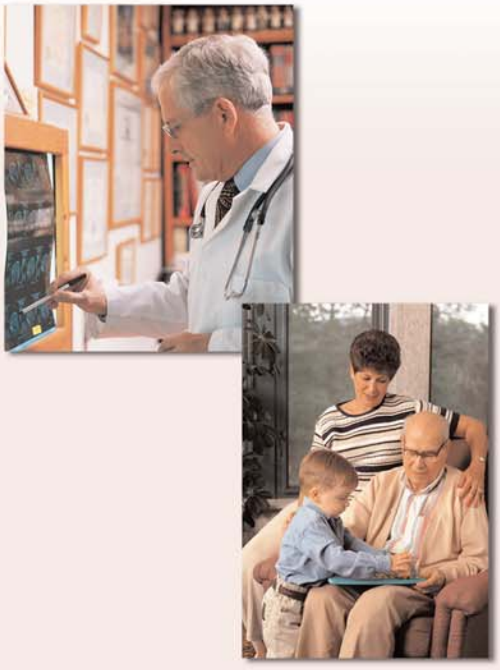
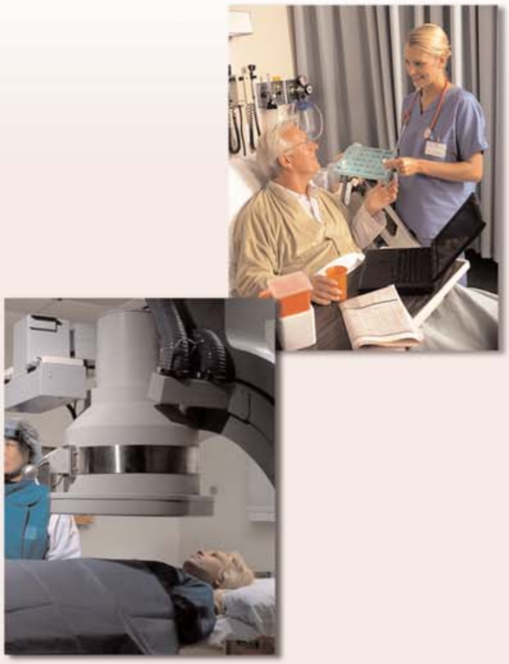
Access to Quality Cancer Care Workshop Report

June 14th, 2005 - Vancouver, British Columbia





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Executive Summary

Introduction

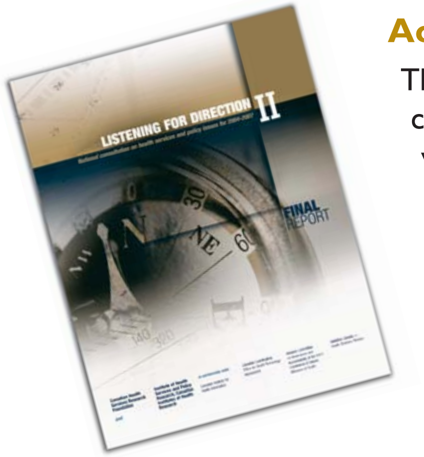
Timely access to high quality health care remains a top priority for Canadians. In recent months, access to health care has received a great deal of publicity in response to concerns that access to many Canadian health care services and programs is not optimal. Attention has focused primarily on excessive wait times for health services across the spectrum of care and questions about the impact of unreasonably long delays for medical interventions and treatments on the quality of life and survival of patients. In response to this growing concern about the public health care system, the First Ministers, at their September 2004 conference, made a commitment to reduce wait times and improve access by determining evidence-based benchmarks for medically acceptable wait times in identified priority areas, including cancer. Since then, there has been a flurry of activity across the country including the creation of the Wait Time Alliance, the publication of a number of provincial and Canada-wide reports on the status of the Canadian health care system and the launch of a research initiative by the Canadian Institutes of Health Research (CIHR) that will provide evidence to inform the work of the Provincial/Territorial Deputy Ministers of Health.

ICR's Institute Advisory Board discusses Access to Quality Cancer Care, a new Institute strategic research priority

Access to Quality Cancer Care

Issues related specifically to access to cancer care include concerns about excessive wait times for primary/community and specialized/diagnostic services throughout the entire cancer control spectrum - prevention, screening, diagnosis, treatment, quality of life and palliation. However, for cancer, the problem extends beyond wait times to include the economic factors related to the spiraling cost of the new generation of available technologies and treatments. Inequality of access is also of concern particularly for those living in rural and northern communities and for vulnerable and marginalized populations.

The CIHR Institute of Cancer Research (ICR) is committed to supporting outstanding research to address important priorities in cancer control. In response to the concern over access to care, the Institute recently adopted 'access to quality cancer care' as a seventh Institute strategic research priority. As a first step, ICR invited health services researchers and representatives from 18 organizations with an interest in access to care issues to attend a one-day workshop in Vancouver (for details, please refer to the Workshop Report, page 5).



Access to Quality Cancer Care Workshop

The workshop combined a review of issues related to access to quality cancer care and an overview of existing health services research opportunities, with free ranging discussions on priority research questions and solutions. The primary objective of the workshop was to gather information to inform ICR and partners on the appropriate course of action in the development of a Request for Applications (RFA) designed to provide answers to important policy questions on the organization and delivery of cancer care. To guide the discussions, participants were provided with the research synthesis questions identified in the national consultation process that led to the release of the Listening for Direction II (LfDII) report by the CIHR Institute of Heath Services and Policy Research, the Canadian Foundation for Health Services Research, and partners. This report is the product of a two-stage consultation with health service researchers, service providers, and decision/policy makers and is a reliable resource for identifying Canada's health services research issues and priorities. Workshop participants were asked to look at these priorities through a "cancer lens" and identify areas of particular relevance to cancer control. Participants identified several aspects of LfDII themes that applied to concerns relating to access to quality cancer care. They were:

