said out-of-pocket costs influenced treatment decisions. Among prostate cancer patients, use of drug and appointment related costs saving strategies were significantly associated high costs; however, there was no association between out-of-pocket costs and the belief that costs influenced treatment decisions. Among breast cancer patients, there was no association between costs and use of cost saving strategies or the belief that costs influenced treatment decisions. Although out-of-pocket costs are high for a small group of breast and prostate cancer patients in NL, they do not appear to have a substantial impact on care decisions.

Co-Author: Emma Housser, Memorial University of Newfoundland

Using Canadian Partnership Against Cancer’s Cancer Risk Management Model to Undertake Costing Analyses

The Canadian Partnership Against Cancer (the Partnership), established in 2006 by the Canadian federal government, is implementing a national cancer control strategy to reduce the impact of the disease on all Canadians. The Cancer Risk Management Model (CRMM), initiated by the Partnership in 2008, is a collaboration of Statistics Canada, clinical experts, health economists, and web developers to design and develop a decision-support web-based microsimulation platform. The CRMM uses microsimulation to synthesize a representative sample of the entire Canadian population. The model generates new cancer cases from risk-incidence equations, by year age sex, and produces a time series for cancer incidence. These incidence patterns are then benchmarked against the Canadian Cancer Registry. To build in the direct health care costs of cancer of the model, a “bottom up” approach was used to map out cancer management, which are detailed in model companion workbooks for Lung, Colon and Rectum Cancer. Each of the nodes on the cancer management diagrams relate to an aspect of the treatment of the cancer, such as surgery, chemotherapy, and radiotherapy to arrive a cost per person per type of treatment. To provide a way to compare and validate the cost output and to provide a plausible range, cancer costs were also estimated from a “top down” approach. It starts with a total aggregate cost for cancer from the Economic Burden of Illness in Canada (EBIC) published by PHAC, and estimate the share attributable to lung cancer and to colorectal cancer by taking the proportion of all incident cancer cases that are lung cancers and multiply it by the total cost of cancers in EBIC.

Medical Costs of Care for Childhood Cancer in British Columbia and Ontario

Costing studies can be used to describe the burden of disease and enhance the scientific credibility of economic evaluations. Due to advances in treatment, over 80% of children diagnosed with cancer will survive for five or more years and it is estimated that there are approximately 35,000 childhood cancer survivors living in Canada. The number of childhood cancer survivors is rapidly increasing, yet little is known about childhood cancer costs. This proposal will provide much needed childhood cancer cost estimates for future economic evaluations. We will estimate lifetime and phase-specific childhood cancer costs in British Columbia and Ontario (accounting for more than half of the childhood cancer survivor population in Canada) with a focus on healthcare costs incurred by provincial governments. The results of this work will be important to understand how much we are spending on cancer care for children and how costs differ among treatments and resources. From a health delivery perspective, these findings will be used to describe where our healthcare dollars are being spent, and how they can be spent more efficiently. Further, by comparing results from two provinces, we will be able to determine how costs are allocated, highlight any differences in patterns and quality of care, and contrast differences in healthcare access and delivery. Our findings can be used by Ministries of Health and cancer care managers to provide adequate resources and to maximize value. Cost estimates will also be useful for policy makers to plan for future healthcare budgets, and for researchers to conduct future cost-effectiveness analyses.
Health Technology Assessment and Health Systems, Services and Policy
1:30pm - 3:00pm

A Theoretical Framework for Exploring System-Level Accountability in Ontario's Cancer Services System

*Presented by:* Jessica Bytautas, Graduate Student and Research Officer, University of Toronto

Accountability is a key dimension of health system governance. The cancer services system in Ontario has a well-articulated accountability framework that is now being used as a model to shape reform activities across the province. However, there is no paradigmatic consensus on the concept itself or its mechanisms. We conducted a modified meta-narrative review to illuminate approaches to accountability by considering how it has been differently conceptualized and empirically studied in key fields (e.g., health services and policy research, public health, public administration). Specifically, we focused on: (i) how do researchers in these fields define accountability, (ii) what goals and mechanisms are attributed to accountability, and (iii) are specific accountability goals and/or mechanisms in tension in one another. Multiple databases were searched to identify and retrieve relevant published scholarly articles, policy documents, and reports. Researchers attribute a range of meanings to the term accountability, but with near unanimity agree that it is an ill-defined concept. Definitions include aspects of responsibility, answerability, availability of sanctions, provision of information, and trust, and converge on the premise that accountability is a relationship involving mutual expectations about conduct. Multiple goals emerge that have been classified as instrumental (e.g., control of resources, ethical behaviour, performance) or intrinsic (e.g., integrity, legitimacy/trust, justice/fairness). Mechanisms to achieve these goals often depend on the organizational context in which they are applied. Further, some accountability goals and mechanisms may be in tension with one other. We present a framework that may be applied to aid health system planning. By making sense of the goals, mechanisms, and consequences of accountability in the context of Ontario's cancer services system, our study aims to contribute to what is known about effective and appropriate models of health system governance.

*Co-Authors:* Dr. Mark Dobrow, Assistant Professor, University of Toronto; Dr. Terrence Sullivan, Professor, University of Toronto; Dr. Adalsteinn Brown, Associate Professor, University of Toronto

The Evaluation of Cancer Control Interventions in Lung Cancer Using a Canadian Cancer Risk Management Model

*Presented by:* Dr. William K. Evans, President, Juravinski Hospital and Cancer Centre

To assist policymakers in making difficult decisions based on the potential benefits and costs of new healthcare interventions, the Canadian Partnership Against Cancer commissioned the development of a Cancer Risk Management Model (CRMM). This computer microsimulation model projects future population health and economic impacts of cancer control programs in Canada. Lung cancer was the first simulation module to be developed and was selected because of the magnitude of lung cancer burden in Canada and recent screening and treatment interventions that require policy decisions. The model simulates one individual life at a time, from birth to death taking account of Canadian demographic and labour force characteristics, risk factor exposures and health histories and then combines this information from the simulated lives to produce aggregate measures of health outcomes for the Canadian population as whole or for particular subpopulations. The direct costs of medical care can be estimated, as well as lost earnings and impacts on tax revenues. The lung module is available through the Canadian Partnership Against Cancer website (www.cancerview.ca/cancerriskmanagement.ca) to registered users where structured scenarios can be explored for their projected impacts. A Canadian Cancer Risk Management model for lung cancer is now available via the internet to assist healthcare policy analysts, researchers and decision-makers in their work.

*Co-Authors:* Dr. Michael Wolfson, Canada Research Chair, Population Health Modelling/Populomics, University of Ottawa; William M. Flanagan, Chief of Microsimulation Health Analysis and Modelling Division, Statistics Canada; Janey Shin, Director, Analytics and Surveillance, Canadian Partnership Against Cancer; Dr. John R. Griffin, Medical Oncologist, Juravinski Cancer Centre; Keiko Asakawa, Researcher, Health Analysis Statistics Canada; Dr. Nicole Mittmann Executive Director, HOPE Research Centre, Associate Scientist, Sunnybrook Health Sciences Centre, Lee Fairclough, Vice-President, Knowledge Management, Canadian Partnership Against Cancer

Does the Healthcare Resource Utilization of Patients with Metastatic Gastric Cancer Vary Between Local Health Integration Networks in Ontario?

*Presented by:* Alyson Mahar, Queen’s University

Healthcare resource consumption by metastatic gastric cancer (GC) patients has never been studied in the Canadian healthcare system, and it is unknown if regional variation exists. Our purpose was to describe the resource utilization of metastatic GC patients in Ontario and compare resource utilization among Local Health Integration Networks (LHINs). In a retrospective cohort study of metastatic (stage IV-M1) gastric adenocarcinoma patients registered in the Ontario Cancer Registry between April 1, 2005 and March 31st, 2008, we linked chart review and administrative healthcare data to study treatment strategies, non-therapeutic endoscopic, radiologic and surgical investigations. This study was performed from the healthcare system perspective, using a two-year time frame. Chi square tests for independence were used to compare proportions of resource utilization, and non-parametric one-way ANOVA compared per patient mean usage among LHINs. Kaplan Meier curves and log-rank tests were used to compare and compare survival distributions. The cohort of 1435 patients received 4695 endoscopic investigations, 1,206 computed tomography scans, 12,829 x-rays and 5085 ultrasounds. The mean number of these investigations per patient varied significantly by LHIN. Nearly all patients were seen at least once by a general practitioner (98%) or a specialist (99%), were admitted to hospital (95%) or visited the emergency department (ED) (87%). Whether a patient visited an ED varied significantly among LHINs. The mean number of GP and specialist visits and mean number of hospital admissions per patient varied among LHINs. Less than half of the patients received chemotherapy (43%), gastrectomy (37%) or radiotherapy (28%). The proportion of patients who received radiotherapy or stent placement varied significantly among LHINs. Variations in healthcare resource utilization exist between LHINs in Ontario for the care of metastatic GC patients. Whether these differences reflect differential access to resources, patient preference or physician preference is not known. Further research needs to examine deviations from standards of care and how they impact clinical disease outcomes.

*Co-Authors:* Dr. Natalie Coburn, Sunnybrook Health Sciences Centre; Dr. Raymond Viola, Queen’s University; Dr. Ana Johnson, Queen’s University
Simulation of Lung Cancer Control Programs in Canada  
*Presented by: Dr. Sonya Cressman, The Canadian Centre for Applied Research in Cancer Control (ARCC)*

The Cancer Risk Management Model (CRMM) is a microsimulation platform that can be used by policy makers and researchers to inform program planning. In this initial case study we used the CRMM to project impacts of potential lung cancer screening and/or smoking cessation programs in Canada. The CRMM was used to simulate Canadians who would qualify for entry into a lung cancer screening program based on their age and smoking history. Screening protocols, test sensitivity and specificity, costs and resource utilization expected in an early detection environment were used as inputs to determine total program costs of lung cancer screening with varying rates of smoking cessation. The differences in costs and life years gained from the unscreened scenario were used to establish estimates of the incremental cost-effectiveness of different lung cancer screening and smoking cessation interventions. The model was able to identify the proportion of Canadians who would have qualified for the National Lung Cancer Screening Trial (NLST) and simulate an equivalent screening protocol. The model projected comparable incidence rates to the NLST and an 18% mortality benefit from screening was calculated relative to the unscreened scenario, over eight years. Lung cancer and all-cause mortality could be reduced with the inclusion of an effective (>10%) smoking cessation program during screening years. The cost and frequency of CT scans and the numbers of people needing to be screened were significant drivers of cost-effectiveness. In this initial case study of the CRMM we show the model's ability to incorporate different levels of evidence to project the population-based impacts of potential lung cancer screening and smoking cessation programs in Canada.

Co-Authors: Bill Flanagan, Chief of Microsimulation, Statistics Canada; Fei Fei Lui, Program Manager, The Canadian Partnership Against Cancer; Dr. Stuart Peacock, Co-Director, Associate Professor, The Canadian Centre for Applied Research in Cancer Control (ARCC); Dr. John Goffin, Associate Professor, McMaster University Juravinski Cancer Centre; The Canadian Early Detection of Lung Cancer Study Group

Evaluation Of The Diagnostic Assessment Program And The Electronic Pathway Solution. A Multidimensional Cycle Of Improvement And Assessment  
*Presented by: Dr. Julie Gilbert, Manager, Research and Evaluation, Cancer Care Ontario*

To improve coordination of care, reduce wait times and improve patient experience in cancer diagnosis, our organization is supporting the development of Diagnostic Assessment Programs and building an electronic tool to help physicians and patients share information. This presentation describes how the impact of these programs will be evaluated. The Diagnostic Assessment Program is intended to improve the quality of cancer care from patient, provider and system perspectives. A logic model has been developed to identify evaluative streams according to the goals and objectives of the initiative. A benefits evaluation will be described, which outlines how physician and patient user groups will benefit from the tool. The usability and use of the electronic tool will also further evaluation to ensure that the conditions of benefit realization are met. A range of metrics is identified to evaluate the various aspects of where the program is intended to have an impact. The Diagnostic Assessment Program and the Electronic Pathways Solution represent a significant change in how patients access diagnostic testing and have the potential to improve the patients experience as they undergo diagnostic testing for cancer. They also have the potential to make the work of the primary care physician and specialist more effective and the use of their time more efficient. The evidence that is generated from the evaluation of these programs will help shape their implementation and integration into the cancer system and the health care system more broadly. The iteration of program development, implementation and evaluation will help to refine and improve the process of diagnostic assessment as these programs become part of usual practice in cancer care. This presentation will provide an example of a broad and systematic evaluation of a program that has multiple stakeholders and a wide array of potential system benefits. Suggestions for further evaluation and research opportunities related to these initiatives will be discussed.

