



## Access to Quality Cancer Care Workshop Workshop Report

### **Introduction**

As described in the Canadian Institutes of Health Research (CIHR) Five Year Strategic Plan for 2009-2013, one of the five CIHR strategic research priorities is to provide the evidence necessary to support a high quality, accessible and sustainable health care system. The CIHR Institute of Health Services and Policy Research (IHSPR) is the champion for research in this domain and has developed many innovative programs to support the generation of new knowledge, build capacity and ensure that knowledge translation (KT) initiatives are developed and implemented to address health system challenges and strengthen the Canadian health care system

The CIHR Institute of Cancer Research (ICR), identified access to quality cancer care, as one of its strategic research priorities in 2005. The same year, ICR hosted a workshop for researchers, clinicians, health system managers and policy makers to identify research priorities and recommendations for action. The workshop was followed by the launch of the Access to Quality Cancer Care (AQCC) Request for Applications (RFA). The RFA was launched in collaboration with 13 partners, including eight provincial cancer agencies, to encourage applications directly linked to provincial priorities. Seven emerging teams were funded under this initiative, covering a variety of topics under the umbrella of access to quality cancer care (see table 1). In October 2009, these teams reached the mid-point of their five year grants and were brought together to exchange information on common challenges, lessons learned, and the strengths and weaknesses of their knowledge translation strategies.

**Table 1: Access to Quality Cancer Care New Emerging Teams**

Principal Investigator	Institution Name	Project Title
Doll, Richard	B.C. Cancer Research Centre	CIHR Team in Supportive Cancer Care
Elias, Brenda	University of Manitoba	CIHR/CCMB Team in First Nations Cancer Research
Grunfeld, Eva	Dalhousie University	CIHR/CCNS Team in Access to Colorectal Cancer Services in Nova Scotia
Katz, Alan	University of Manitoba	CIHR/CCMB Team in Primary Care Oncology Research
Mackillop, William	Queen's University	CIHR Team in Access to Quality Radiotherapy
Menon, Devidas	University of Alberta	CIHR Team in Cancer Technology Decision Making
Tyldesley, Scott	University of British Columbia	CIHR Team in Operations Research for Improved Cancer Care

### **Access to Quality Cancer Care Workshop**

The workshop was held in Vancouver on October 8<sup>th</sup> and 9<sup>th</sup>, 2009. Each of the seven funded teams was invited to bring up to five members of their team to the workshop, although some flexibility was allowed (see Participant List – Appendix 1). The original RFA had three fundamental objectives:

- to build cancer health services research capacity;
- to encourage and facilitate team building among researchers and decision makers; and
- to promote the development of functional KT implementation strategies

The goal of the workshop was to provide an opportunity for teams to learn from each others' experiences in these common areas, in order to strengthen their KT strategies.

The workshop was comprised of a combination of presentations, open discussions, poster sessions and breakout groups. As there is considerable diversity in the research topics among the seven teams, opportunities for inter-team networking and discussion of the science and research progress were provided during two poster sessions. The presentations were designed to provide information and observations considered to be of relevance to the teams' research and to stimulate discussion among workshop participants. Highlights of the presentations are briefly summarized below.

### **Presentations**

#### **Overcoming Perceived Barriers to Health Service Research**

##### **Ellen Melis, IHSPR**

Many of the barriers to health services research identified at the original AQCC workshop in 2005, have been addressed and at least partially resolved. Although the percentage of CIHR funding dedicated to health services research (about 5%) has not changed significantly, the amount of funds this represents has increased quite dramatically since 2001. This increase has translated into increased research capacity. IHSPR, alone, has supported several Research Chairs and many emerging teams in addition to a total of 32 strategic training programs in health services and policy research. As well as increasing capacity, including research training for decision makers, these programs have served to strengthen the integration of research and practice and improve the level of institutional respect for health services research. Since 2005, several new health services and policy scientific journals have emerged providing increased opportunities for publication. To address the challenges of data sharing and regulatory issues, a Health Information Summit was held in 2008, which was followed by the development of action and implementation plans. As a further measure to support KT and strengthen the links between researchers and decision makers, the CIHR Partnerships in Health System Improvement (PHSI) program has been strengthened to provide increased funds for team support and KT delivery. IHSPR's Evidence on Tap program provides an opportunity to deliver accessible and timely evidence, through 'best brain' consultations and expedited research syntheses, to inform key decisions related to health and health care delivery. Finding funds for research centre and infrastructure support still presents some challenges, although the situation in Manitoba serves as an example of the impact core infrastructure funding can have on the ability to create networks to conduct and translate health services and policy research.