Organizational Aspects of Access to Quality Cancer Care

- *Management issues - a need for improved models for the organization and delivery of services;*
- *Integration issues - a need for a dynamic, nimble and fully integrated system designed for easy patient navigation. There is an urgent need to bring together researchers, the public, patients, front-line workers and decision makers to ensure two-way knowledge translation and rapid uptake of research results into practice;*
- *Continuity of care - a need for research across the whole cancer continuum from prevention to palliation that explores the relationship between primary care, chronic care and survivorship; and*
- *Disadvantaged populations - a need for research on appropriate outreach programs and services to better serve those living in rural and northern areas and vulnerable and marginalized populations.*

Ethical Funding and Resource Allocation

- *Treatment protocols - a need for ethically sound decisions on treatment that takes into account new information and promotes individualized treatment modalities based on a patient's ability to respond. This will lead to more efficient and cost effective services and treatments that make better use of the knowledge we already have, in an equitable manner; and*
- *Cost of treatment - a need for health economics research. Forecasting cost is essential to provide solutions to the spiraling cost of new technologies and new drugs.*

Information gathering in a break-out group

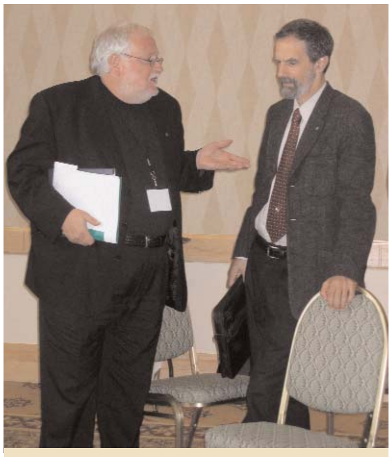
Enhancing Information Systems

- *Measurement issues - a need for better determinants and benchmarks for wait times for all cancer services across Canada;*
- *Standardization issues - a need for standardized definitions, metrics, procedures and methodologies that can be adopted uniformly across the country;*
- *Improved informatics systems - a need for accessible and compatible electronic patient data across Canada to provide real time informatics and a streamlined REB process;*
- *Improved access to information - patients and the healthy population need better access to information to reduce anxiety and enable effective decision making throughout the entire cancer continuum from prevention to palliation; and*
- *Patient Outcomes - more information is needed on the relationship between wait times and outcome (survival, satisfaction, quality of life) rather than just access to services.*

The Recommendations

Information gathered at the workshop pointed to a disconnect between those who have the information and those who use it at several levels within the health care system. The overarching recommendation from the workshop participants was for improved system management and integration that aligns with patient needs across the entire cancer care system, so that the system becomes more flexible and responsive to the needs of the population. This improved system would need to be supported by strong technology and informatics platforms that were uniform across the country. In order to accomplish this goal, a research infrastructure is required that will focus on integration and team building across sectors. There were several recommendations for appropriate funding programs. They included:

- *Small team grants - create new interdisciplinary teams designed to build linkages between researchers, health care providers, patients and decision makers and ensure the timely uptake and implementation of research findings;*
- *Larger team grants for pre-existing teams who wish to extend their scope of research and networking capabilities;*
- *Salary awards - to recruit new researchers likely to attract operating funds and build capacity;*
- *Career transition awards - to recruit researchers in other areas of health services research to the cancer field; and*
- *Training programs - to increase capacity in the long term by training the next generation of health services researchers.*



Phil Branton, Scientific Director of the Institute of Cancer (ICR) discusses access to quality cancer care with Morris Barer, Scientific Director of the Institute of Health Services and Policy Research (IHSPR)

Path Forward

The information gathered at the workshop and the recommendations made by participants will be used as the basis for the development of an RFA focused on access to quality cancer care for launch in December 2005. The workshop report will be considered by partner organizations including members of the Canadian Cancer Research Alliance, and the exact scope of the RFA and the funding tools selected will depend on the results of these discussions and the commitment of partners to support the initiative.

Workshop Report

Welcome and Introductions

The workshop was called to order by Judith Bray, Assistant Director of the CIHR Institute of Cancer Research (ICR) who welcomed participants (see Participants List, Appendix 1) and thanked Erik Blache and Amanda Devost for their hard work in organizing the event and also steering committee members Bill Mackillop, Margaret Fitch and Roy Cameron, for their contribution to workshop planning and facilitation. Many of the participants were representing organizations and agencies with an interest in health services research (Table 1). It is hoped that these organizations will participate as partners in the design and launch of a research initiative on access to quality cancer care.

J. Bray introduced the Scientific Director of ICR, Philip Branton who began by describing the extremely successful Palliative and End-of-Life Care initiative as an example of the accomplishments possible through partnership and community engagement. The launch of this initiative, in partnership with seven other CIHR Institutes and eight external organizations, resulted in the funding of a Strategic Training Centre, a Career Transition Award, 19 one-year Pilot Project grants and 10 five-year New Emerging Teams for a total financial commitment of over $16.5 million. The recent creation of a dedicated peer review panel and the initiation of an international partnership with the National Cancer Institute - NCI (US) and the National Cancer Research Institute - NCRI (UK) have made this initiative the largest of its kind, changing the face of palliative care research in Canada and setting an example for the rest of the world. Based on this success, ICR hopes that through a combined effort involving the key stakeholders represented at this workshop, we can launch a research initiative that will have a similar dramatic impact on Canadian health services research in the cancer field. ICR has committed up to $1.5 million per year for five years in support of research on access to quality cancer care. It is hoped that this amount can be significantly increased through partnership, perhaps via the recently created Canadian Cancer Research Alliance (CCRA). CCRA for the first time brings together 24 organizations with a commitment to cancer control, including all the major Canadian cancer research funding agencies, to create and support a national research agenda. CCRA has replaced the research action group of the CSCC.