Co-Author: Melissa Kaan, Program Manager, Diagnostic Assessment Program, Cancer Care Ontario
Knowledge Translation
1:30pm - 3:00pm

Clear as Mud: Decision Making in the Face of Uncertainty
Presented by: Dr. Melissa Brouwers, Associate Professor, Department of Oncology, McMaster University

Cancer control policy is often made in an environment of complex uncertainty. Sources of uncertainty, their impact, strategies to navigate it, and tools to measure and mitigate it are poorly studied. This project will address each of these gaps. We are conducting a mixed methods approach: (1) An integrated review of both empirical and non-empirical research to identify sources of uncertainty, their impact, and existing tools. (2) Key informant interviews and focus groups among stakeholders to understand what elements are relevant to policy in the areas of breast screening, HPV vaccine, PSA testing, and funding of expensive systematic therapies. (3) Test construction methods using the data collected will be used to develop, test, and refine a suite of items that can be used to measure uncertainty in decision making and tools to mitigate it. The integrated review of research on uncertainty in health policy decision making consists of a systematic review of qualitative empirical studies and a scholarly review of qualitative empirical studies and non-empirical research. This review will be one input to the design of the qualitative strategy (key informant interviews, focus groups) and test construction strategy. The integrated review search strategy combines clusters of keywords related to uncertainty, health policy, and decision making across multiple clinical contexts in addition to cancer. 1676 articles have been identified and screened for eligibility. Data extraction is in progress, to be followed by data synthesis and analysis using appropriate methods. The qualitative strategy is currently being refined with the research team and advisory panel, with recruitment to begin in spring/summer 2012. We will create a common nomenclature and rubric to enable a more systematic approach to the study of uncertainty in decision making. We will assess what is known (and not) about this factor as a determinant of knowledge use. We will create a metric and strategy by which the concept can be identified and measured and managed.

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Modeling the Cost-Effectiveness of Prostate Cancer Screening in British Columbia
Presented by: Reka Patany, Data Linkage Coordinator, Canadian Centre for Applied Research in Cancer Control (ARCC), BC Cancer Agency

To evaluate the cost-effectiveness of candidate prostate-specific antigen (PSA) screening strategies for prostate cancer in British Columbia (BC). We validated a previously developed model of prostate cancer natural history to reproduce prostate cancer incidence patterns in BC before and after the introduction of PSA testing. Combining this model with BC data on treatment distributions and survival, we projected outcomes for men age 40 beginning in the year 2000 under 16 candidate PSA screening strategies with varying age ranges, screening frequencies, PSA thresholds, and compliance frequencies. In addition to overdiagnoses and lives saved, we recorded person-years in relevant health states and combined this information with utilities derived from the literature and local data for testing/biopsy/treatment costs to evaluate cost-effectiveness. The natural history model successfully reproduced historical prostate cancer incidence trends in BC, and assumed survival benefits of early detection and primary treatments are consistent with historical mortality rates. Preliminary results indicate that relatively less intensive PSA screening strategies can achieve the majority of the lives saved under the more intensive PSA screening strategies but with lower overdiagnoses and other harms. Cost-effectiveness analysis is currently underway. Currently, the BC Cancer Agency’s Genitourinary Tumour Group recommends PSA screening, but there is no organized screening program and PSA tests for asymptomatic men are not covered in the province. This study provides useful evidence to inform the discussion of prostate cancer screening policy in BC and other jurisdictions.

Co-Author: Roman Gulati, Statistical Research Associate, Division of Public Health Sciences, Fred Hutchinson Cancer Research Centre; Dr. Ruth Etzioni, Full Member, Division of Public Health Sciences, Fred Hutchinson Cancer Research Centre; Dr. Stuart Peacock, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC), BC Cancer Agency

Practice Variation and Consistency in the use of Radiation Therapy between Regional Cancer Centres
Presented by: Dr. Ivo Olivoto, VP Radiation Therapy and Functional Imaging, BC Cancer Agency

Consistent care generally improves outcomes while reducing costs but little is known about the consistency of practice in Canadian Radiation Therapy (RT) centres. This study evaluated consistency of RT clinical practices between regional cancer centres as a baseline audit to initiate dialogue within and between centres to improve consistency. A database including all patients who received RT in 5 regional cancer centres in a single province was interrogated for 10 common RT clinical interventions during 2010 and repeated for 2011. Interventions evaluated were selected to reflect the breadth of RT practice and included curative and palliative interventions, fractionation patterns and brachytherapy utilization. Consistency was compared between centres and on the basis of patient residence at diagnosis. Between centres, some practices were quite consistent (e.g. use of short fractionation for breast tangents; 71% to 81% as 16 fractions) whereas others were quite variable (e.g. use of a single fraction for bone metastases; 25% to 75% as a single fraction and use of pre-operative RT for rectal cancer; 5% to 54%). Some variation was explainable (e.g. IMRT limited by treatment unit technical limitations) but others were not. By health region of residence, prostate brachytherapy utilization was 6% to 21% of prostate cancer incidence. CNS stereotactic RT utilization was consistent between regions but palliative whole brain RT was used less commonly in the region most remote from an RT facility. Practice patterns were similar in 2010 and 2011. Explainable and unexplained variation existed across 5 regional RT centres in a single province. Availability of utilization data creates an opportunity for practice audit and could support efforts to reduce unexplained variations in RT practice.

Co-Authors: John French, Senior Director, RT Program, BC Cancer Agency; Barb Baerg, Data Analyst, BC Cancer Agency; Stewart Jackson, Professor Emeritus, University of BC; Dr. Scott Tyldesley, Head, Breast Cancer Outcomes Unit, BC Cancer Agency
Establishing Evidence-Based Workload and Staffing Reallocation within a Provincial Radiation Therapy Program

Presented by: John French, Senior Director, Operations, Business and Strategic Planning, BC Cancer Agency

Within a provincial program structure it is desirable that staffing resources are allocated equitably across regional cancer centres. We developed a series of metrics to evaluate Radiation Therapist (RT) staffing levels, and then used these metrics to reallocate staffing across a provincial program, and evaluated the impact of reallocation with a view to reducing variation in workloads across the province. The following metrics were established and evaluated across regional cancer centres: Number of treatment fractions per Radiation Therapist Full Time Equivalent RT, (RT FTE), Number of treatment visits per RT FTE Number of treatment courses per RT FTE. The number of treatment fields per fraction, visit and course respectively. The data was used as a decision making tool to reallocate staffing resources as a component of provincial budget planning, and subsequently to evaluate relative workload for RTs at each centre. Between centres, variation existed in each of the metrics developed. In fiscal year 2009/10 the number of fractions per RT FTE ranged from 649 to 1123, the number of courses per RT FTE ranged from 40 to 69, and the number of visits per FTE from 574 to 956. Measures of treatment complexity were similar over time at each centre, but varied between centres. However, the centres with the highest workload measures also had the highest complexity measures, suggesting that complexity was not a factor in the relative distribution of workload. After reallocation resources and some shifts in workload between centres the variation has lessened. The workload projections for fiscal 2011/12 are per RT FTE 879 - 1087 for fractions, 52-67 for courses and 721-899 for treatment visits. Variation existed across 5 regional RT centres in a single province in relation to the relative workload per FTE of Radiation Therapist. These data were used to redirect resources within the province, resulting in reduced variation. Measuring workload with these metrics provided a rational means to effectively manage resources within a provincial system.

Co-Author: Dr. Ivo Olivotto, BC Cancer Agency

Adherence to Human Epidermal Growth Factor Receptor-2 (HER2) Testing & Adjuvant Trastuzumab Treatment Guidelines in Ontario

Presented by: Dr. Craig Earle, Ontario Institute for Cancer Research

We evaluated the use of reflex HER2 fluorescence in situ hybridisation (FISH) and predictors of trastuzumab use in early-stage breast cancer (ESBC) in the province of Ontario. The adherence of practice patterns to adjuvant trastuzumab treatment guidelines (Cancer Care Ontario; CCO) and HER2 testing consensus guidelines (Canada) was assessed. A retrospective cohort of ESBC patients diagnosed between January 1, 2006 and December 31, 2007 was identified in the Ontario Cancer Registry (OCR). HER2 test type, sequence, result(s) and status, tumour grade and hormone receptor status were determined from centrally-held (OCR) pathology reports. Trastuzumab treatment was determined from New Drug Funding Program (NDFP) records. Demographic, LHIN, surgical, prior radiological and anthracycline treatment and comorbidity data were determined from administrative data sources (Ambulatory Care, Discharge Abstract, Ontario Health Insurance Plan, Registered Person’s, Same Day Surgery Databases). Logistic models were used to estimate adjusted odds ratios for factors associated with guideline (non-)adherence. The 1st HER2 test result was the largest predictor of reflex testing, with HER2 equivocal tumours being significantly more likely to be retested vs. positive (OR 115.8 [79.3, 169.2]). Reflex testing varied by LHIN but not by age. Patients diagnosed with stage III disease had significantly higher odds of receiving a reflex test vs. stage I (OR 1.5 [1.1, 2.1]). HER2 status was the largest predictor of trastuzumab use in the cohort, with HER2 equivocal, negative or unknown status patients significantly less likely to receive treatment than positive. Patients with advanced age at diagnosis (≥70y) had lower odds of trastuzumab treatment compared to younger patients (OR 0.48 [0.32, 0.73]). Increasing tumour grade was associated with higher odds of treatment. Treatment varied significantly by LHIN. Despite limitations in centrally-reported tumour pathology at the time, we demonstrate that the use of reflex FISH testing in Ontario was largely consistent with Canadian guidelines. Trastuzumab use in the cohort was consistent with CCO guidelines on HER2 status in many patients, though practice varies across LHINs.

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Algorithms to Identify Significant Adverse Events (AEs) for Colorectal Cancer Screening Program Population

Presented by: Pascale Levesque, Institut national de santé publique du Québec; Sophie Pouliot, Institut national de santé publique du Québec

(1) to develop algorithms that exploit administrative databases to classify endoscopy-related AEs according to their level of severity and causality link and (2) to identify the most significant AEs that should be measured in a colorectal screening population. Algorithms will be used to measure AEs in the province of Québec. We conducted a population-based retrospective cohort study using databases from the Quebec health insurance agency. In order to develop our algorithms, we identified bleeding, perforation, cardiovascular events and death related to the 256,500 endoscopies performed between January 1, 2000 and December 31, 2004. We associated AEs with sets of medical acts to attribute a severity level. Finally, we analyzed the delay between identified AEs and endoscopy over a 30 day period to establish a causality link. Specific severity levels and causality links were combined to identify significant AEs. Bleeding was categorized in three severity levels: high for those followed by an endoscopy and coagulation act, moderate for those followed by an endoscopy without coagulation act and low for those who did not require endoscopy. Two levels of severity were applied to perforation: high when perforation was followed by an endoscopy and repair act and moderate when it was followed by an endoscopy without a repair act. All cardiovascular events were considered as highly severe. Causality link was high for bleedings and perforation that occurred 0 to 3 days after endoscopy. A high causality link was attributed to cardiovascular events that occurred between 0 to 1 day after endoscopy. Deaths could not be directly linked to endoscopy but result from previous AEs. Combining severity level to causality link is a new approach for identifying and characterizing AEs. Once validated with medical records, those algorithms could be used as a standardized tool for the Quebec colorectal screening program to account for significant AEs.

