

*Colorectal Cancer Roundtable:
Innovations and Management
Five Years and Beyond*

Thematic Report

Colorectal Cancer Association of Canada

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Table of Contents

Welcome Letter	1
Conference Overview	2
Tailored Treatment Stream	2
Opening Presentations	2
The Evolution of Treatment—A Journey to a New Hope.....	2
Targeted Treatment Approaches.....	3
Breakout Presentations	4
Colorectal Cancer Targeted Approaches:	
KRAS, MSI, and Bionetworks	4
Discussion.....	5
Taking Note from Past Experience in Breast Cancer Targeted Treatment.....	5
Discussion.....	6
Multidisciplinary Teams: What, Why, and How	6
The Evolution and Future of Radiation Therapy in the Treatment of Patients with Rectal Cancer	7
Planning for Reimbursement for Tailored Treatment	8
Workshop Discussions and Recommendations	8
Summary of Workshop Discussions.....	9
Timely Access to and Integration of Medical Breakthroughs	9
Discussion outcomes.....	9
Other outcomes and recommendations.....	10
Integrating Multidisciplinary Team Management	11
Discussion outcomes.....	11
Other outcomes and recommendations.....	12
Future Advancements and Patient Care Paths	13
Discussion outcomes.....	13
Other outcomes and recommendations.....	14
Managing Reimbursement Barriers to Integrate Tailored Treatment into Cancer Care	15
Discussion outcomes.....	15
Other outcomes and recommendations.....	16
Wrap-Up	16
Screening Stream	18
Opening and Breakout Presentations	18
Primary Research Methods of Colon Cancer Screening, & Overview and Focus on the Future of Colorectal Screening	18
Blending Future Science Breakthroughs with Innovative Approaches The Tailored Treatment Revolution.....	19
Colorectal Cancer Screening:	
The Future is Now False-Negatives in Immunochemical FOBT Screening Due to Delayed Return of Fecal Samples	19
Can Genetics Enable an Individualized Approach to Colorectal Cancer Screening?	20
ColonSentry™: Blood-Based RNA Profiling.....	21
Population-Based Strategy for Reducing Colon Cancer Mortality Using a Metabolite-Based Blood Test (the Phenomenome gTA Test).....	21
Workshop Discussions and Recommendations	22
Recommendations	22

Clinical Trials, Programs, and Collaborations.....	22
Infrastructure Support.....	24
Cancer Support Stream.....	24
Opening and Breakout Presentations	24
The Future of Cancer Support and Its Impact on Outcomes and Implementing the Distress Thermometer by Reaching All Newly Diagnosed Patients	24
The Princess Margaret Hospital Distress Screening and Response Program	25
Workshop Discussions and Recommendations	26
Recommendations	26
Integrating new tools, innovations, and concepts in supportive care.....	26
E-Health Technology	26
Psychosocial Care—Referral Process Change	27
Integrated Non-Profit Organizations and their Resources.....	28
Roundtable Conclusion.....	29
Appendix 1	
Algorithm per Dr. Calvin Law’s presentation.....	30
Appendix 2	
Detailed Outcomes of Each Tailored Treatment Workshop	31
Timely Access to and Integration of Medical Breakthroughs	31
Discussion outcomes.....	31
Recommendations from Workshop 1	34
Integrating Multidisciplinary Team Management.....	35
Discussion outcomes.....	35
Recommendations from Workshop 2.....	38
Future Advancements and Patient Care Paths.....	38
Discussion outcomes, Part 1	39
Discussion outcomes, Part 2	41
Recommendations from Workshop 3.....	43
Managing Reimbursement Barriers to Integrate Tailored Treatment into Cancer Care.....	44
Discussion outcomes.....	45
Recommendations from Workshop 4.....	47
Appendix 3	
Discussion Outcomes of Screening Stream Workshop	47
Appendix 4	
Discussion Outcomes of Cancer Support Stream Workshop	49

Welcome Letter

Barry Stein
President
Colorectal Cancer Association of Canada (CCAC)

Dear Friends,

Welcome to Vancouver and the second Canadian Colorectal Cancer Roundtable—Innovations & Management 5 Years and Beyond!

This Roundtable has been planned with the perspective of obtaining your input to foster better collaborative action between all stakeholders as we face the challenges of integrating new and innovative technologies in colorectal cancer prevention, treatment, and cancer care as a whole in Canada.

From new and innovative screening technologies, earlier detection, improved treatments and individualized care, the future is revolutionary for the management of colorectal cancer. These technologies will bring about improved patient outcomes and health care system efficiency. However, overall systematic changes and decisions are required today from all levels of cancer care to ensure these advances are incorporated in a timely manner to the benefit of all patients.