Table 1 - Organizations represented at the meeting

Organization	Acronym
British Columbia Cancer Agency	BCCA
Canadian Association of Provincial Cancer Agencies	CAPCA
Canadian Health Services Research Foundation	CHSRF
Canadian Institute of Health Information	CIHI
Canadian Institutes of Health Research	CIHR
• Inst. of Cancer Research	ICR
• Inst. of Health Services and Policy Research	IHSPR
Canadian Medical Association	CMA
Canadian Strategy for Cancer Control	CSCC
Cancer Care Ontario	CCO
Cancer Care Manitoba	CCM
Cardiac Care Network of Ontario	CCNO
Health Canada	HC
Institute for Clinical Evaluative Sciences	ICES
Ministère de la santé et des services sociaux	MSSS
National Cancer Institute of Canada	NCIC
Ovarian Cancer Canada	OCC
Public Health Agency of Canada	PHAC
Royal College of Physicians and Surgeons of Canada	RCPSC
Statistics Canada	SC

Setting the stage

The primary purpose of the workshop was to obtain advice and input from a diverse group of individuals representing both the health services research community and organizations with an interest in access to quality cancer care. The day began with four short presentations to set the stage and ensure that participants shared a common understanding of the important research issues in access to quality cancer care and ongoing health services research in Canada.

The first speaker was Dr. Bill Mackillop, ICR Institute Advisory Board

"ACCESS TO QUALITY CANCER CARE: BACKGROUND AND OBJECTIVES"

Highlights of the Presentation and Discussion

Due to our aging population cancer control has become an escalating public health problem and access to cancer care has become a major public policy issue characterized by a focus on excessive wait times for both primary/community care and specialized/ diagnostic services. However, access to care involves far more than just improved management of waiting lists, and encompasses the availability of human resources, facilities and equipment, the awareness of the population in terms of available services and the accessibility of care for rural/remote communities and minority/vulnerable groups. Access to health care is also closely linked to quality of care and improved access must not be achieved at the expense of the quality of that care. There is a danger that the current heightened public and political awareness of issues around access to care may mask equivalent problems related to quality of care.

The role of research in cancer control is to reduce the burden of cancer through the discovery of new or improved ways to prevent, detect and treat cancer. The role of health services research is to learn how to get the most out of new technologies and treatments in a way that will be of greatest benefit to the patient. Health services research in cancer is important because access to programs for prevention, screening and treatment, and the quality of cancer control programs in Canada is not optimal. These defects in accessibility and quality represent opportunities for improving outcomes. Identified problems related to health services research include the following:

- *Low capacity for cancer-related health services research - although the funding rate in health services research is comparable to other areas of research, the number of applications received is relatively low and of the health services research that is funded, only a small percentage is specifically focused on cancer;*
- *Lack of ownership of health services research - providers regard health services as the responsibility of the research community and vice-versa;*
- *Insufficient infrastructure - health services research would benefit from the kind of infrastructure available for clinical trials such as the NCIC clinical trials group;*
- *Inadequate communication and collaboration between health system managers, researchers and other stakeholders;*
- *Inadequate integration of health services research with health economics and ethical allocation of resources; and*
- *Perception at some academic institutions that health services research is somehow 'less important' than basic or clinical research.*

ICR has adopted access to quality cancer care as a strategic research priority because it is a public policy priority. The purpose of this workshop is to get advice on the status of research on access and quality in the field of cancer control and define a role for ICR in promoting and supporting research on access to quality cancer care. IHSPR and CHSRF have already identified national priorities for health services research and CSCC has a strong interest in this area. Unlike basic and clinical research that generally yields results that are broadly applicable internationally, health services research is often specific for individual health care systems and if we don't support strong health services research in Canada, no one else will.

The second speaker was Susan Law, Director, Research Programs, CHSRF

“CHSRF - Priorities, Programs and Opportunities”

Highlights of the Presentation and Discussion

CHSRF is a private, non-profit foundation that is incorporated as a registered charity under the Canadian Corporations Act. The CHSRF mission is to support evidence-based decision-making in the organization, management and delivery of health services through funding research, building capacity and transferring knowledge. Supported by a $120 million endowment fund, CHSRF operates on a $15 million per year annual budget and is governed by a Board of 15 trustees comprised of researchers and decision makers with regional representation. CHSRF led, in partnership with IHSPR, the Listening for Direction (LfD) I and II exercise which, through broad national consultation, identified a series of health system priority issues and related research themes and questions. The process involved information gathering, a series of regional consultation workshops, a national workshop and the subsequent sorting, translating and validation steps that led to the development of the report 'Listening for Direction II'. LfDII identified the following 10 priority research themes:

- *Workforce planning, training and regulation*
- *Management of the healthcare workplace*
- *Timely access to quality care for all*
- *Managing for quality and safety*
- *Understanding and responding to public expectations*
- *Sustainable funding and ethical resource allocation*
- *Governance and accountability*
- *Managing and adapting to change*
- *Linking care across place, time and settings*
- *Linking public health to health services*

CHSRF has adopted four strategic themes for 2004/2007: primary healthcare, nursing organization, leadership and policy, management of the healthcare workplace and managing for quality and safety. The first two of these themes have been long-standing commitments of the foundation. A fifth theme, managing and adapting to change was adopted as a cross-cutting theme for foundation activities. The LfDII priority setting process has been used widely across Canada and internationally and is a useful and reliable platform for discussions at this workshop.

The basic 'tools' or activities funded by CHSRF and its partners include research, knowledge transfer, capacity development and 'linkage and exchange' (bringing researchers and decision makers together). The foundation launched a new health services research program "Research, Impact, Exchange for System Support" in 2005 in addition to its synthesis and commissioned research program. The CADRE program (jointly funded by CHSRF and CIHR) builds capacity in health services research through a 10-year program of individual Chairs and regional training centre awards and funds post-doctoral and career reorientation awards. Through these and related initiatives, CHSRF has made a modest contribution to health services research in the cancer field. Since 1999, 13 projects have been funded that are directly related to cancer while many more generic projects may be applicable to health services research in cancer. CHSRF programs offer an ideal opportunity for combining research, knowledge translation and capacity development and it is hoped that this workshop will encourage more cancer researchers to take advantage of these programs.