Co-Authors: Jean Rousseau, Institut national de santé publique du Québec; Marc Simard, Institut national de santé publique du Québec; Roxanne Gagnon, Institut national de santé publique du Québec; Bernard Candas, Institut national de santé publique du Québec et le Département de médecine sociale et préventive, Université Laval; Gilles Jobin, Hôpital Maisonneuve-Rosemont et Université de Montréal

Incidence of Endoscopy-Related Adverse Events in a Screening Program Population: Results from Algorithms based on Medico-Administrative Databases

Presented by: Sophie Pouliot, Project Manager, Institut national de santé publique du Québec; Pascale Levesque, Research Professional, Institut national de santé publique

To (1) determine the incidence of endoscopy-related adverse events (AEs) occurring in a population similar to the one targeted by the Quebec colorectal cancer screening program (PQDCCR) and to (2) identify patients and endoscopies’ characteristics associated to the most acute AEs, i.e., bleeding, perforation, cardiovascular event, and death. This retrospective study used medico-administrative databases to identify endoscopy-related bleeding, perforation, cardiovascular events and death that occurred in the province of Quebec from 2000 to 2004. The study population includes medium risk individuals, aged 50-74 years old, who were selected to correspond to the PQDCCR audience. Algorithms previously developed by our team were used to classify AEs according to their severity level and causality link. Association between patients and endoscopies’ characteristics and AEs was evaluated using univariate analyses. These characteristics were: sex and age of the patients, endoscopists’ specialty, volume of endoscopy performed annually and manipulations. We identified 299,500 endoscopies among 241,049 persons. AEs included in the study occurred in a delay of 14 days following endoscopy. Results obtained with the algorithms reveal that the cumulative incidences of endoscopy-related bleedings, perforations and cardiovascular events were 8.32/10,000; 4.13/10,000, and 3.43/10,000 respectively. The death cumulative incidence was 0.51/10,000. Age of the patients, manipulations, medical specialty and volume of endoscopy performed annually by endoscopists affect the incidence of AEs. The risk of dying is significantly higher for patients with endoscopy-related bleeding or perforation. According to our algorithms, endoscopies performed in the context of PQDCCR would induce 7 to 17 perforations and cardiovascular events, 14 to 27 hemorrages and a single death yearly. Our study is the first to report incidence of endoscopy-related AEs for the province of Quebec. According to our results, endoscopies practiced in Quebec generate an equivalent proportion of AEs than those reported in a similar study. Characteristics identified for their impact on AEs could be used to minimize them.

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Do Patient Symptoms Predict for Emergency Department Visits? A Population Based Analysis

Presented by: Dr. Luis Barbera, Clinician Scientist, Odette Cancer Centre

Since 2007 in Ontario, the Edmonton Symptom Assessment System (ESAS) has been routinely used to assess symptoms in cancer out-patients. The purpose of this study was to determine the relationship between individual patient symptoms, and their severity, with the likelihood of an emergency department (ED) visit. The cohort includes all cancer patients in Ontario who completed an ESAS assessment between January 2007 and March 2009. We linked multiple provincial health databases to describe the cohort and determine if an ED visit occurred within 7 days of the patient’s first ESAS. Multivariate logistic regression was used to determine the association between symptom scores (absent: score 0; mild: 1-3; moderate: 4-7; severe: 8-10) and the likelihood of an ED visit. The cohort included 45,118 patients whose first assessment contributes to the study. 3.8% had an ED visit. The patients with ED visits were more likely to be men, to have lung or gastro-intestinal cancer, to have had recent radio or chemotherapy, and to have a shorter survival. The proportion of patients with ED visits increased from 2% to 10-12% as individual symptom scores increased from 0 to 10. Anxiety and depression were not associated with ED visits, regardless of severity. Pain, nausea, drowsiness, appetite and shortness of breath with moderate or severe scores were associated with ED visits. Tiredness and wellbeing were the only symptoms to show a significant association for mild, moderate and severe scores. A severe well being score had the highest odds. Worsening symptoms clearly contribute to ED visits. While specific symptoms like pain are obvious targets for management in the outpatient setting, constitutional symptoms like wellbeing or fatigue are associated with even higher odds. Though difficult to manage, such symptoms also warrant detailed assessment in order to optimize patient outcomes.

Co-Authors: Dr. Clare Atzema, Institute for Clinical Evaluative Science; Dr. Rinku Sutradhar, Institute for Clinical Evaluative Science; Dr. Hsien Seow, McMaster University; Dr. Doris Howell, University Health Network; Dr. Amna Husain, Temmy Latner Centre for Palliative Care; Dr. Jonathan Sussman, Supportive Care Cancer Research Unit; Dr. Craig Earle, Institute for Clinical Evaluative Sciences; Ying Liu, Institute for Clinical Evaluative Sciences; Dr. Deborah Dudgeon, Queen’s University
Family Physician Continuity of Care in End-of-Life Homecare Cancer Patients and its Association with Acute Care Services Use  
*Presented by: Dr. Hsien Seow, Assistant Professor, McMaster University, Juravinski Cancer Centre, Escarpment Cancer Research Institute*

Previous research has examined the effect of family physician continuity of care within end-of-life care cancer patients and its association with reduced use of acute care services. However, such research has not been examined in the end of life homecare cancer population. Our objective is to investigate the association of family physician continuity with location of death, hospital and emergency room (ER) visits in the last 2 weeks of life in end of life homecare cancer patients. In a retrospective study of 8 linked administrative databases we examined all patients who died of cancer between April 1 2008 to March 31, 2009 in Ontario who had at least 1 visit to a family physician and enrolled in homecare for at least 2 weeks. The relationship of family physician continuity of care and location of death, and hospital and ER visits in the last 2 weeks of life was examined using logistic regression. The Usual Provider of Care (UPC) measure demonstrated a dose response relationship with increasing continuity resulting in decreased odds of dying in the hospital and visiting the hospital and ER in the last 2 weeks of life. The FP visits per week measure demonstrated a threshold effect relationship with location of death and hospital visits and dose response relationship with ER visits in the last 2 weeks of life. These results demonstrate an association between family physician continuity of care and location of death and visits to the hospital and ER in the last 2 weeks of life. This indicates the need for more involvement of family physicians in end of life cancer care.

Co-Authors: Ummukulthum Almaawiy, McMaster University; Dr. Gregory Pond, McMaster University, Juravinski Cancer Centre, Escarpment Cancer Research Institute; Dr. Jonathan Sussman, McMaster University, Juravinski Cancer Centre, Escarpment Cancer Research Institute

How Effective is Population-Based Cancer Screening? Regression Discontinuity Estimates from Across Canadian Provinces  
*Presented by: Dr. Erin Strumpf, Assistant Professor, McGill University, Department of Economics and Department of Epidemiology, Biostatistics and Occupational Health*

Significant regional variation in adherence to cancer screening guidelines’ recommended initiation ages has been documented across Canada. We use this variation as a natural experiment to estimate the effectiveness of current population-based breast and colorectal cancer screening. We use a regression discontinuity design to estimate the impact of population-based cancer screening on case detection and stage at diagnosis at age 50. Self-reported screening rates (CCHS 2003-2008) and registry-based detection rates (Canadian Cancer Registry 2005-2008) are calculated at the age-province-year level. OLS and local linear regression (with triangle kernel) analyses are used to estimate the change in screening rates and detection rates at age 50, and the effect of screening on cancer detection. Sensitivity analyses test robustness to bandwidth selection and standard errors are calculated via robust or bootstrap methods. Minimum sample size requirements restrict the colorectal cancer analysis to the Atlantic provinces, Ontario, Manitoba/Saskatchewan, Alberta, and British Columbia, and the same regions plus Quebec for breast cancer. Past year breast cancer screening increases by about 20 percentage points at age 50 in Quebec and Manitoba/Saskatchewan and by about 10 percentage points in Ontario. Past year colorectal cancer screening increases by 6 percentage points at age 50 in ON. These plausibly exogenous changes in screening suggest that increasing screening rates by 1 percentage point at age 50 detects approximately 3 additional cases of breast cancer per 100,000 women and 1 additional case of colorectal cancer per 100,000 adults (precise estimates under disclosure review). Limited data availability regarding stage at diagnosis resulted in unstable estimates with limited generalizability. Quasi-experimental design approaches allow researchers to estimate the impact of current cancer screening policy and practice. These estimates of the causal effects of screening can be used in cost-effectiveness calculations and in comparisons of policies across jurisdictions, adding an important complement to estimates derived from trials and simulation models.

Co-Authors: Jeremey Drosdeck, Research Assistant, McGill University; Srikanth Kadiyala, Economist, RAND Corporation
Integration Between Family Physicians and Regional Cancer Systems in Ontario: Opportunities and Obstructions  
*Presented by: Dr. Daryl Bainbridge, Senior Research Coordinator, McMaster University*

Provider integration is critical to providing care to cancer patients, especially at the transition points of the diagnostic and survivorship phases. In this study we examined family physician (FP) perspectives on care processes across the cancer trajectory to identify gaps and competencies in integration between practices and regional cancer programs. A cross-sectional survey of all FPs in Ontario. The survey instrument was created specifically for this study that built on the Cancer Care Ontario integration framework, with items generated from published literature and expert input. Response options were quantitative, as well as open-ended to allow for response elaboration. A modified Dillman method was used for survey administration, with multiple contacts for non-responders. Responses were obtained from 2054 FPs representing an adjusted response rate of 23%. The majority of respondents were aware of screening programs for breast (92%) and colorectal (84%) cancer and felt the relevant provincial guidelines were clear. Responses were more heterogeneous for cervical and prostate cancer screening. During workup of a suspected cancer 70% of respondents felt that diagnostic tests are done in timely fashion. Almost a third of FPs were uncertain about the referral process to the regional cancer program (RCP). Overall, 66% reported good integration between their practice and the RCP. About the same number were satisfied with their involvement and the information exchanged, across the care trajectory. The lack of role clarity and access to referral guidelines were prominent issues that emerged. Cancer systems need to be more responsive to the needs of FPs to better integrate these providers and facilitate optimal quality of care for cancer patients. Policies to clarify and support roles and responsibilities are necessary to ensure that FPs are integrated team members within regional cancer programs.

Co-Author: Dr. Jonathan Sussman, Rad Onc / Associate Professor, McMaster University

The Cost-Effectiveness of Rituximab in Advanced Follicular Lymphoma  
*Presented by: Corneliu Bolbocean, Ph.D. Candidate, The University of British Columbia*

To characterize the use of rituximab in the treatment of advanced follicular lymphoma (first-line and relapsed/refractory), including cost-effectiveness, clinical effectiveness, and safety. Particular emphasis was placed on the cost-effectiveness of rituximab when used with chemotherapy as induction therapy or as maintenance monotherapy following induction. We conducted a targeted literature search to examine the clinical effectiveness, safety and cost-effectiveness of the addition of Rituximab to chemotherapy for the induction of remission in patients with advanced follicular lymphoma. The search was limited to English language articles published in peer-reviewed journals. For the cost-effectiveness component, we searched MedLine and Web of Science using key words “Rituximab” AND (“Follicular” OR “Indolent”) AND “Lymphoma”) AND “cost-effective”, and reviewed all abstracts and additional references identified within relevant articles. Data extraction tables were used to extract standardized information from all cost-effectiveness articles. Based on literature review, we found that the inclusion of rituximab to induction and maintenance therapy has clinical benefits to disease control and improves progression-free survival. Preliminary evidence suggests the potential for rituximab to improve overall survival outcomes, particularly for relapsed/refractory patients; moreover, the drug had been established as having a favorable risk-benefit profile with respect to safety and tolerability. Rituximab was found to fall within standard thresholds for cost-effectiveness, both as maintenance and induction therapy. Incremental cost-effectiveness ratios (ICERs) ranged from €8,729 for maintenance therapy in relapsed/refractory patients in France, to $28,565 when added to chemotherapy in first-line induction therapy in the US. Sensitivity analyses found results to be most sensitive to utility values, treatment and relapse costs, and assumptions about rituximab efficacy. Rituximab had been found to have a favorable profile in terms of clinical efficacy, safety and tolerability. Cost-utility analysis across different countries had consistently shown that Rituximab provides good value for money in the treatment of advanced follicular lymphoma as ICERs fall within widely acceptable cost-effectiveness thresholds.