#### **Knowledge Transfer – Content, Culture and Connections**

##### **Simon Sutcliffe, Canadian Partnership Against Cancer (CPAC)**

Many different players are required for effective KT - from both public and private sectors and academic and clinical environments. However, the way research centres are organized and managed is very different from how hospitals and community services are run and so a common ground must be found. Collaborations between researchers, decision makers and others must be based on: trust and respect; commitment; available resources; and sustainability. At the same time, to be truly effective, collaborations must be contextually relevant, culturally compatible, politically acceptable, and have a defined leadership and program structure. Different decision makers are governed by

different considerations. For the politician, it is public policy based on political capital, risk and profile. For the health system administrator, it is a question of balanced affordability, return on investment and the risks of inaction. For the health professional the guiding principle is based on the strength of the evidence for medical benefit and whether a policy change or intervention is truly a medically necessary advance on standard practice. For sustainable collaborations to evolve it is necessary to provide incentives and create a culture of sharing and nurturing within an accountable structure that provides strong leadership. Any collaboration can be challenging – in the case of researcher/decision maker partnerships, for example, how much influence should a decision maker have and what demands can they reasonably make of the researcher? What if they don't like the results of a study they requested? In the case of politicians, good evidence may not be sufficient as decisions tend to be made in response to public opinion. There is also a delicate balance between addressing questions that arise in real time versus those can be anticipated several years later. This requires an approach that frames the research in a context and an environment appropriate for the decision makers. CPAC provides an excellent platform for partnership and in providing added value across federal, provincial and territorial boundaries in situations where agreement already exists.

### **Knowledge Translation: Knowing what we do, Doing what we know**

#### **Jon Kerner, CPAC**

There is a tendency to assume that the science community knows what policy or decision makers need, and when that differs from what they may want, it may be assumed that policy or decision makers are just looking for confirmation that they are right. This is not necessarily the case and researchers should be aware that sometimes research outcomes need to be framed and packaged in a way that is more digestible by end-user groups. Engagement of the appropriate “knowledge users” from the very beginning of the research process goes a long way towards ensuring that the evidence provided will be relevant, timely and useful. Research conducted by teams of researchers, practitioners and policy specialists allows for a two-way exchange of information and feedback throughout the process. Facilitating this mechanism was one of the objectives of the AQCC initiative. However, a show of hands among workshop participants suggested that some of the teams had not yet realised this partnership goal – most of the people in the room were researchers, with very few representatives of other groups. The question was raised as to whether teams that were further advanced in terms of actively involving policy and decision makers in their research would be prepared to share information, activities and resources with other teams – thus meeting one of the goals of the workshop. One team reported that their success in working with their provincial partner was based on the fact that 50% of their funding comes from the provincial government. Every year five deliverables are jointly set and the outcome data is freely shared. This is a win-win situation as the team has the necessary funding to do the work, while maintaining academic freedom. A review of the original applications in response to the RFA, revealed that the number of times KT was mentioned, ranged across proposals from once to 47 times, suggesting a wide variation among teams, with respect to an understanding of and a commitment to KT activities. Successful teams need to focus on data use, rather than just the data; ensure that they have the required data use competencies as part of their team structure; secure adequate institutional and community support; and, most importantly, develop a social strategy to make use of the data collected in order to better align the political will necessary to support evidence-based change.

CPAC could provide a forum for networking and information exchange for the AQCC teams and others. Created to maximize synergies and strengths across the country; provide a platform to optimize the sharing of best practices; and support a population and disease continuum approach, CPAC is ideally placed to serve as a catalyst for knowledge exchange and uptake. The CPAC web



portal (<http://www.cancerview.ca>) was designed as a knowledge management platform for cancer control. The portal is already being used to support knowledge management and exchange for strategic initiatives focused on colorectal cancer screening, navigation and screening for distress, and synoptic reporting in surgery. The portal could serve as one receptor site for the results emerging from the AQCC teams. The Canadian Association of Provincial Cancer Agencies (CAPCA), already a partner on one of the teams, represents another potential vehicle for knowledge exchange and transfer. It is important that the results of any research, not just health services research, are contextually relevant to and noticed by those making funding decisions. This factor is key for sustainability – a concern for many of CIHR’s emerging team grants that face uncertainty at the end of the five-year funding cycle.