The third speaker was Dr. Morris Barer, Scientific Director of IHSPR

“Access to CIHR $$ for Research on Access to Care”

Table 2: Projects funded under the “Toward Canadian Benchmarks for Health Services Wait Times - Evidence, Application and Research Priorities” RFA

Applicant	Project Title
Mackillop, William, J. Queen's University	Toward Canadian benchmarks for waiting times for radiotherapy for cancer: Synthesizing the evidence and establishing research priorities
Moayyedi, Paul McMaster University	An evidence-based assessment of appropriate waiting times for gastrointestinal cancers
Taylor, Mark CancerCare Manitoba	Determining acceptable waiting times for the surgical treatment of solid organ malignancies
Winget, Marcy D. Alberta Cancer Board	Moving evidence to application: A three province cancer collaborative

Highlights of the Presentation and Discussion

IHSPR has launched the following health services research programs based on LfDII recommendations and identified priorities:

- June 2004 pilot projects
- June 2004 scoping/synthesis RFA
- September 2004 Partnership in Health System Improvement (PHSI) competition (transferred from CHSRF and now a standing CIHR program)
- December 2004 scoping/synthesis RFA (now a standing CIHR program)
- February 2005 wait times RFA

Several projects have already been funded in the timely access to health care, and wait time management and reporting themes, but the response from the cancer health services research community has been poor and ICR has only been a partner on one initiative - the "Toward Canadian Benchmarks for Health Services Wait Times - Evidence, Application and Research Priorities" RFA in which four projects related to cancer were funded (see Table 2).

This is a disappointing response, particularly in the case of the PHSI program. PHSI is the ideal vehicle for health services research across the health spectrum and offers the advantage of a built-in knowledge translation component and partnership opportunities. PHSI supports teams of researchers and decision-makers doing applied health systems/services research useful to managers and/or policy makers in LfD II themes and in areas of nursing leadership, organization and policy. The program provides up to three years of operating grant funding and applications are subject to a merit review by a panel comprised of equal numbers of researchers and decision makers. Of the 39 full applications received for the 2004 competition, 10 were related to the theme 'access to quality care for all', but none were specifically related to access to cancer care.

In addition to the ongoing opportunity of the PHSI and Scoping/synthesis programs, additional CIHR opportunities for health services research include the large team grants that will replace CIHR group grants, the interdisciplinary health research teams (IHRT) and the community alliances in health research (CAHR) programs, and the smaller new team grants that will replace programs such as the new emerging teams (NET) program. Large scale training programs may also be an option and discussions are just beginning regarding the next steps following the success of the two previous rounds of CIHR's Strategic Training Programs in Health Research initiative. There is also always the opportunity of creating purpose-built research programs, although this practice is likely to be discouraged in the new era of a "Better, Simpler CIHR".

The fourth speaker was Dr. Simon Sutcliffe, Chair, Governing Council, CSCC

"ACCESS TO QUALITY CANCER CARE FROM THE CSCC PERSPECTIVE"

Highlights of the Presentation and Discussion

The presentation began with the caution that we need clear definitions and terminology relating to the terms access, quality, care and performance. We need to be able to transfer definitions and values across the system. It's not always clear what we are measuring and whose perception we are using e.g. patient, provider, researcher, funder. We also need to establish which parts of the cancer control spectrum will be included in our discussions on access to quality cancer care and whether we will consider the entire continuum from prevention to palliation.

The Canadian Strategy for Cancer Control (CSCC) is a unifying approach to cancer control that has been developed to facilitate knowledge transformation and transfer across Canada as a means whereby the goals of the Strategy can be achieved.

The goals of the CSCC are to:

- Reduce mortality, incidence and morbidity (through unified, evidence-based actions across the spectrum of cancer control);
- Increase access to care; and
- Increase the quality of life of Canadians and their families living with cancer.

Key elements of the Strategy are an evidence-based information platform, identification of priorities, and integration and respect for Federal/Provincial/Territorial roles.

CSCC has identified the following eight priority areas and has established an action group in each area:

- Primary prevention
- Clinical practice guidelines
- National standards
- Rebalancing the focus ('person-centred care')
- Human resource planning
- A national cancer research plan
- Targets (indicators)
- Surveillance and outcomes analysis

Many of these priorities intersect with issues related to access to quality cancer care and also with the research themes identified in LfDII. Access to cancer care is perhaps more about patient satisfaction and perceptions than actual wait times, so it is important to determine what can be done to improve patient satisfaction and consider out of all the things we could do to enhance performance, which would give the best return on investment and how can we obtain national consensus on the value and definition of benchmarks. We need to set long term goals that will have the greatest impact on incidence, mortality and quality of life for those living with cancer. At the centre is the patient experience from diagnosis to palliation and the broad range of factors that affect satisfaction and outcome including access in rural and remote areas and the special needs of vulnerable or marginalized populations. The patient and broader community should be engaged when addressing issues related to cancer care to ensure two-way transfer of the knowledge used for decision making and to include their input and perspective in the design of programs and research initiatives aimed at improving the patient experience.

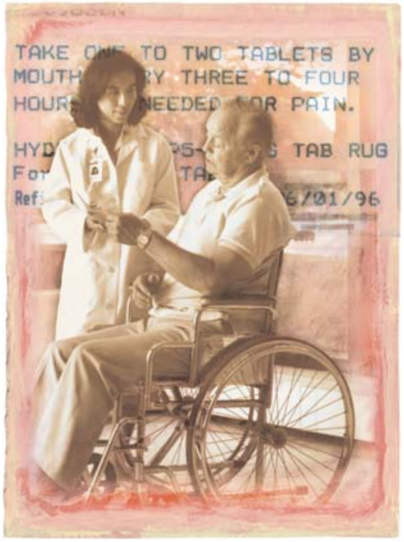
Break-out Session 1

Participants were divided into three break-out groups. Each group was asked to identify priority research issues and questions related to access to quality cancer care and consider existing Canadian research strengths and weaknesses. Participants were provided with the research synthesis questions generated by LfDII and also the eight specific research questions identified under the theme of 'Timely Access to Quality Care for All'. Rather than "reinvent the wheel", participants were encouraged to use this information as guidance when determining priorities specific for cancer care.