Co-Author: Karlotta Johnston, Oxford Outcomes Ltd; Dr. Stuart Peacock, Canadian Centre for Applied Research in Cancer Control (ARCC)
SAGE Directory of Cancer Guidelines  
*Presented by: Dr. Melissa Brouwers, Associate Professor, Department of Oncology, McMaster University*

The SAGE (Standards and Guidelines Evidence) directory of cancer guidelines is a resource designed to facilitate evidence-based clinical practice and policy formation, and reduce duplication in guideline development. Developed in 2008, SAGE is a publically available (www.cancerview.ca - www.cancerguidelines.ca), searchable database of English language cancer control guidelines and standards released since 2003. Each SAGE record is rated on the Appraisal of Guidelines for Research and Evaluation II (AGREE II) tool, with scores presented and used to determine trends in guideline quality. The status of records is also categorized, in that SAGE can accurately present current guidelines, guidelines in progress, those in need of an update and guidelines undergoing updates. SAGE contains 1867 indexed records from 271 developer organizations spanning 27 countries and international jurisdictions (new update data are currently being indexed). There is considerable variability in guideline quality both within and across guideline developers, and AGREE II quality domains of applicability and editorial independence are the poorest performing. SAGE has the ability to inform guideline topic gaps and overlap, where it is shown that the majority of completed guidelines target breast, lung, colorectal and prostate cancers, and focus on the treatment stage of the cancer continuum. This provides a channel of communication amongst organizational groups and facilitates guideline development partnerships. The value-add of SAGE to mitigate inconsistencies in guideline quality is the appraisal component of its records. It is the ultimate goal that SAGE will continue to coordinate efforts to leverage positive change in the field of clinical practice guidelines, patient care and system performance.

Co-Authors: Ellen Rawski, McMaster University; Lavannya Bahirathan, McMaster University; Caroline Zwaal, McMaster University; Karen Spithoff, McMaster University

Chemotherapy Waste: Implications for Value in Health  
*Presented by: Dr. Shawn Bugden, Associate Professor, Faculty of Pharmacy, University of Manitoba*

Economic assessment is an integral part of the assessment of new medications in oncology. Frequently, wastage is not fully considered in these assessments. As evidence guides the adoption of new therapies into practice, it is important to consider the potential implications of waste on both budget impact and cost effectiveness. Despite the potential importance of this issue in high cost oncology medications, little is known about the impact of wastage on the return on investment for these products. CancerCare Manitoba coordinates a province-wide program (Provincial Oncology Drug Program) for all Manitobans. Through this program data is now collected on all wastage of chemotherapy products in Manitoba. This data allows for an examination of the impact of wastage and the factors that contribute to higher levels of wastage. Only through examination of this information can we begin to understand the magnitude of the issue and the potential management implications. As we learn more, it is hoped that we can use real world wastage assessment to guide our evaluation of the potential impact of wastage on budget impact and cost effectiveness when considering potential investment in new oncology medications.

Why do Provinces make Different Coverage Decisions for the same Cancer Drugs?  
*Presented by: Dr. Roger Chafe, Assistant Professor, Memorial University*

To determine the factors which led to divergent coverage decisions for a group of cancer drugs in three Canadian provinces. Multi-case comparison based on document analysis and key informant interviews with oncologists and decision makers in three provinces - British Columbia, Ontario, and Newfoundland. The cases examined are coverage decisions for Bevacizumab (Avastin) (for both colorectal and breast cancer); Trastuzumab (Herceptin) (for adjuvant breast cancer); Panitumumab (Vectibix) (for colorectal cancer) and Ibrutinumab (Imbruvica) (for lymphoma). 17 key informant interviews were conducted and more than 40 relevant documents were reviewed. The review found that strength of the clinical evidence was the most important factor influencing cancer drug coverage, which accords with previous work on this topic. There was general agreement on the level of clinical benefit of drugs across provinces, but unique issues to each case lead to variations in coverage. The whole of the provinces face difficult decisions regarding new cancer agents for which there is only a small demonstrated benefit or for which there is insufficient evidence to accurately determine their level of benefit. It is for these difficult decisions which variation in coverage across the provinces is most likely to occur.

Co-Author: Dr. Mark Dobrow, Assistant Professor, University of Toronto

Health Economic Analysis of a Multi-Centre Pan-Canadian Clinical Trial for the Treatment of Oral Cancer (the COOLS Trial)  
*Presented by: Ian Cromwell, Health Economist, Canadian Centre for Applied Research in Cancer Control (ARCC)*

Oral cancers affect thousands of Canadians, with approximately 3,600 new cases detected each year. Treatment of cancerous lesions in the mouth is accomplished primarily through surgery. A novel approach in guiding oral cancer surgery has been developed and is undergoing clinical testing and health economic analysis. A large, multi-centre prospective randomized controlled trial is currently underway (the Canadian Optically Guided Approach for Oral Lesions Surgical (COOLS) Trial) at nine hospitals across Canada. The trial is made up of 400 patients with a diagnosed cancerous oral lesion, and will evaluate the clinical outcomes associated with using a new fluorescent light tool to visualize tumour margins for surgery (FV), compared to using standard white light (WL) visualization techniques. The primary outcome of the health economic analysis is the calculation of the incremental cost-effectiveness of FV vs. WL-guided surgery. Supplemental analyses of trends of cost, effectiveness, and quality of life will also be performed. Costs are collected for three principal domains: those costs associated with surgery, management of recurrence, and loss of productive working time due to illness. These variables are measured prospectively from surgical procedures, chart review, and questionnaires. Recurrence-free survival is the primary outcome measure, and overall survival (expressed as life years gained) is modeled statistically. Quality of life is measured using validated instruments, including the EQ-5D, the Head and Neck module of the Functional Assessment of Cancer Therapy (FACT - H&N), and the Voice Handicap Index. Preliminary results will be shown. This project will contribute valuable information to the scientific literature. This component of the project is linked to three other lines of scientific inquiry, including a knowledge translation component. Consequently, the results will provide a powerful policy lever to help guide and improve the treatment and management of oral cancer.

Co-Autors: Dr. Catherine Poh, Principal Investigator, British Columbia Cancer Agency; Dr. Scott Durham, Principal Investigator, Otolaryngology, Head and Neck Surgery, Vancouver General Hospital; Dr. Miriam Rosin, Principal Investigator, British Columbia Cancer Agency; Dr. Stuart Peacock, Principal Investigator, Canadian Centre for Applied Research in Cancer Control (ARCC)
Developing a Canadian Research Network for Adolescent and Young Adult Oncology

Presented by: Sonja De Pauw, Research Coordinator, McMaster University

The main objective of the Canadian Task Force on Adolescent and Young Adult (AYA) Cancer’s research working group is to explore, promote and facilitate a broad spectrum of research activities relevant to AYA oncology. The research working group was established in 2010. Its initial focus has been on three main areas of interest: clinical trials, fertility, and surveillance. Group members have been tasked with identifying and developing research agendas in these areas. Over the last two years this group has met to develop proposals, conduct surveys, and plan major data collection initiatives. Future work will focus on developing a large-scale, national research agenda and the creation of a research network to address the wide array of issues that are relevant to the AYA cancer population. The group has developed a proposal to determine the availability of clinical trials to AYA in Canada, using the clinicaltrials.gov website to collect data. The group has also completed national surveys of fertility clinics to assess the services being provided to AYA cancer patients and survivors, in order to address fertility issues in these populations. To facilitate future surveillance research, the group has been working with CYP: a cancer surveillance database maintained at the Public Health Agency of Canada, initially for children, to expand data collection to the 15-19 year-old age group. Further plans include examining the feasibility of extending data collection to the 20-25 year-old age group. A comprehensive research agenda for AYA cancer will also be developed for the next 5 years. The research working group of the AYA Task Force is providing a base and stimulus for expanding research into AYA oncology in Canada. Initial work in the three areas of interest has formed an important foundation for future research and policy initiatives in these areas.

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Cost-Effectiveness of Hormone Therapies for ER+ Women with Early Breast Cancer in Canada: Exploring the Potential for the CYP2D6 Genetic Test

Presented by: Sandjar Djalalov, Post-Doctoral Fellow, St. Michael’s Hospital, Li Ka Shing Knowledge Institute, Health Economics, Canadian Centre for Applied Research in Cancer Control (ARCC)

To evaluate the cost-effectiveness of adjuvant mono and sequential hormone therapies, and CYP2D6 testing in combination with tamoxifen mono and sequential (with AIs) therapies for ER+ hormone sensitive women with early breast cancer in Canada. We performed a cost-effectiveness analysis using a Markov model from a societal perspective with a lifetime horizon. An embedded decision tree was used to identify best treatment strategy according to CYP2D6 gene polymorphisms. Our comparator is optimal treatment strategy without genetic testing. Patient population is 65-year-old ER+ hormone sensitive women with early breast cancer. Expected value of perfect information was performed to identify future research directions. Probabilistic sensitivity analysis was used to incorporate parameter uncertainties. Outcomes were quality-adjusted life years (QALYs) and costs. Pharmacogenomics (genetic test and targeted therapy) strategy resulted in the gain of 0.003 QALYs, when compared to no testing (letrozole-tamoxifen sequential therapy). The Incremental cost was CAD $ 380 with tamoxifen treatment; consequently, the incremental cost-effectiveness ratio (ICER) for the base case is estimated to be CAD $139,939. The results were sensitive to assumptions related to disease progression, mortality rate and the drug cost. The marginal gain in effectiveness and extra cost will not warrant a recommendation for routine CYP2D6 genetic testing in combination with tamoxifen monotherapy for ER+ women with early breast cancer in the current setting.

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Closing the Personalized Medicine Information Gap in Breast Cancer: Central HER2 Test Documentation Practice in Ontario

Presented by: Ilia Ferrusi, McMaster University

Uncertainty about human-epidermal growth factor receptor-2 (HER2) testing practice in Canada hinders efforts to study and improve personalized medicine practice. We sought to understand the patterns of HER2 test documentation for early-stage breast cancer (ESBC) patients in Ontario using tumour pathology reported centrally to the Ontario Cancer Registry (OCR). A population-based retrospective cohort of patients diagnosed with ESBC in 2006 and 2007 was identified from the OCR and for whom ≥ 1 centrally-held pathology report was available. Information was collected from pathology reports, provincial and CIHI databases (Ambulatory Care, Discharge Abstract, Ontario Health Insurance Plan, Registered Persons, Same Day Surgery Databases) to determine surgical procedure, stage, hormone receptor status, HER2 test documentation, income quintile, urbanicity, most responsible physician and local health integration network (LHIN). Univariate odds ratios (ORs) were estimated to determine association of HER2 testing with covariates and multivariate logistic regression assessed HER2 documentation patterns. We reviewed 29,764 reports of breast tissue reported to the OCR. A HER2 test was documented for 66% of the 13,396 patient cohort. Higher odds of HER2 documentation were associated with stage, hormone receptor and tumor grade documentation in multivariate analysis. Higher stage and grade at diagnosis were also associated with higher odds of HER2 documentation in adjusted models. All models suggested variable documentation patterns by LHIN (global likelihood ratio test p<0.001). Test documentation did not differ by urbanicity, income, presence of comorbidities or type of surgery. Reporting of HER2 testing to the central OCR was incomplete for 2006-07. Completeness of reporting was better for those with more aggressive disease which could reflect need to access trastuzumab therapy. Differences in regional reporting likely reflect ascertainment bias inherent to centralized pathology reporting rather than use of testing.