New strategies in cancer care management must be viewed with the patient as the focal point. As we redefine cancer care in Canada, addressing the psychosocial needs of patients and their families is essential to improve patient outcomes and increase the quality of cancer care. The future of supportive care will be collaborative and dynamic and shared among our varied resources.

The diverse representation of members from the cancer care community present at this Roundtable provides us with a unique opportunity to vision the future. Your experience and creative recommendations are not only welcome, but essential to ensure an effective contribution to planning the future of colorectal cancer prevention and care. I look forward to sharing your vision of the future of cancer care in Canada.

Together we can make a difference!

Enjoy the conference.

Conference Overview

The 2009 Colorectal Cancer Roundtable contained three discussion streams: Tailored Treatment, Screening, and Cancer Support. Presentations and workshops for the Tailored Treatment stream took place over both days of the conference, while the Screening stream was held on the first day and the Cancer Support stream was organized for the second day.

Conference participants heard opening presentations from each subject area, then broke out into separate sessions for panel talks and workshop discussions related to their chosen stream. A panel comprising conference presenters with expertise in the discussion area presided over each workshop to answer specific questions and give comment. At the end of the workshops, participants analyzed the discussion for critical points and areas of commonality, and formed these outcomes into a list of recommendations. The recommendations were then presented to the larger group in the plenary sessions at the end of each day.

Tailored Treatment Stream

Opening Presentations

Within the Tailored Treatment stream, speakers and participants examined two themes: the evolution of colorectal cancer treatment, and approaches to incorporating new innovations into cancer care.

The Evolution of Treatment—A Journey to a New Hope

Dr. Calvin Law
Surgical Oncologist
Odette Cancer Centre
Sunnybrook Health Sciences Centre

Comprehensive team care for patients with colorectal liver metastases took years to evolve. This is the most effective approach to delivering colorectal cancer care, and should be made a priority in clinics everywhere. Team members from many different departments must come together in a precise, co-ordinated effort to provide the patient with the optimal outcome. For cases of metastatic colorectal cancer, this approach includes the possibility of cure.

A century and a half ago, few believed colorectal cancer was operable, and only a few decades ago, a leading oncologist said untreated and treated patients had equivalent survival chances. But improvements in surgery techniques brought a new dawn for metastatic colorectal cancer treatment.

As tools, skills, techniques, and survival rates rapidly developed through the 1990s, the balance in perspective tipped from technical resectability of the liver to identifying metastatic colorectal cancer patients with the right biological indicators for a successful cure. The resulting good outcomes motivated surgeons to find solutions for those with less favourable factors.

The next generation of clinical trials has made it possible to determine the type and duration of chemotherapy to be administered (e.g. 5-FU and oxaliplatin-based chemotherapy with or without a biologic) prior to liver resection to increase survival rates and decrease morbidity.

Today, few cases are seen as impossible. Dr. Law described this optimism and the need for organized comprehensive team management, noting that patients with metastatic colorectal cancer are now living longer, and some are being seen alive and cancer-free seven years after their initial metastatic diagnosis. A multi-disciplinary approach including a surgeon, a medical oncologist, a radiologist, and an interventional radiologist help increase survival rates for metastatic colorectal cancer patients.

Illustrating this point, Dr. Law described a patient with sigmoid cancer whose liver had metastases in the right lobe, and a left lobe too small to function on its own if a metatectomy were to be performed. Through embolization and interventional radiology, Dr. Law's team forced the left lobe to grow, thereby making a metatectomy of the right lobe possible; the patient then proceeded with chemotherapy following surgery.

"You need a good team for a tough journey," Dr. Law said. "We're only limited in our imagination to think of how far we can go."

Targeted Treatment Approaches

Dr. Hagen Kennecke
Oncologist
BC Cancer Agency

Dr. Hagen Kennecke gave a "big picture" overview of the history of colorectal cancer research and the growing understanding of tumour biology, therapy, and patient factors.

- Historically, leucovorin and fluorouracil (5-FU) were the accepted treatments for colorectal cancer.
- New chemotherapy compounds introduced in the early 1990s led to a steady increase in duration of survival, but each agent came with side effects for the patient.
- Today, new targeted therapies arising from the biotech revolution have the potential to further increase effectiveness while reducing toxicities. These therapies offer greater benefits such as survival for new patient groups and longer remission times.

Looking at population data from British Columbia, Dr. Kennecke illustrated the advantages of bevacizumab in combination with other chemotherapy. While bevacizumab is not effective

alone, when combined with other chemotherapies it provides significant advantages. Comparing survival rates from 2005, prior to bevacizumab's availability, and 2006, the first year the drug became available, Dr. Kennecke said the B.C. data indicates important new survival and longer remission advantages for metastatic patients.