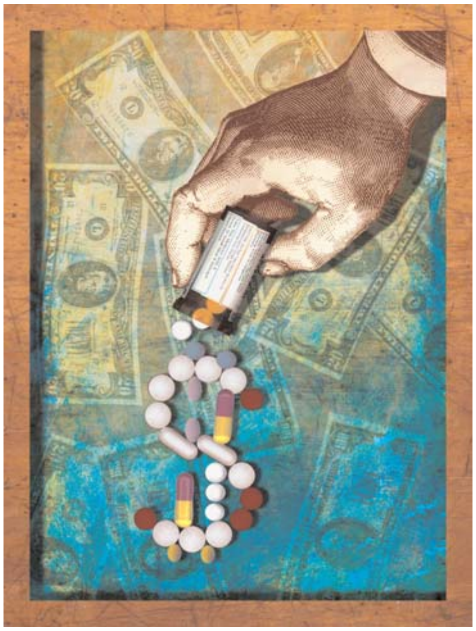
Following the breakout session the whole group re-convened in plenary. Many different ideas and themes emerged as being important to access to quality cancer care, but the following issues (in no priority order) emerged consistently among the groups:

Priority Research Issues

Organizational Aspects of Access to Quality Cancer Care



- Many of the factors that cause excessive wait times are related to management issues and a failure to appropriately manage flow, rather than a lack of capacity in either human resources or infrastructure. There is a need for research on advanced practice models that involve inter-professional teams, including linkages between primary care providers and specialists, and also experiments to compare different approaches in organization and delivery of care, e.g. nursing teams, and to explore the relationship between primary care, chronic care and survivorship.
- The cancer care system should be viewed as an integral part of the overall health care system but should be designed to be nimble in its capacity to respond to changing conditions and emerging opportunities. We need a more in depth understanding of how cancer care services are organized and delivered across the country including regional variations.
- Populations need to be better equipped to navigate the health care system. A single point of access would be ideal, combined with an integrated team approach for the whole process of care. In BC for example, there is a new service in which private companies are paid to help the patient navigate the system from the point of entry.
- There is a communication breakdown between the people with the information and those that manage the cancer system. Researchers, decision makers, patients and their families, funders, front-line workers and the 'well' population need to be brought together to provide an integrated system in which knowledge translation and uptake is two-way. We need to do a better job of applying what we already know and engaging the provinces in bringing managers and researchers together to build capacity around cancer systems.
- Research on access to care should include the whole cancer continuum from prevention to palliation. Access to prevention is becoming increasingly important as our population ages and the incidence of cancer increases. We could focus on the care side of prevention e.g. access to a primary care physician, access to information on prevention. We need to focus on interventions rather than analysis and synthesis of information. There are many areas where interventions can occur e.g. cigarette smoking, pesticides, diet.
- Access for rural, and vulnerable populations (non-Caucasian, no college education, don't live in an urban area) is a big issue as much of Canada is rural and we have a multicultural population. Outreach programs are required that are adaptable. There are many different considerations e.g. the inconvenience and costs of travel, lack of adequate communications eg. phones, internet. We need to assess a patient's willingness to travel for access. In some rural areas, patients would prefer to wait for access to care rather than travel even if this reduces the quality of care. We need to explore opportunities for outreach by bringing technologies and services to rural areas and underserved populations.



Ethical Funding and Resource Allocation

- We need to set acceptable priorities to ensure that we don't provide access to a drug that might prolong survival for six weeks at the expense of one that might cure. Decisions must apply equally to patients with both short and long-term prognosis.
- We need to explore the benefits of individualized patterns of care and personalized medicine. Reducing unnecessary procedures and therapies based on the patient's ability to respond would be both more efficient and cost effective, and would increase access for patients who would derive a real benefit. Such information is increasingly becoming available and will allow us to improve the efficiency of how we use new cancer technologies and therapies. We also need to evaluate and better use the technologies we have such as mammography - there is a need to increase the rate of breast screening to around 70% in order to see a benefit at the population level. Currently there is a lack of knowledge on how provinces allocate resources and how such decisions could be influenced. There is also a lack of capacity to analyze return on investment for different treatment options.
- Research is needed in the area of health economics particularly on how to price new drugs and technologies so that they are affordable rather than treating medical advances as a burden on the system. Forecasting cost will soon become a major issue. There is a need for economic evaluation in all aspects of care. We need to explore opportunities for private/public partnership and establish inter-provincial links with industry, e.g. bulk buying of drugs across provinces.

Enhancing Information Systems

- We need a standard definition for 'wait times', as there is currently variation between provinces which makes it difficult to compare issues, and a better measure of current wait times for various types of cancer services to provide a baseline against which to measure improvements. We need to identify the determinants of wait times and know what data is available and how it is used across the country. We also need to take advantage of information and successful practices in other domains that are applicable to cancer and within the cancer field itself, such as the Alberta project aimed at reducing the wait time between diagnosis and first treatment in breast cancer patients from 11 weeks to four weeks.

- We need a more in depth exploration of the results and consequences of lengthy wait times and to set nationally acceptable benchmarks. We need to focus on outcomes (survival, satisfaction, quality of life) rather than access to a process of services and study the natural variability in outcomes as a function of wait times. Currently, we have no good evidence as to the effect of wait times on eventual outcome. Maybe waiting six weeks rather than four for adjuvant chemotherapy has no impact on outcome. The purpose of access should be to have a better outcome, not just survival. We also need comparative studies of outcomes between regions.
- Patients need more information to reduce anxiety about treatment and wait times. We should engage the "well" population and study the role of healthy people in wait-time issues (symptom development till presentation). We need standard electronic records as patients proceed through the system including a record of medications. We also need timely access to compatible data systems including pre-existing, administrative and clinical data and more compatibility between provincial systems. There is a need for real time informatics, improved data warehousing and a streamlined REB process that is compatible between provinces.
- We need standardized operational definitions and metrics and also standardized procedures and methodologies e.g. staging, surgery, radiotherapy that can be adopted uniformly across the country including rural and remote areas.