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Variation in Treatment Patterns for Breast Cancer Patients in Alberta

**Presented by:** He Gao, Department of Public Health Sciences, University of Alberta; Dr. Marcy Winget, Leader, Research and Evaluation, Community Oncology, Alberta Health Services - Cancer Care

Standard treatment guidelines for stages I-III breast cancer include receipt of either breast conserving surgery (BCS) plus post-surgical (adjuvant) radiation therapy or a mastectomy; long-term survival is equivalent between these treatment options. The purpose of this study is to examine adherence to treatment guidelines and variation in treatment patterns. Female residents of Alberta who were diagnosed with stage I-III breast cancer in 2006 to 2009 were identified from the provincial cancer registry. All first-ever incident cases in the time period in a given breast were included. Patients who had any other cancer diagnosed within 6 months prior to the breast cancer diagnosis were excluded. Clinical, demographic and treatment information were obtained from the cancer registry. The relationship between surgical and radiation treatments received and patient age, region of residence, year of diagnosis, stage, estrogen/progesterone receptor status, and receipt of pre or post-surgical chemotherapy were examined. There were 6833 women residents of Alberta comprising 6938 cases diagnosed with stage I-III breast cancer 2006-2009 who met the eligibility criteria. Of those, surgery was performed on 6806 (98%) of the cases. 2973 (44%) cases underwent breast conserving surgery (BCS) of which 2596 (87%) also received adjuvant radiation. All factors evaluated except for year of diagnosis were significantly associated with receipt of BCS (as opposed to mastectomy) and subsequent receipt of radiation therapy. Of interest is that 47-48% of women residing in urban regions received BCS compared to 34-38% of those residing in rural or remote regions (P<0.0001). Only 16% of women with stage III disease received BCS compared to 58% with stage I disease (P<0.0001). Although most women with stage I-III breast cancer received treatment consistent with guidelines, it is surprising, given the equivalent survival, that less than half received BCS. The variation in receipt of BCS by urban/rural residence suggests that proximity to radiation therapy facilities may be an important issue for women.

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Monitoring Emerging Scientific Evidence to Guide Colorectal Cancer Screening Programs and Policies: a Prospective Multiple Case Study

**Presented by:** Hannah Geddle, Research Associate, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC)

Colorectal cancer screening programs have been and continue to be implemented across Canada. However scientific evidence continues to emerge, posing new opportunities for health system improvement. This study's aim is to examine how policy-makers monitor this emerging scientific evidence, and use it to make substantive changes to existing screening programs. This study employs a prospective multiple case study design. Methods of data collection include key informant interviews and document analysis in five provinces including Ontario, Manitoba, Alberta, Nova Scotia and Quebec. In each province, policy-makers are asked to consider randomized controlled trial evidence on flexible sigmoidoscopy for colorectal cancer screening, including how individuals initially became aware of this evidence and the impact of this and other forms of evidence for existing programs. Particular emphasis will be placed on information pertaining to the program's context, including how 'contextual' evidence is identified and integrated with scientific evidence to address challenging policy decisions. Although data collection for this study is ongoing, preliminary findings are informative. Pilot interviews conducted with key policy-makers and screening experts have provided valuable insight into the importance of national networks for monitoring emerging scientific evidence, the need to engage multidisciplinary groups to consider the implications of this evidence for a specific context, and the variability in what constitutes relevant contextual evidence. Approximately twenty additional interviews will be completed by April, 2012. Findings will continue to provide insight into how policy-makers in different jurisdictions and at varying stages of program implementation consider prospectively whether or how to expand the role of flexible sigmoidoscopy for population-based screening. This issue is timely and relevant in Canada as well as other jurisdictions. Findings will contribute to the literature on evidence-based health policy, and will help to support policy-makers in responding to ongoing changes in the scientific evidence base, and addressing challenging policy decisions about health system improvement.

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Patient Navigation Tools and Resources: a Systematic Scoping Review
Presented by: Hannah Geddie, Research Associate, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC)

Patient navigation has been identified as a valuable means of addressing gaps in cancer care. It is important to understand better what tools and resources exist for patient navigation, and how virtual/online tools may be used to address the needs of patients at various stages of the cancer journey. We present a systematic scoping review of tools used to address the navigation needs of patients with cancer. OVID Medline, PubMed, CINAHL, PsychINFO, Scopus, and Google Scholar will be searched using a combination of the terms ‘patient navigation,’ ‘cancer/chronic disease,’ and ‘tools/resources.’ Google and organizational webpages will be searched for grey literature using broad and targeted search strategies. To ensure comprehensiveness, electronic and paper-based tools will be included for cancer or chronic disease. Articles will be excluded if they are published before 2000, non-English, focus on human navigators, or tools used by non-patients. Searches will be completed by March, 2012. The results of this review will be used to identify: 1) the needs that patient navigation tools and resources may be used to address; 2) the characteristics of existing patient navigation tools; 3) the efficacy of patient navigation tools; and, 4) considerations for implementing these tools in a practical setting. Findings will support the development and operationalization of virtual navigation tools as part of an initiative within Cancer Care Ontario (CCO) to develop patient pathway maps. An offshoot of CCO’s Disease Pathway Maps initiative, patient pathways will provide a holistic disease-specific framework of the cancer journey which will be accessible online. Populating these maps with interactive navigation tools will help to address patients’ need for self-management and engagement in decision-making across the cancer continuum. As the delivery of healthcare interventions via the Internet garners increasing attention, it is important to understand how virtual navigation tools may be used to address patients’ need for support and self-management. Findings of this review will support ongoing initiatives to improve the patient experience in Ontario’s cancer system.

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The Cost of Public Cancer Prevention in Alberta
Presented by: Dr. Philip Jacobs, Department of Medicine, University of Alberta and Institute of Health Economics

We provide an estimate of public expenditures on cancer prevention in Alberta. Our estimate covers all three levels of government – federal, provincial, and municipal. Public cancer prevention is a government activity whose purpose is to expressly reduce the future incidence of cancer. As part of a wider initiative, we conducted a survey of ministries, in search of all programs whose express purpose was to promote health and prevent illness. We searched web pages, ministry annual reports and federal and provincial budget papers. We collected data on program type, type of intervention, and program cost. We then verified the results with each ministry. We sorted the data by risk factors, and selected those risk factors that were related to cancer. Expenditures for those risk factors that are related to cancer are shown in Table 1. In total expenditures on these risk factors were $206. Of this, about two-thirds were expenditures that were incurred by non-health, provincial ministries. The risk factor with the highest preventative expenditures was environmental health. In Alberta, all levels of government spent $206 per person on risk factors that can prevent cancer, mostly in the long run. Without a cost–effectiveness analysis, we cannot say that this amount is too much or too little. However with this data, and a cost effectiveness analysis, we can in fact say whether we are spending too much or too little.

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Investigating the Effectiveness of Predictive Genetic Testing for Colorectal Cancer in Modifying Health Outcomes and Health Behaviours
Presented by: Joanne Kim, PhD Candidate, Institute of Health Policy, Management and Evaluation, University of Toronto, Canadian Centre for Applied Research in Cancer Control (ARCC)

Personalized medicine is expected to revolutionize health care. The use of individual genetic profiles to identify at-risk populations for disease prevention promises to improve population health but premised on change in individual health behaviours. In this study, the effectiveness of predictive genetic testing for colorectal cancer in modifying health outcomes and health behaviours will be assessed. The proposed study will take the form of an observational, retrospective cohort study, informed by the U.S. Preventive Services Task Force’s framework on preventive services and an economic model of health investment. Specific aims of the study are to: 1) evaluate the effect of genetic information obtained from predictive genetic testing for colorectal cancer directly on health outcomes such as cancer incidence, death rates, and survival times; and 2) determine the effect of the obtained genetic information on individual health behaviours such as the intake of vitamins and other supplements and smoking habits. The study aims will be fulfilled using Australian and Canadian colon cancer registries which prospectively collect health behaviour information on colorectal cancer cases and their kin. From the registries, unaffected users and non-users of predictive genetic testing for colorectal cancer will be identified amongst the kin as those who underwent the testing and those who did not, respectively. To fulfill the first study aim, the effects of the user/non-user status on subsequent health outcomes such as cancer incidence, death rates, and survival times will be determined using regression and survival analysis. To fulfill the second study aim, the effects of the positive/negative genetic testing results amongst the users of the testing on their health behaviours such as the intake of vitamins and other supplements and smoking habits will be determined using regression. Results of the analyses will be reported. Forthcoming.

Building on Existing Programs and Partnerships to Better Respond To the Needs of a Diverse Cancer Survivors’ Population
Presented by: Dr. Anne Leis, Professor and Dr. Louis Schulman Cancer Research Chair, Department of Community Health and Epidemiology

While returning to wellness, cancer survivors live with the possibility of recurrence and may experience negative long-term effects and unexpected obstacles. This presentation will summarize the Live Well program which, in collaboration with cancer survivors, was developed to address the needs of cancer survivors. The Live Well program was designed to provide support and education to cancer survivors to improve their quality of life and promote healthy living. The program is led by cancer survivors and is delivered by a multidisciplinary team of experts, including oncologists, nurses, and social workers. The program is delivered through a variety of formats, including in-person and online, to meet the needs of cancer survivors. The program’s success is evidenced by positive feedback from participants, who report increased confidence in their ability to manage cancer-related symptoms and improved quality of life. This presentation will discuss the challenges and successes of the program, as well as strategies for expanding access and increasing program impact. The presentation will also highlight partnership opportunities and collaborations that can help to further enhance the program’s reach and effectiveness.
A Pilot Study Evaluating Canadian Cancer Patients' Treatment Related Out-of-Pocket Costs

Presented by: Dr. Christopher Longo, Associate Professor, McMaster University

Limited published research exploring patients’ out-of-pocket costs (OOPC) has been undertaken in Canada. Especially absent are more in-depth investigations on the nature of these costs and the impacts they have on patient’s overall quality of life (QoL). This study was undertaken in an effort to address this current research gap. We undertook in-depth semi-structured interviews with breast, colorectal, lung and prostate cancer patients at the Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, Ontario between June 2011 and February 2012. Although this work is still in progress, we have transcribed the initial 6 interviews. The research team determined an initial coding framework based on the first three interviews. Interviews will continue until no new themes have emerged (typically 15-20 subjects in total). In total six participants have been interviewed to date (3 breast, 1 colorectal, 1 lung, and 1 prostate). Several preliminary themes emerged from these interviews. Much of what was uncovered is consistent with existing literature as it relates to drugs, devices, homecare, and homemaking expenses. New emerging themes not highlighted in the existing literature include financial impacts/consequences related to: housing arrangement/mortgages, healthy food choices, maintaining a healthy/healing exercise regime, loss of economic self-reliance, and the value of supplemental health insurance. Additionally participants expressed significant stress related to financial issues that impacted their QoL. Questions specifically related to insurance behavior suggest that a number of those interviewed were unprepared for the financial shock associated with a cancer diagnosis and treatment, and in hindsight felt supplemental health insurance would have mitigated many of these concerns. Although literature exists providing a quantitative analysis of the magnitude of the costs associated with cancer treatment, this research uncovers a number of issues not otherwise well described. Future quantitative work would be well served by examining these types of qualitative studies to ensure all aspects of financial shocks to patients are captured.