## **Lesson Learned from the Palliative and End-of-Life Care Initiative**

### **Mark Bisby**

The CIHR Palliative and End of Life Care initiative (PEOLC) was launched by ICR and 16 partners in 2003. Supported by a total investment of \$16.5 million, the PEOLC was the biggest initiative of its kind in the world and represents the single largest program developed by ICR to date. The initiative included support for 10 New Emerging Teams, whose five-year funding has now finished. An impact assessment of the initiative was recently undertaken by Mark Bisby and Michelle Campbell and it was felt that many of the findings were likely to be of interest and relevance to the AQCC teams. The PEOLC initiative succeeded in building research capacity and establishing broad networks. Publications increased dramatically over the five years of the grant and a dedicated peer review panel was created to provide an avenue for sustainability through the open competitions.

Many of the team members were experienced health professionals, already with leadership roles in the health system and able to implement changes in practice. These individuals, while critical to CIHR’s KT mission, are not generally competitive in the world of operating grants and many of them are not interested in a purely academic future. Many of these individuals will now return to their original roles within the health care system and this essential capacity will be lost.

The PEOLC teams serve as an excellent example of successful integrated KT, with all teams having engaged end-user communities, despite the fact that the original RFA has no specific requirement for a KT strategy. Their success illustrates the importance of engaging potential stakeholders, including decision makers and patients, from the very beginning. Team members have also been prolific users of CIHR’s dedicated KT programs. Their results are already being integrated into practice and guidelines, health professional training, and policy discussions.

However, despite several attempts to find a source of sustainable funding for these highly successful teams, the termination of strategic funding will mark the end of many of the collaborations and networks formed through the initiative. This is a recurring problem with the CIHR five-year funding cycle, especially when applied to team and capacity building. There are no longer any open team grant competitions at CIHR for teams to “grow into” during their initial five year period. Teams are an effective structure for integrating key users, communities and collaborators from beyond mainstream academia. It is essential that the AQCC teams start planning an exit strategy and a means to sustain their teams well before the end of the granting period in order to maintain momentum. To make the case for sustainability, teams need to collaborate on accessing dedicated KT resources and creating a coherent “package” of results for dissemination.



## **Knowledge Translation Opportunities in the Knowledge Syntheses and Exchange (KSE) branch at CIHR - IRSC**

### **Ellen Melis**

The CIHR KSE branch offers an expanding suite of funding mechanisms and opportunities to support: knowledge syntheses; integrated KT; end-of-grant KT; the science of KT; and KT training. More information on all these opportunities can be found on the CIHR website, or by contacting a member of the KT portfolio.

### **KT in Action**

#### **Stuart Peacock, National Centre for Health Economics, Services, Policy and Ethics in Cancer**

This presentation provided examples of hands-on experience in the KT field in Canada, the United Kingdom (UK) and Australia from the perspective of a health economist. The National Centre for Health Economics, Services, Policy and Ethics in Cancer (HESPE), based in Vancouver and Toronto, is a national research centre with KT at its heart. HESPE is supported by a large grant from the Canadian Cancer Society, and represents a partnership between the British Columbia Cancer Agency, Cancer Care Ontario, the Canadian Cancer Society, University of British Columbia and the University of Toronto. HESPE will establish links between researchers, policy makers, practitioners, trainees and the public. By building on the centre's expertise in linkable administrative data, HESPE plans to design a best practice, multi-province data platform to address cancer control for all Canadians. The centre includes a strong training component for researchers, decision-makers and practitioners.

In Canada, as in other countries, cancer control faces many challenges, including the rising costs of innovation and technology and the difficulty in systematically allocating scarce resources. At HESPE, a team has been assembled to develop and pilot a novel, evidence-based method for resource allocation and decision making. Funding for this program is provided through the CIHR Partnership in Health System Improvements (PHSI) program. To date, a steering committee has been established and a suite of programs has been selected for evaluation. Programs relate to frequency of mammography screening and comparisons between MRI and standard mammography; PET/CT scanning in lung cancer; Herceptin treatment for breast cancer; and the cost effectiveness of Avastin treatment for colorectal cancer. Evidence is generated using Markov/simulation modeling approaches and early results are already validating the value of this method of analysis. The PHSI program has proven to be an effective mechanism in this situation, for developing collaborations between researchers and decision makers and establishing criteria for priority setting.

Another successful undertaking in the UK – the York formula – demonstrated a different approach based on the UK National Health System which is very different from our Canadian model of health care delivery. In the UK, a steering committee was formed with the CEOs of all the regional health authorities and an executive contract was awarded that included strong incentives for policy-maker involvement. Progress was guided by a technical committee that included applicants who were not awarded the contract. Their vocal input was important for keeping the project on track. The end of project KT was funded by the health authorities – in other words the researchers were paid to go out and explain their results. This experience served as a good example of contract research but also highlighted the fact that in the UK, as in Canada, researchers need to work closely with decision makers in order to translate knowledge effectively.