Canadian Strengths and Opportunities

- Existing cancer research structure and core infrastructures, cancer report cards and accountability measures;
- Large administrative databases, Statistics Canada surveys available;
- Canadian public health care system with population based, manageable electronic records;
- Growing research strength in health services research that could be harnessed to address cancer;
- Growth of organizations focused on health services research eg. IHSPR, CHSRF, ICES;
- Many existing centres of research excellence in agencies, hospitals, universities, government, NGOs;
- Strong public interest in health care;
- Technology assessment capacity;
- Support of nationally coordinated organizations such as CSCC, NCIC, CAPCA, CCRA; and
- Current window of opportunity based on public and political awareness of access to care issues.

The group presentations were followed by a lively discussion. It was agreed that most of the issues raised were inter-related and could have an impact on both access to and quality of cancer care. The point was made that there would be little point taking measures that would improve access to care at the expense of the quality of care, although the assumption that excellent access and excellent quality are even achievable at the same time might be optimistic. There was also discussion about what an initiative might look like and whether it should start out as a pan-Canadian study or have an initial focus at the provincial level. The need for appropriate peer review was also addressed.

Break-out Session 2

This breakout session focused on the barriers to health services research in cancer and the appropriate funding tools for a research initiative. Several barriers to health services research in cancer were identified including:

Barriers to Health Services Research

- Lack of infrastructure - no on-site support for health services research as there is for clinical trials;
- Lack of a critical mass of investigators and health professionals (e.g. pathologists) due in part to a lack of career opportunities and structures for health services research. Protected time is required to engage health professionals;
- Challenges in the integration of research and practice - inadequate interaction between clinicians, health services researchers and decision makers;
- Lack of decision makers trained in health services research;
- Lack of adequate sustained, long term funding that is appropriate for the kind of research programs required to address the issue of access to quality cancer care;
- Few peer reviewed journals for health services research;
- Regulatory issues surrounding REB approval and privacy legislation;
- Inadequate data sharing - need timely access to patient records, compatible clinical info-systems. Data systems not coordinated with research;
- Perceived lack of respect for health services researchers in some institutions; and
- No clear definition of indicators.

Funding Tools

It became clear during the initial presentations that there are an increasing number of opportunities for health services research in Canada but that so far the cancer community has not been taking full advantage of these opportunities. One reason could be a lack of awareness of the available funding programs, but it is perhaps more likely that the lack of response represents a capacity issue and that the barriers to health research listed above have served as a deterrent to health services researchers in the cancer field.

There was consensus among participants that an urgent need exists to "connect the dots" and form linkages between the various groups involved in access to health care issues e.g. the healthy population, cancer patients, survivors, researchers, front line health care workers, experts (e.g. radiologists, surgeons, primary care physicians, pediatric oncologists), decision/policy makers, funding organizations and more. Knowledge uptake and changes in management structure and policy are more likely to occur if these different groups are involved from the beginning in the design, execution and implementation of research programs.

Given the success of the Palliative and End-of-Life Care initiative and based on similar needs in the two communities, it was widely acknowledged that a flexible funding tool will be required that offers a number of different opportunities under one large initiative. Suggested programs included the following:

Small Team Grants

The purpose of these grants is to build capacity in new and developing areas of research, to build new research teams and to give researchers a building block for applying for research funding in future years. The objectives of the Small Team Grants program are to:

- Create or develop new competitive research teams, which show potential for successfully applying for other infrastructure team funding in the future;
- Foster multidisciplinary and cross-theme research in identified areas of focus;
- Train and establish new investigators in identified areas of focus; and
- Create a team environment that favors the development of new fundable research projects.

Grants are funded at a maximum level of $300,000/year for five years unless stated otherwise in the Request for Applications (RFA).

CIHR Team Grant

This program is an ongoing program of CIHR, now part of the regular suite of programs offered by CIHR to the research community. The second competition will be launched in June, 2005. The objective of the CIHR Team Grant program is to strengthen Canadian health research by supporting teams of talented and experienced researchers conducting high-quality research and providing superior research training and mentorship. The program emphasis is on the production of new knowledge, and the translation of research findings into improvements in the health of Canadians and the Canadian health care system. These results will be realized more rapidly and more efficiently through the CIHR Team Grant program than if the components were to be funded as a series of separate operating grants. Eligible teams will consist of at least three independent investigators, each of whom has an established research track record in areas related to the collaborative project(s) proposed. The unifying element underlying all successful CIHR Teams is a commitment to excellence and the pursuit of a problem-based, collaborative approach to health research. Only in exceptional circumstances will individual grants exceed $2 million per year.

Strategic Training Program Grant

This program was originally designed to build capacity within Canada's health research community through the training and development of researchers, and foster the development and ongoing support of the scientific careers of individuals in health research. Funding is for up to six years and CIHR's contribution to a single grant cannot exceed $300,000. The program is now up for review and discussions are ongoing concerning a possible third launch.

Salary Awards

CIHR offers a number of short and long term career award programs, including a variety of Salary Awards (e.g. New Investigators, Industry-partnered Investigators, Research Chairs) and many different kinds of training awards (eg. Clinician Scientist Awards, Doctoral Research Awards and Fellowships).