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The Need for a New Model of Young Adult Cancer Follow-up Care in Canada

Presented by: Dr. Baukj (Bo) Miedema, Director of Research, Dalhousie University

The purpose of this study was to assess the need for a new model of cancer follow-up care for young adults. This qualitative study involved telephone interviews with 55 cancer survivors diagnosed between the ages of 18 and 39 years, 1-5 years post treatment, from across Canada. The overall theme that emerged from the data was the need for age-specific cancer follow-up care (CFC). All participants had received biomedical care; however, participants felt there was not enough emphasis on fertility preservation and cancer testing. Due to the lack of family, couple and sexuality counseling, participants also felt that the current psychological care offered was not sufficient. Participants expressed a need for social and system care; e.g., better access to supplemental health insurance and survivorship care plans. Hence we propose a new model of young adult CFC that encourages clinicians to provide age-specific care, broaden psychological care and to focus on social and system issues in addition to biomedical care. The current Canadian model of CFC is not adequate and does not provide comprehensive age-specific care to address the needs of young adult cancer patients. A new model would meet more of the care needs of this population so they can be empowered to achieve full independence.

Co-Author: Julie Easley, Dalhousie University

KT-Net: Improving Cancer Control in Ontario Through Knowledge Translation

Presented by: Dr. Mary Ann O’Brien, Post Doctoral Fellow, University of Toronto

To describe the activities of the Knowledge Translation Research Network (KT-Net). KT-Net is a key component of Ontario Institute for Cancer Research, Health Services Research Program (HSRP). The HSRP goal is to provide knowledge to optimize the delivery of cancer services and to ensure appropriate dissemination of health service (HS) innovations and technologies. KT-Net’s goal is to provide a platform for conducting fundamental research in knowledge translation (KT) (e.g., developing or testing models) and to provide a means for applying KT techniques and tools (such as, communities of practice, evidence summaries, or use of knowledge brokers) to policy and practice. Towards this aim, KT-Net endeavours to create a province-wide network of researchers focused on KT and cancer control. Since 2009, KT-Net has held three grant competitions and funded five teams to conduct cancer KT research. The total funded is over $600,000 (CAD). A fourth competition will be launched in March 2012. The first study reviewed KT frameworks and interventions applicable to cancer. Subsequently, four other teams have investigated: 1) KT screening tools and instruments; 2) examined how personalized medicine tools are integrated into clinical practice; 3) developed clinical pathways for pancreatic cancer surgery; and 4) developed a decision aid for hormonal treatment in breast cancer. In addition, three annual HSRP/KT-Net meetings have been held with investigators across Ontario. To encourage the KT-Net to communicate to a wider audience, KT-Net has instituted a new standing section on cancer KT in Current Oncology. Since 2009, KT-Net has engaged in several activities consistent with its mandate. Its challenge is to encourage linkages between HS researchers and policy makers. Future endeavours will include workshops in end-of-grant KT and funding opportunities for trainees to encourage KT skill development for the next generation of HS researchers.

Co-Author: Dr. Eva Grunfeld, Ontario Institute for Cancer Research

Surgeons’ Views of Facilitators and Barriers to Optimal Breast Cancer Surgery Quality Indicators

Presented by: Dr. Mary Ann O’Brien, Post Doctoral Fellow, University of Toronto

A surgeon-directed quality improvement strategy in a large region of Southern Ontario facilitates surgeon selection of quality indicators (QIs) related to breast cancer surgery, and interventions to optimize the selected QIs. We conducted tailoring interviews with surgeons to identify facilitators or barriers to achieving optimal scores for four key QIs. Forty-four surgeons sit at 12 hospitals provide breast surgery to patients in the study region. The key selected QIs included: 1) rate of preoperative diagnosis; 2) rate of positive margins after breast conserving surgery; 3) rate of reoperation following positive margins; and, 4) rate of sentinel lymph node biopsy. We interviewed a subset of 21 surgeons. The Pathman framework (awareness, agreement, adoption and adherence) informed the interview guide design and analysis. Coding was completed independently by 2 members of the study team. Twenty-one surgeons (8 academic; 13 community) of 31 surgeons (68% of those approached) agreed to be interviewed. For QI #1, nearly all respondents were adherent with obtaining a preoperative diagnosis. Comments included ‘facilitated surgical decision making’, ‘minimized re-operation’, and ‘enhanced physician-patient communication’. For QI #2, 1 surgeon at 1 hospital identified ‘lack of facilities for preoperative wire localization’ as a barrier to minimizing rates of positive margins. For QI #3, reoperation after a positive margin, ‘margins location’, ‘extent of margin’, ‘breast size’, and ‘patient age/comorbidities’ were common influencing factors. For QI #4, all surgeons agreed with the importance of sentinel lymph node biopsy. Four surgeons at 3 hospitals identified ‘facility limitations (e.g., lack of nuclear medicine)’ and ‘surgeon training’ as barriers to QI #4. Surgeons in this study agreed with the QIs chosen by the larger group. Barriers to quality care were viewed as relating to lack of appropriate hospital equipment and surgeon training rather than disagreement with the indicators.

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Quantification of the Amount of Data Collected and Reported in Cancer Clinical Trials
Presented by: Erin O’Leary, Research Coordinator, McMaster University

The financial cost and personnel time required to coordinate a cancer clinical trial has continued to increase. A large amount of staff time and trial cost is related to the collection and validation of data. We will highlight opportunities to reduce excessive or unnecessary data collection and improve trial efficiencies. A retrospective review was performed of five published cancer clinical trials completed through the Ontario Clinical Oncology Group (OCOG). The number of data items collected in each case report form (CRF) was counted and sorted into 18 categories representing different clinical trial components, such as administration, eligibility, baseline characteristics, medical history, quality of life, toxicity, recurrence, etc. The data items in each category were then counted within the corresponding published manuscript to determine percent of used clinical data. The total number of variables collected on all CRF ranged from 186 to 836 per trial. Across the 5 trials, a median of only 81.5% (17%) of data items were reported in the published manuscripts, ranging from 11% to 27% per trial. Less than 10% of the collected data was eventually used in each of the following categories: comorbidities at baseline, costs and concomitant medications. In contrast, over 40% of data items from the stratification and randomization, medical history, follow up and tumour & biopsy categories were used in the manuscripts. Administrative and patient identification data, as well as investigators signature were also frequently required on CRF despite the fact they are not used for manuscript reporting or scientific analysis. This review describes a need to reduce potential excessive data collection across a variety of data item categories. Less than 27% of data items were used to produce peer-reviewed journal manuscripts, revealing points of excess data collection. Investigators should streamline data collection, thereby optimizing resources and improving efficiency.

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Short-Interval Follow-up Recommendation after Imaging Assessment of an Abnormal Screening Mammogram: Frequency and Determinants
Presented by: Eric Pelletier, Institut national de santé publique du Québec (INSPQ)

After imaging assessment of an abnormal screening mammogram, some women are asked to come back for a follow-up examination six months later. Our aim was to identify which characteristics of women, physicians and centers influence this recommendation of short-interval follow-up in the Quebec Breast Cancer Screening Program (PQDCS). Short-interval follow-up is considered among women who, after imaging assessment of an abnormal screening mammogram, are diagnosed with a probably benign lesion. Such follow-up includes unilateral mammography at six months and bilateral mammography at one and two years. Our cohort includes 1,839,401 consecutive screening mammograms realized in the PQDCS between 1998 and 2008. A total of 114,782 abnormal screening mammograms were assessed by imaging only. Short-interval follow-up recommendation and characteristics of women, physicians and centers were identified by linkage with administrative databases. Data were analysed by Generalized Estimating Equation (GEE) using Poisson regression models and generalized linear mixed models (GLMM). Short-interval follow-up was recommended in 26.7% of assessments with imaging only. When microcalcifications were observed at screening, the relative risk (RR) of having a short-interval follow-up recommendation reached 1.51 (95% confidence interval (CI), 1.36-1.69) compared to mammograms with a mass at screening. Radiologists with high recall rates (≥15%) at screening had a high proportion of short-interval follow-up recommendation (RR= 1.67; 95% CI, 1.26-2.20) compared to radiologists with low recall rates (<5%). The adjusted proportion of short-interval follow-up recommendation was 30.3% for non-academic medical hospitals compared to 23.2% for academic medical hospitals and 19.1% for privately-run clinics (p-value <0.0001). In the period 2006-2008 and after adjusting for women characteristics, the proportion of short-interval follow-up recommendation varied substantially by radiologist (10th and 90th percentiles=10.2% and 45.4%). To our knowledge, this is the first Canadian study on the frequency and determinants of short-interval follow-up recommendation. This recommendation is frequent in our program and comparable to the practice in the United States. The substantial variability in such recommendation suggests that indications for short-interval follow-up need to be clarified.

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Using Prognostic Indices to Guide Clinical Care in Elderly Cancer Patients  
*Presented by: Mayvis Rebeira, Doctoral Candidate, University of Toronto*

Prognostic indices are gradually being used to provide guidance to some clinicians on the type of care to be given to their patients based on mortality risks. The development of the online tool (ePrognosis) developed by the UCSF has greatly aided the use of these indices by clinicians. Various indices are explored as potential for use in cancer patients. The type of indices used is dependent on the location of the patient (living in the community or in the nursing home or hospitalized) and the clinician's estimate or guess of the patient's one-year mortality. The risk score is then calculated based on the type of indices used that will indicate the risk of the patient's 1 year mortality. The application of some of these indices is then investigated for different scenarios of elderly cancer patients. The Walter index is used as one of the case studies for inpatient elderly patients based on the extent of cancer (solitary, metastatic or minor). The Schonberg index is used as another case study to estimate all cause five and nine-year mortality risks. The right type of prognostic indices can be used as a tool to guide decision-making for clinicians on the optimal path of care for cancer patients on a case-by-case basis and potentially avoid overtreatment of patients who have high mortality risks. This in turn may result in increased efficiencies to the health system as well as cost savings to the system.

Integrating Evidence and Action for Cancer and Chronic Disease Prevention: The Propel Centre for Population Health Impact  
*Presented by: Dr. Barbara Riley, Executive Director, Propel Centre for Population Health Impact, University of Waterloo*

In Canada, preventable cancers and other chronic diseases undermine public health, health care system sustainability, and Canada’s global competitiveness. Reducing the incidence of these diseases requires “upstream” interventions that promote healthy living conditions and reduce the prevalence of risk factors at a population level. Propel’s mandate is to accelerate the generation and use of relevant evidence in developing and implementing these upstream interventions effectively. In particular, we were encouraged by policy and practice leaders to specialize in evaluation science, to learn from ‘natural experiments’ (as innovative interventions are introduced) what works, for whom, under what circumstances, at what cost. Propel takes an integrated knowledge translation approach by starting with active and emerging program and policy agendas. We serve as a catalyst and resource to support programs of research in cancer and chronic disease prevention. This includes leading the development of a University of Waterloo centre of excellence in chronic disease prevention, with plans to launch in the fall 2012. Propel brings together collaborative teams to set priorities, conduct studies and move evidence into action. Teams are multi-disciplinary and multi-sector (research, policy, practice). Current programmatic areas include tobacco control (prevention, cessation and policy foci at local through international levels), youth health (with a focus on environments to support healthy living), and capacity building (including partnership development, methods development, evaluation research, and a pan-Canadian graduate student training program in population intervention for chronic disease prevention). Examples of major initiatives in the three program areas are described, along with sample metrics for research excellence and impact at programmatic and centre levels. The Propel team includes 45 scientists and staff at the University of Waterloo, Ontario, and a network of science, policy and practice collaborators across Canada and beyond. The centre is supported by a CCSRI major program grant (2011-16), the University of Waterloo, and more than 30 grants and contracts from government and non-government organizations.

Co-Authors: Propel Centre for Population Health Impact

Is “Quick and Dirty” Always Bad?  
*Presented by: Jillian Ross, Director, Clinical Programs – Strategy and Integration, Cancer Care Ontario*

Cancer Care Ontario (CCO), the government’s cancer advisor, is responsible for continually improving services. Faced with increases in disease burden, fiscal constraint, anticipated human resource shortages and changing patient expectations, CCO is working with stakeholders to develop and implement new models of care with the goal of a sustainable, high-quality patient-centred system. In the Ontario Cancer Plan, CCO commits to 1. Develop new models of care delivery to support evidence-informed, efficient, patient-centered care. 2. Implement the models and address necessary remuneration, regulatory, scope of practice and policy changes. and 3. Develop and implement a mechanism for continuous evaluation, modification and improvement of the models. Two key issues are that we need to deliver the same or better care for less and to address the fact that it is not possible to meet the demand for new oncologists if the current model remains in place in the face of rapidly growing disease burden. As CCO rolls out changes to the model of care, how will we know if we have reduced the costs, particularly when we do not know the costs of the current model? How will we show that the need for new oncologists is reduced as a result of new model implementation? How can we do all of this quickly enough to meet the expectations of a system funder facing serious financial challenges? This poster will describe the “models of care” challenge and other, similar challenges facing Cancer Care Ontario and will ask: Could a partnership with the ARCC community provide quick (but not so dirty) answers to questions like these?