One example of a less successful undertaking was a project relating to the conformity assessment testing for medical devices in Australia. In this case, conflicting objectives between government and



the ministries created a public service climate that was not conducive to open dialogue around key research and policy issues, resulting in a lack of engagement by many key stakeholders. The situation was compounded by weak evidence relating to the research and policy questions at hand, and serves as an illustration that for KT to be successful, strong incentives are needed and the ‘climate’ has to be right.

### **Discussion on Challenges and Successes**

Time was allocated for in-team discussions on the successes and challenges experienced to date. Information was shared during an open discussion period intended to identify best practices for the group as a whole. There were many examples of situations where a success for one team, represents a challenge for another, which to some extent is a reflection of the broad diversity of topics addressed by the teams.

All teams identified challenges encountered when trying to develop functional teams comprised of individuals from very different backgrounds and often dispersed over a wide geographic area. Team building takes time and requires well-defined strategies that are agreed to by all team members ahead of time. Frequently teams arise from existing collaborations and networks creating challenges for new researchers wishing to work in a team environment. It is particularly difficult to engage medical practitioners in research activities in addition to their clinical workload, and improved mechanisms are needed to provide adequate financial support and incentives to support clinician scientists’ involvement in research projects. However, several teams reported having established strong teams with full engagement of both clinical practitioners and end-users, including collaborators from outside the traditional disciplines. Students and trainees were an important component of many of the teams, as the team environment provides access to large numbers of experts. Many teams cited the presence of a team champion to pull the team together as being a key element in their success.

The need for effective and regular communication was identified as a key component for successful and sustainable team building. In the case of large teams, it is especially important to keep everyone up to date on plans and progress – internal KT. Finding both the time and the funds to facilitate regular face-to-face meetings can be a challenge, especially for widely dispersed teams. For some teams this challenge was resolved through quarterly workshops for the entire team. In other cases the team included a designated knowledge broker to facilitate communication both within the team and with external parties and end-user groups.

Several teams stressed the importance of engaging end-user communities early in the project and described challenges encountered in identifying the appropriate individuals and persuading them to become involved in advance of any results or evidence to convince them of the value of engagement. This is particularly true for Departments of Health and Deputy Ministers, who are the ones responsible for service delivery, but who are extremely difficult to access for meetings, especially if more than one department is involved. Challenges also occur in adjusting to constant staff turnover in some departments and organizations making it difficult to maintain continuity. Teams reported variable success in their ability to engage policy and decision makers and in forming links between provinces.

Frustration was expressed around ethics approval and privacy issues and the variability across and between provinces. Protocols are needed that can be adopted across the country and some teams are making inroads in this direction. In some cases a complete change of mindset is required (e.g. Indian

and Northern Affairs), not just for ethics approval but also in the data quality and the way the data is collected. The goal is to be able to implement decisions according to a set of ethically sound principles.

Additional challenges concerned dealing with unexpected circumstances, such as when a result attracts the attention of the courts and the legal system, and situations in which the resources in a system are redirected because of a national crisis, such as H1N1.

## Conclusion

During the course of the workshop a number of themes emerged which were of interest to several teams and individual team members. On the second day of the workshop, time was set aside for informal small group discussions on topics of shared interest. The intent was to provide an opportunity for team members to share their experiences and lessons learned in order to learn from each other and perhaps generate new collaborations and alliances. The discussion topics chosen were: economics of care; administrative databases; social marketing/knowledge brokers; sustainability; and relationship building. Meeting space was provided for groups that wished to continue the discussions, after the end of the workshop, either within their own teams or across teams.

Overall, workshop participants expressed satisfaction with the workshop as a networking and learning opportunity. Over the course of the day and half, many realised that despite the diversity of research topics, there were many similar challenges that could be addressed collectively.

Potential action items identified included:

- **A national health services research meeting** - Health services research is a broad field and the seven AQCC teams represent just a small portion of the total research taking place in Canada. It was suggested that a national health services research meeting, perhaps organized by CPAC, would be a worthwhile endeavour as there are many challenges still to be faced in delivering health care across a country as vast as Canada.
- **A networking workshop at the beginning of five-year Team Grants** - It was also suggested that, given the value of workshop such as this and the potential to learn from the experiences of others, it might have been more appropriate to have had the workshop at the beginning of the five-year funding cycle rather than half way through. ICR will take this suggestion into consideration when organizing similar events.