Career Transition Awards

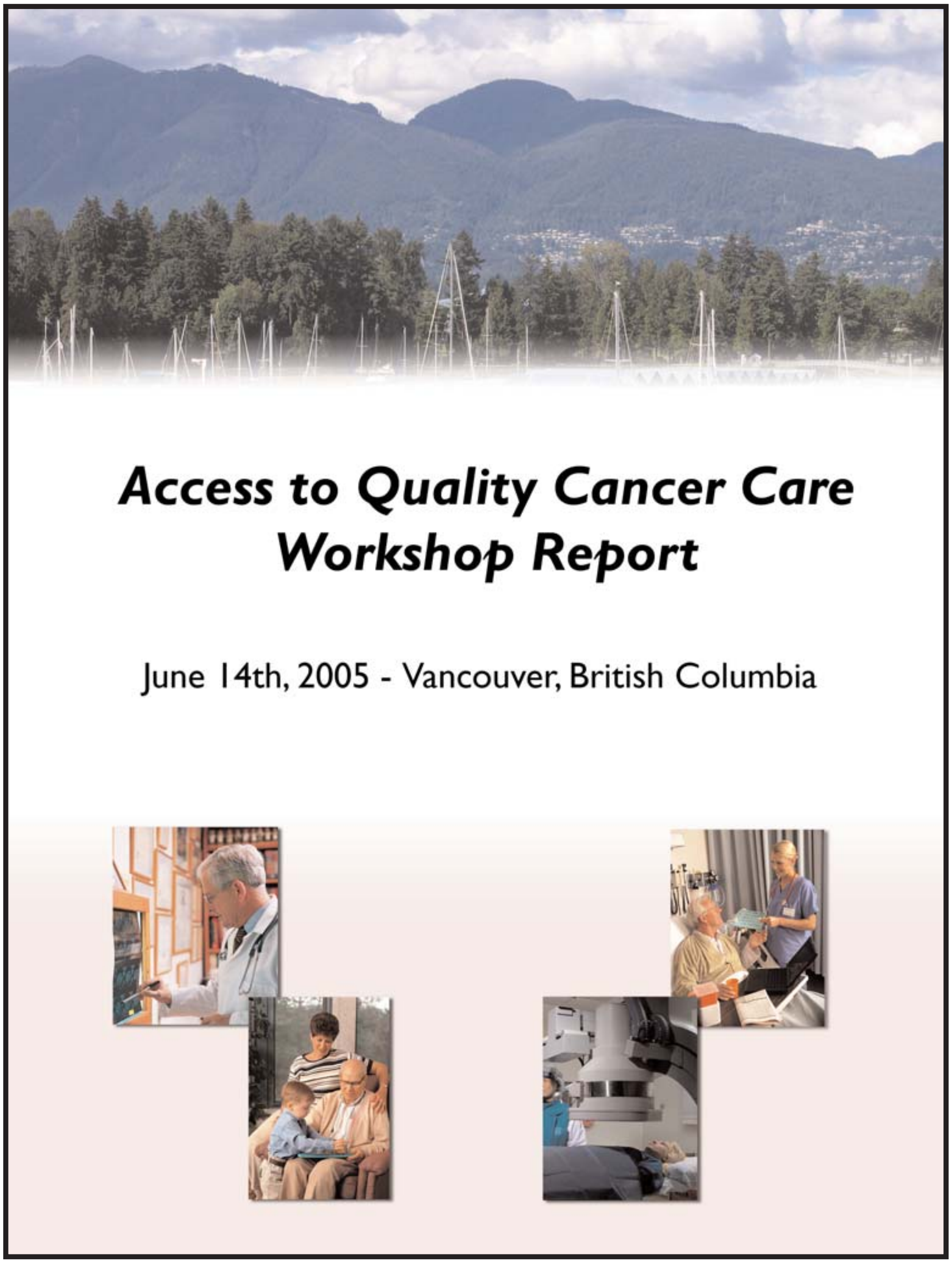
These awards are designed to attract existing faculty members to undertake rigorous training outside of their primary research area, either to broaden their perspective in a complementary research area or to prepare for a career move into a new field of research. Awards are for one year and provide up to $70,000 to support 100% release from teaching and administrative responsibilities, plus an additional $10,000 research allowance. This program might be an appropriate way to attract health services researchers from other fields into the cancer arena.

Discussion focused on Small Team Grants with an opportunity for the addition of Salary Awards and Training Grants if required. The Small Team Grants offer the potential for the kind of networking between disciplines, expertise and even location (pairing rural with urban institutions) that emerged as an essential component for success during the workshop. Emphasis was placed on the need to bring policy/decision makers and health services researchers together to ensure that knowledge translation is an integral part of the grant with concrete plans for mechanisms of knowledge uptake. It was suggested that some team grants could be site-specific and act almost as demonstration projects. For example a study focused on all possible aspects of access to quality care for breast cancer from prevention to palliation. Other teams could be thematic and focus for example on health economic aspects of access, or specific areas such as access to and quality of radiotherapy or surgery, across the entire cancer spectrum.

Next Steps

Phil Branton thanked participants for contributing their knowledge, experience and unique perspectives to the day's discussions. Based on the information gathered at the workshop and the recommendations and suggestions of the participants, ICR staff will consult with potential partners regarding the next steps. The workshop recommendations will be considered at the next CCRA board meeting and may form the basis of the first CCRA initiative. It is hoped to be able to develop an RFA for launch in December 2005. The specific focus of this RFA and the programs offered within it will be based on the workshop recommendations but may be refined in response to input from partners. Partnership opportunities with both IHSPR and CHSRF will be explored in the coming months to try and increase the number of applications from the cancer community to existing health services research programs.