The Canadian Task Force on Adolescents and Young Adults (AYA) with Cancer: a Process for Change  
*Presented by: Dr. Brent Schuster, Professor, CancerCare Manitoba*

To ensure that Adolescent and Young Adult (AYA)-aged Canadians with cancer and AYA cancer survivors have prompt, equitable access to the best care, and to support research to optimize health outcomes and quality of life in this population. Disparities in care facing AYA cancer patients and survivors is in part due to the dichotomy and disconnect in cancer care between the pediatric and adult health care systems in Canada. While cancer is relatively uncommon among AYAs, its personal, societal, and socioeconomic impact is disproportionately greater than in other age groups. The Canadian Task Force on AYA with Cancer was established in 2008 to address these issues. The Task Force is comprised of healthcare professionals, researchers, and community members including survivors from across the country. Working groups have been formed to address the Task Force’s objectives. A survey of existing AYA cancer services in Canada identified disparities in care for this cohort which highlighted the need for age-appropriate psychosocial, palliative and medical care. Based on the survey results and workshop discussions with survivors, healthcare professionals, and policy makers, the Task Force identified principles of care, priority issues for research, and strategies for implementing change for this specific cohort of patients and survivors, to redress inequities in the care provided relative to both younger and older cancer patients. Recommendations have been formulated for AYA cancer care in Canada. The Task Force is now embarking on a communications strategy for knowledge dissemination and to gain support from all stakeholders for the challenge of implementation. Improved care for this group will enable individuals to reach their full potential as productive, functioning members of society, and will provide economic and other societal benefits. National research initiatives underway include a surveillance program, an examination of clinical trial accruals and a survey of oncology services.

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Assessment of the Non-Medical Costs of Treating Metastatic Colorectal Cancer at the Segal Cancer Centre Using Time and Motion Methodology

The primary objective was to determine the non-medical costs involved in physician and treatment visits of metastatic colorectal cancer patients at the Segal Cancer Centre. A secondary objective was to map the work steps involved during these visits and assess patient flow. A work flow diagram was created to map tasks where there is direct interaction with the patient (direct steps) and behind the scenes tasks required in preparation for, or as a result of, the patient’s physician or treatment visit (indirect steps). Staff was timed as they performed tasks and personnel costs were determined using this timing data as well as compensation costs for each particular staff category. Mean work times and 95% confidence intervals (CI) were calculated. Operation and maintenance costs including equipment were calculated using information from hospital databases. Treatment was with either FOLFOX/bevacizumab or XELOX/bevacizumab. Non-medical costs per physician visit were $69.46 (95% CI: $67.21 - $71.72); personnel $9.25 (95% CI: $7.00 - $11.51); operation and maintenance $60.21. Non-medical costs per treatment visit were $133.91 (95% CI: $107.53-$160.29): personnel $71.91 (95% CI: $45.53 - $98.29); operation and maintenance $62.00. In both instances, non-medical costs represented less than 5% of the overall health care costs. When calculated for treatment alone according to treatment type, the total non-medical costs were $136.06 (95% CI: $109.16 - $162.95) for FOLFOX/bevacizumab and $119.94 (95% CI: $96.89 - $142.99) for XELOX/bevacizumab. The highest cumulative personnel costs were for the pharmacists and nurses ($38.87 and $34.82 respectively). Total direct interaction with the patient (direct steps) and behind the scenes tasks required in preparation for, or as a result of, the patient’s physician or treatment visit (indirect steps) was 77.6 and 49.5 minutes for a physician or treatment visit respectively. This time and motion study showed that personnel and operation and maintenance costs do not contribute greatly to the overall cost of treating metastatic colorectal cancer. Improvements need to be made in patient flow to reduce wait times in the clinic.

Knowledge Sharing in Cancer Control: Online Learning Increases Provider Knowledge and Improves Cancer Outcomes in First Nations Communities

Conference delegates will learn how online learning is improving cancer outcomes for First Nations through effective knowledge translation. The bilingual @YourSide Colleague® First Nations Cancer Care course has been developed with and for health care providers working in First Nation communities and is available at no cost to the communities. The growing burden of chronic disease, including cancer, among First Nations, creates an urgent need to systematically address prevention, screening and management through education. However, accessing professional development opportunities can be challenging for health care providers in rural, remote and isolated communities. The @YourSide Colleague® First Nations Cancer Care course is available for self-paced learning, anytime and anywhere, and is complemented with real-time e-learning events that connect health care providers across the country to discuss cancer control, community leading practices, and First Nations approaches. The system is evidence-based, culturally appropriate, contextually relevant, cost effective and accessible. There are more than 1100 providers from over 320 First Nation communities and organizations who currently have access to the First Nations Cancer Care course. Prior to the launch of the course, 85% of participants indicated they had no prior education or training in cancer control, yet 77% provided weekly care/support to community members with cancer. Course evaluations demonstrate that the program is relevant and immediately applicable and has directly contributed to improved patient assessment and care, supporting early detection, treatment and better outcomes. First Nation communities have identified @YourSide Colleague as an effective vehicle to support local capacity and First Nations-driven health services. The @YourSide Colleague® First Nations Cancer Care course is filling a critical gap in cancer control professional development by successfully overcoming barriers posed by geography, isolation and limited health human resources, demonstrating the power of partnerships and innovation, and improving the quality of care in First Nation communities.

Funding Academic Oncology Clinical Trials: An Inadvertant Ponzi Scheme

Many oncology Clinical Trials Departments (CTDs) are in serious fiscal deficit and their sustainability is in jeopardy. This study investigates if the payment models used to fund industry versus cooperative group trials contribute to the fiscal deficit of a CTD. We examined the lifetime costs of all cooperative group and industry trials activated in a CTD of a cancer center between 2007 - 2011. A trial's lifetime included when the first patient was accrued until the last patient's actual or projected final follow-up visit. For each trial, we calculated the lifetime monthly net income, which was defined as monthly revenue minus monthly costs. Data sources included study protocols, trial budgets, and accrual data. Of the 97 trials analyzed, 64 (66%) were cooperative group. The pattern of lifetime net income for cooperative group trials has a positive peak during patient accrual followed by a negative trough during follow-up. In contrast, the pattern for industry trials resembled an 'L-shape'. The patterns reflect differing payment models: upfront, lump-sum, payments (cooperative group) versus milestone payments (industry). The negative trough in the lifetime net income of a cooperative group trial occurs because follow-up costs are typically not funded or underfunded. CTDs accrue more patients in new trials to offset that deficit. The CTD uses revenue from accrual to existing trials to 'cross-subsidize' past trials in follow-up. As the number of patients on follow-up increases, the fiscal deficit grows larger each year, perpetuating the cycle.

Co-Authors: Patrick Whelan, McMaster University; Dr. Mark N. Levine, McMaster University; Juravinski Cancer Centre, Escarpment Cancer Research Institute; Brenda Kowaleski, Juravinski Cancer Centre; Dr. Andrew Arnold, Juravinski Cancer Centre, Escarpment Cancer Research Institute

Knowledge Sharing in Cancer Control: Online Learning Increases Provider Knowledge and Improves Cancer Outcomes in First Nations Communities

Presented by: Dr. Gayle A. Shinder, Program Co-ordinator, Department of Oncology, McGill University

Presented by: Suzanne Stephenson, Engagement Liaison, Saint Elizabeth First Nations, Inuit and Métis Program

Presented by: Dr. Hsien Seow, Assistant Professor, McMaster University, Juravinski Cancer Centre, Escarpment Cancer Research Institute
Health Services Utilization Among Hepatocellular Carcinoma Patients; a Population-Based Study

Presented by: Dr. Rosie Hla-Hla Thein, University of Toronto Dalhousie School of Public Health

To compare health services utilization between people diagnosed with hepatocellular carcinoma (HCC) and matched controls without HCC over the study period between January 1, 2002 and December 31, 2008, one year following diagnosis, and at the end of life (i.e., in the last 6 months of life); and to explore treatment utilization in HCC patients. The Ontario Cancer Registry, Registered Persons Database, and health claims data were used to identify two matched cohorts of HCC cases and non-HCC controls by age and gender. Health claims data identified family physician, specialist, emergency department, hospital, same-day surgery and home care visits, and the number of prescription medications. We estimated the mean number of health care visits per 100 person-days and compared between cases and controls using Poisson regression. Propensity score matching will be used to adjust for index year, age, gender, income quintile, rurality, Charlson-Deyo Comorbidity Index, and the interaction between age and comorbidity in the final analysis. Over the period 2002-2008, 2,422 HCC cases and 158,266 controls were identified; the number of new HCC cases increased, and the proportion of those aged 80 and above increased. There were significant differences in the mean number of visits for all service categories between cases and controls over the study period, one year following diagnosis, and at the end of life. Among HCC cases, 19.1% had liver resection, 14.1% had liver transplant, 9.6% had radiofrequency ablation, 7.3% had transarterial chemoembolization, 1.7% had percutaneous injection, 12.8% had chemotherapy, and 3.5% had sorafenib after diagnosis. Most treatments occurred during the year following diagnosis. Approximately two-thirds of liver transplants (69%) occurred during the year following diagnosis. Over the period, treatments with liver transplant, radiofrequency ablation, or transarterial chemoembolization in the year following diagnosis increased; however, liver resection decreased. This study provides understanding of the current patterns of health service utilization among HCC patients. Our results suggest that health services utilization among HCC patients is significantly higher than non-HCC controls except the number of prescription medications at the end-of-life. Furthermore, the rate of health services utilization at the end of life is greater than in the first year following HCC diagnosis. These results show that the burden of HCC is significant and help inform policy decision making for early detection and prevention.

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A Pan-Canadian Perspective of Variations in the Surgical Treatment of Cancer

Presented by: Brandon Wagar, Methodologist, Canadian Institute for Health Information

Surgery is a critical part of cancer care, yet we lack important information about the use of surgery in the treatment of cancer in Canada. The Canadian Institute for Health Information (CIHI) is working to provide comparative, pan-Canadian information to assist stakeholders across the country to create evidence-based surgical practices. Two main areas are explored where selected aspects of surgeries are known to be effective, yet there is evidence from the literature of variable uptake of these effective practices: 1. The relationship between hospital volume and in-hospital mortality for pancreatic and esophageal cancer surgery. 2. The surgical treatment of women with breast cancer. CIHI’s administrative databases are used to capture all inpatient and day surgery cases. Records are linked to depict the surgical treatment of cancer. The methodologies adopted to deal with limitations of administrative data when analyzing the surgical treatment of cancer will be presented. Results focus on provincial/ regional variation in surgical practice patterns and outcomes, as well as patient characteristics which influence these rates. Specific findings include: 1. The extent to which surgery for pancreatic and esophageal cancer has been centralized and carried out in high-volume acute care hospitals. 2. The volume-outcome relationship for pancreatic and esophageal cancer surgery. 3. Use of axillary lymph node dissection among women with ductal carcinoma in situ. 4. Use of axillary lymph node dissection versus sentinel lymph node biopsy for women undergoing breast cancer surgery. 5. Choice of mastectomy versus breast conserving surgery among women with breast cancer. 6. Rates of surgical complications, readmissions and reexcisions among women undergoing breast cancer surgery. This information can be used to support population-based, regional planning of cancer surgery services, and will be helpful in bringing forward comparable data that will help surgeons, hospital and health authority administrators and cancer agencies understand variation in surgical practice and outcomes across Canada.