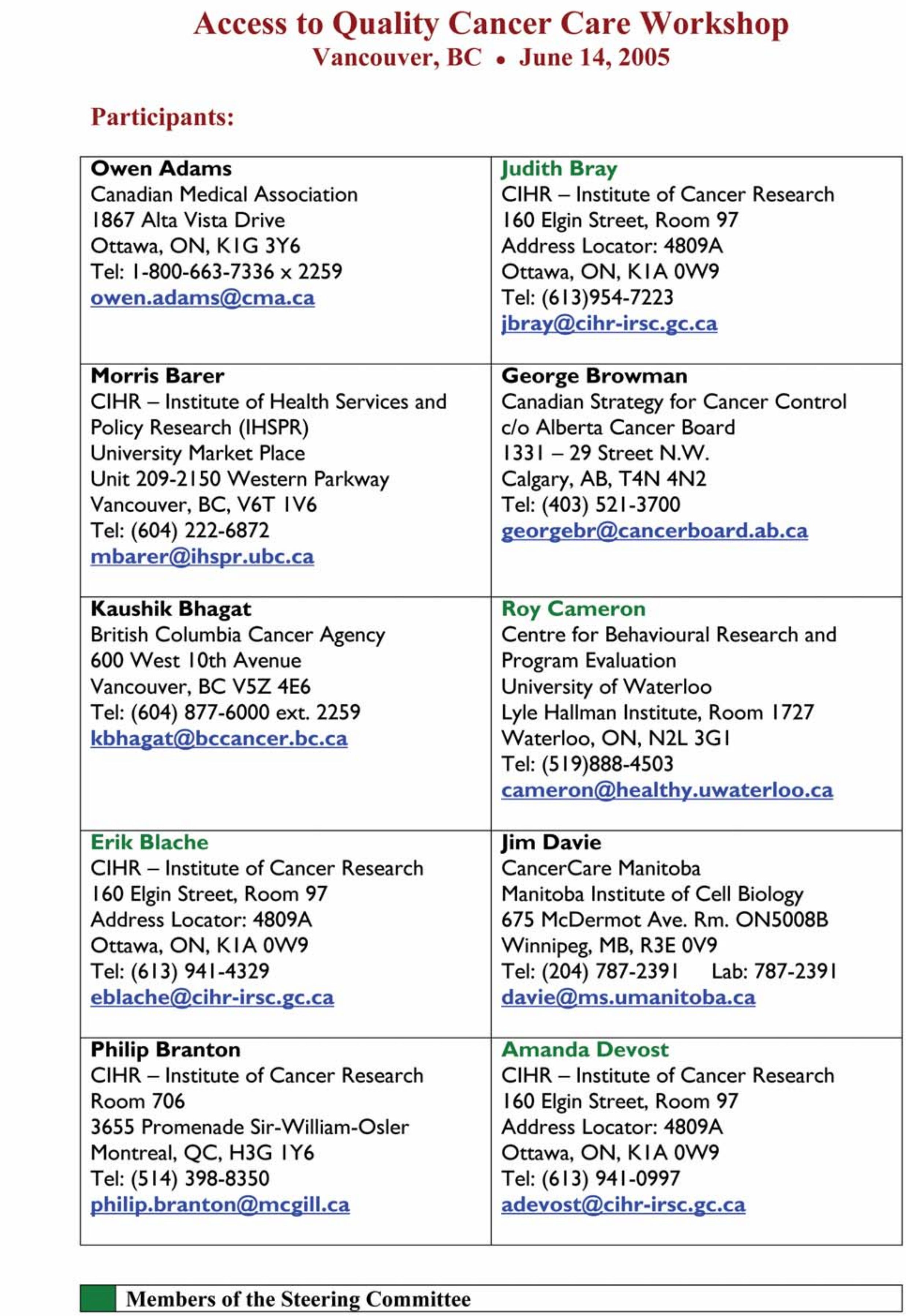
Appendices



Access to Quality Cancer Care
Workshop Report

June 14th, 2005 - Vancouver, British Columbia

Appendix I



Access to Quality Cancer Care Workshop
Vancouver, BC • June 14, 2005

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Appendix 1 (cont'd...)

Access to Quality Cancer Care Workshop

Vancouver, BC • June 14, 2005

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Appendix 1 (cont'd...)

Access to Quality Cancer Care Workshop

Vancouver, BC • June 14, 2005

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Appendix 1 (cont'd...)

Access to Quality Cancer Care Workshop

Vancouver, BC • June 14, 2005

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🟩 **Members of the Steering Committee**

Appendix 2

Access to Quality Cancer Care Workshop - Agenda
Tuesday, June 14th, 2005 - The Westin Bayshore Resort & Marina

Time	Item	Location
8h00	**Registration/ Breakfast**	**Outside of Oak Room**
8h45	Welcoming remarks on behalf of CIHR-ICR ***P. Branton***	**Oak Room**
9h00	"Access to Quality Cancer Care: Background and Objectives" ***W. MacKillop***	**Oak Room**
9h20	"CHSRF-Priorities, Programs & Opportunities" ***S. Law***	**Oak Room**
9h40	"Access to CIHR $$ for research on access to care" ***M. Barer***	**Oak Room**
10h00	"Access to Quality Cancer Care from the CSCC perspective" ***S. Sutcliffe***	**Oak Room**
10h20	Meeting Objectives and Logistics ***J. Bray***	**Oak Room**
10h30	**Health Break**	**Outside of Oak Room**
10h45	**Breakout session 1:** ➢ Round table introductions ➢ Review of health services research priorities identified in Listening to Direction II from the perspective of the cancer control community ➢ Identification of up to 10 research synthesis questions that are currently of high priority in the area of access to quality **cancer** care ➢ Determination of the extent to which these research priorities are currently being addressed in the cancer field ➢ Identification of research gaps/areas of weakness	**Group A–Arbutus Room** **Group B–Fir Room** **Group C-Oak Room**
11h30	Plenary session and report-back. Discussion	**Oak Room**
12h30	**Lunch**	**Chairman's Room (2nd floor of Tower)**
13h30	**Breakout session 2:** ➢ Barriers to research and opportunities for enhancing research productivity in the area of access to quality cancer care ➢ Identification of required resources eg. infrastructure/capacity requirements ➢ Potential research programs – existing/new ➢ Partnerships – how to establish a national, coordinated approach	**Group A–Arbutus Room** **Group B–Fir Room** **Group C -Oak Room**
14h45	**Health Break**	**Outside of Oak Room**
15h00	Plenary session and report-back Discussion	**Oak Room**
16h00	Summary and Path Forward ***P. Branton and W. Mackillop***	**Oak Room**
16h30	Reception, cocktails, informal discussions	**Currents Restaurant (main hotel lobby)**
17h30	**Adjournment**	