Co-Authors: Maria Hewitt; Jin Huang, Analyst, Canadian Institute for Health Information; Janet Manuel, Classification Specialist, Canadian Institute for Health Information; Marilee Allerdings, Manager, Canadian Institute for Health Information

Developing Consensus-Based Research Priorities for Community-Based Integrative Oncology: A Delphi Survey

Presented by: Dr. Laura Weeks, Research Associate, Ottawa Integrative Cancer Centre

Integrative Oncology (IO) is an evidence-based approach to combining conventional cancer therapies with complementary therapies, such as naturopathic medicine, acupuncture and meditation. Our objective is to establish consensus-based IO research priorities to inform the structure and delivery of community-based IO care within a cancer control strategy for Canada. We invited cancer researchers, practitioners, knowledge users and patients to participate in a 3-round Delphi survey to gain consensus on IO priority research areas and topics. In Round 1, participants selected up to 3 priority research areas from a pre-identified list and provided suggestions for priority topics within each area. In Round 2, participants revisited the priority research areas based on Round 1 results and then selected up to 3 priority research topics within each area. In the final Round, participants ranked the priority research areas and topics in order of importance to future Canadian IO practice and policy. Eighty-one participants took part in Round 1, 52 in Round 2 (66.2%) and 45 (50%) in Round 3. Participants identified themselves as practitioners (30%), researchers (21%), knowledge users (21%) and patients (57%). Five priority research areas were identified: clinical effectiveness, developing practice models, education and training, cost-effectiveness and safety. There was clear consensus throughout Delphi rounds of the importance of studying clinical effectiveness: 89% of Round 3 participants ranked this as the top priority. The remaining four areas were deemed important, but consensus was not reached regarding which should receive priority within a research program. Within the area of clinical effectiveness, there is consensus that research should focus on the impact of integrative oncology on symptom management and quality of life. The identified research priorities reflect the needs and perspectives of a spectrum of IO stakeholders and will form the basis for discussion at a stakeholder meeting in 2012. Our goal is to implement a research program to inform the advancement of community-based IO care within a Canadian cancer control strategy.

Co-Authors: Dr. Dugald Seely, Ottawa Integrative Cancer Centre; Dr. Lynda Balneaves, University of British Columbia; Dr. Heather Boon, University of Toronto; Dr. Anne Leis, University of Saskatchewan; Dr. Doreen Oneshuck, University of Alberta; Dr. Stephen Sagar, Juravinski Cancer Centre; Dr. Marja Verhoef, University of Calgary
Adherence to Oncology Guidelines in Clinical Practice: a Quality Assurance Study in Early Stage Breast Cancer

**Presented by: Audrey Wong, St. Michael's Hospital; Ammar Bookwala, St. Michael's Hospital**

Guidelines for staging investigations after breast cancer surgery ensure safety through appropriate investigations. Over-investigation has been shown to be harmful. A previous investigation evaluating adherence rates to this guideline resulted in a knowledge translation intervention (KTI) at this centre. This investigation compares adherence rates before and after the KTI. Patients with early stage breast cancer were identified and charts were audited to determine the staging investigations completed after surgery. The staging investigations completed were compared to the CCO guideline for staging investigations and adherence was marked as adherent, over-staged, or under-staged. Adherence rates were compared pre and post KTI. Patients were then divided into two post-KTI cohorts - those treated immediately after the KTI from May 2010 to December 2010 (immediate cohort), and those seen one year after the KTI from July 2011 to January 2012 (delayed cohort). Both were compared against the initial investigation's adherence rates using chi-square test. A total of 222 patients were evaluated post-KTI compared to 231 patients evaluated in the pre-KTI cohort. There was a significant improvement in adherence from the pre-KTI to post-KTI rate from 45% to 58% ($X^2 = 6.48, p=0.01, N=453$). To further define the time of improvement, two cohorts were analyzed post-KTI. Of the post-KTI cohort, 122 patients were in the immediate cohort and 100 patients were in the delayed cohort. Adherence in the immediate cohort was 52% which was not significantly different from the pre-KTI cohort ($X^2 = 1.76, p=0.18, N=353$). Adherence significantly improved between the pre-KTI cohort and the delayed cohort where adherence in the delayed cohort improved to 65% ($X^2 = 16.16, p=0.000058, N=331$). Adherence rates did not improve significantly in the immediate cohort when compared to pre-KTI cohort. Adherence rates did improve in the delayed cohort when compared to the pre-KTI cohort. The reasons for this are unclear. Further methods to improve knowledge translation should be investigated to increase adherence at this institution.

Co-Authors: Dolly Han, St. Michael's Hospital; Dr. Miriam Sweet Goldstein, St. Michael's Hospital; Dr. Ralph George, St. Michael's Hospital; Dr. Christine Brezden-Masley, St. Michael's Hospital; Dr. Rashida Haq, St. Michael's Hospital; Dr. Christine Simmons, Senior and Corresponding Author, St. Michael's Hospital

Breast Cancer Survivorship Care Tailored to South Asian Women

**Presented by: Dr. Frances Wong, British Columbia Cancer Agency- Fraser Valley Centre**

To explore the experiences and concerns of South Asian (SA) breast cancer survivors (BCS) of different life stages in regards to follow-up care 2) To determine the optimal content and format of a survivorship care plan (SCP) after active treatment at a cancer centre for this population. Phase I involved qualitative semi-structured focus groups and one-on-one interviews with 24 SA BCS utilizing an ethnographic approach. Content analysis then used to develop a survey questionnaire which was mailed out to 286 SA BCS as part of phase II of the project. Target survey participants were SA women with a diagnosis of non-metastatic breast cancer, 18-85 years of age, 3-60 months post-discharge from the BC Cancer Agency, and not on active treatment (except adjuvant hormone therapy). Data was cross tabulated by age: Group A (<44), B (45-54), C (55-64) and D (>64). Concerns voiced during interviews included fatigue, fear of the unknown and a need to normalize. Culturally specific themes emerged, such as Quiet Acceptance, Hounsla (hope and courage), and Faith. They emphasized the need for individualized SCP in their own language. 64 patients completed the questionnaire. Compliance rates were high regarding adjuvant hormone treatments (84%), and follow-up visits with their family doctors (95.4% within 24 months). Fatigue and fear of recurrences were confirmed to be the main concerns. Younger survivors were more anxious about physical appearance, depression, and impact of cancer on the family. In contrast to physical issues support, 29.7% felt little of support for emotional/social issues; especially so for group A regarding family counselling (50%) or sex and body image concerns (66.7%). Despite many similar physical and psychosocial impacts of breast cancer treatments cross ethnic backgrounds, specific cultural nuances are important determinants of individual outcome. Understanding of these nuances are important for health care providers to plan for culturally sensitive survivorship planning. This project provides the perspectives of SA breast cancer patients.

Co-Authors: Dr. Savitri Singh-Carlson, California State University Long Beach, School of Nursing; Dr. Sonia Kim Anh Nguyen, British Columbia Cancer Agency- Fraser Valley Centre
The Needs of Users of Health-Economic Evaluations in the Decision Process to Fund Cancer Therapies
Presented by: Dr. Dominika Wranik, Associate Professor, School of Public Administration, Dalhousie University

Users of health-economic evaluations are stakeholders who are involved in the process of deciding, which cancer therapies to add to the Provincial formulary. Users read and interpret economic evidence as a support tool in their recommendations. Health-economic evaluations are cost-effectiveness (CE) or cost-utility (CU) studies. The objectives are threefold: (i) to describe what kind of information users perceive health-economic evidence should provide; and (ii) to describe the users’ perception of what health-economic evidence does provide; and (iii) to assess the gap between users’ perceived information needs and perceived information gains. This is a qualitative case study. The Nova Scotia Cancer Systemic Therapy Committee is an example of a body charged with recommending whether to publicly fund new cancer therapies. We interviewed members of this Committee via structured qualitative interviews. In broad terms, we asked (i) what they understood economic evidence to be; (ii) what they expected to learn from a CE or CU study; and (iii) what they actually typically did learn from the CE or CU studies presented to them. We also worked through four scenarios of having to assess a cancer therapy on the basis of clinical, economic and ethical considerations. To date we have held eight of the anticipated 25 interviews. The committee consists of government and health authority officials, physicians involved in the treatment of cancer patients, a patient representative, a social worker, an ethicist, a health economist and other stakeholders. Clinicians have the lowest response rate. We will be sending the interview in written format on April 16th. Initial analysis of the interviews to date reveal that many committee members do not have a solid conceptual or technical understanding of economic reports, unless they have training in the area. Surprising is the extent of the gaps in knowledge, and the large distance between information needs and information gains. Economic reports are not presented in a format that is user-friendly. Consistency in reporting standards, coupled with training sessions of basic economic concepts for users might be a first step to improving the utility of CE and CU reports in the policy process.

Co-Authors: Dr. Adrian Levy, Professor, Head of the Department of Community Health and Epidemiology, District Chief, Capital District Health Authority Organization Dalhousie University; Dr. Ana Johnson, Canada Research Chair in Health Policy Organization Queen's University

Value for Money in Cancer - What do we Know?
Presented by: Jean Hai Ein Yong, Lead Analyst, Pharmacoeconomics Research Unit, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC)

To review economic evaluations of interventions across the cancer continuum, from prevention to end-of-life care, in Canada. We searched the Cost-Effectiveness Analysis Registry to identify published economic evaluations of cancer-related interventions that were conducted in Canada from 1976 to 2011 using the keywords 'malignant neoplasms' and 'Canada' in the 'disease' and 'country of study' categories. Because primary prevention interventions against cancer often are classified as 'prevention' but not specifically as cancer-interventions, we expanded the search to include all prevention interventions. After screening for relevant studies that meet the study objective, we categorized the studies by stages in the cancer control continuum: prevention, detection, diagnosis, treatment and survivorship. Between 1976 and 2011, 45 economic evaluations of cancer-related interventions were found in the Cost-Effectiveness Analysis Registry. Most studies were published after year 2000, about 4 studies a year. The number of studies increases over the years, from one in 1988 to 9 studies in 2010. Most studies (80%) evaluated the cost-effectiveness of treatment, few assessed interventions related to prevention, detection and survivorship. We did not find any study assessing the cost-effectiveness of diagnosis. Only four studies assessed the cost-effectiveness of prevention. Our study has likely underestimated the number of published articles because the Registry only retrieves articles from Medline, and there is a delay to update the Registry after an article is published. Nevertheless, our findings highlight areas that have little economic evidence. The number of cancer economic evaluations increased over the years, but most of the literature is on treatment with very few studies on prevention, detection, diagnosis and survivorship of cancer in Canada.

Co-Authors: Dr. Jeffrey S Hoch, Director, Pharmacoeconomics Research Unit, Cancer Care Ontario, Canadian Centre for Applied Research in Cancer Control (ARCC); Dr. Jon Kerner, Chair, Primary Prevention, Canadian Partnership Against Cancer
The ARCC Network is a virtual community of researchers, clinicians, practitioners, students, policy- and decision-makers with expertise in applied cancer control research. The mission of ARCC is to:

• Facilitate collaborative research
• Support knowledge translation and capacity building initiatives

ARCC members have access to:

• Ongoing pan-Canadian database of researchers
• Preferred member rates at the annual ARCC conference
• Workshops and seminars
• Seed grant competitions
• Graduate student scholarships
• Newsletters
• Get Connected – an online networking tool
• Mentorship opportunities
• Post-doctoral fellowships
• Work placements

Members are expected to

• Actively engage in collaborative work within ARCC.
• Participate in ARCC workshops, seminars, and conferences.

Contact us
For more information about ARCC, please see our website at www.cc-arcc.ca or contact us at arcc@cancercare.on.ca

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**Questions? Contact Sarah Benn at sarah.benn@cancercare.on.ca**

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