Compounds that can target very specific stages, such as cediranib and sunitinib, are in active trials, and there have been promising studies on drugs targeting insulin growth factor receptor pathways. In addition, researchers are looking at therapies such as panatumumab that could influence downstream pathways of epidermal growth factor receptors.

At the same time, understanding of colorectal cancer has evolved from a one-size-fits-all approach to an awareness of how signal profiling and markers such as KRAS, BRAF, and microsatellite instability (MSI) can identify subtypes and guide tailored treatment planning. The role of diet and exercise is also becoming better understood, as is the knowledge that "we are dealing with patients, not cancers."

The wealth of therapies now arising from biotechnology research is just the beginning.

"We have not even seen the benefits of cancer vaccine therapy, gene therapy, and stem cell innovations." All of these therapies require better funding if patients are going to benefit. A holistic approach, along with tissue collection and more clinical trial opportunities, is vital.

Tailored Treatment Stream **Breakout Presentations**

After the morning plenary presentations, participants in the Tailored Treatment stream heard presentations on more specific areas of tailored treatment. These were designed to inform and inspire the discussion workshops that followed.

Colorectal Cancer Targeted Approaches: KRAS, MSI, and Bionetworks

Dr. Brent Schacter
Medical Oncologist
Cancer Care Manitoba, and
Canadian Tumour Repository Network

Dr. Brent Schacter explained how a growing understanding of KRAS gene mutations and MSI and their role in treatment planning for colorectal cancer patients was in itself a signifier of the need for well-annotated biobanking.

Databases of human biological materials designed for specific purposes—such as population biobanks, disease-oriented epidemiology biobanks, and disease-oriented clinical biobanks—could offer limitless answers to critical research questions.

The Canadian Tumour Repository Network (CTRN) has collected material from 13,266 patient volunteers, and broken the tissue down by type. Network members have increased the number of collection locations and disease topologies collected, and have made significant inroads into the standardization and implementation of operating procedures. CTRN has also led the way in the work being done by the Marble Arch Working Group on International Biobanking.

Publications on standardization will help international biobanks work together. It is a nascent group, and it has some “lessons learned,” including the need to manage expectations, ensure the autonomy of member biobanks, pool resources, leverage local expertise and partnerships, and fund local research activities.

The future of molecular and translational research depends on the availability and quality of human specimens. How biobanks are funded will influence the effectiveness of this research for decades, which will in turn affect the future health of Canadians.

Discussion

A participant asked how researchers will be able to acquire adequate samples, given that the tumour bank collects samples from a limited number of hospitals. Dr. Schacter said this limitation was why resources for the tumour bank must be expanded, in the same way they have been for genome studies. In response to a question on the future of KRAS testing, Dr. Schacter said that biobanks could help establish the evidence required to convince pathologists and funders to move testing into practice.

A discussion followed on the need to link population biobanks with clinical biobanks.

Taking Note from Past Experience in Breast Cancer Targeted Treatment

Dr. Joseph Ragaz
Medical Oncologist
Rosalind and Morris Goodman Cancer Centre
McGill University

Dr. Joseph Ragaz described the struggles his team has faced in the cost-benefit analysis of new breast cancer interventions, in the hope that his experience would benefit colorectal cancer researchers.

He said rapid reduction in breast cancer mortality continues with each new technology that enters the field and more funding per capita correlates with better outcomes and access to medications. But there are differences among the provinces in delivery of care.

He noted the need for a formula that demonstrates the worth of spending a given dollar for a given gain.

A 2005 study on adjuvant Herceptin in early breast cancer showed profound reduction in recurrences. But the cost of the drug has prevented many provinces from starting it. Dr. Ragaz's group developed a methodology that showed the savings over time with reduced metastases are much greater than the upfront cost of Herceptin. They followed with studies on targeting biologicals with secondary markers and with a controversial trial on the role of the Oncotype DX 21-gene assay in chemotherapy outcomes. Both showed significant cost savings through weeding out patients who would not likely benefit.

Using the biology of the tumour rather than its placement to define treatment represents a paradigm shift.

Further study of exciting developments in KRAS mutation in colorectal cancer research could find funding in Canada, once funders understand how speedy biomarker therapy could save millions of dollars and prevent recurrences.

Discussion

Participants agreed with the need for the further development and use of biomarkers, but many commented on barriers caused by "siloeed" funding in Canada. As each therapy is paid for from a different department, the overall cost savings of biomarker therapy were not being seen. Strategy creation, provincial coordination, and national electronic databases are needed to overcome this problem.

Multidisciplinary Teams: What, Why, and How

Dr. Calvin Law
Surgical Oncologist
Odette Cancer Centre
Sunnybrook Health Sciences Centre

Dr. Calvin Law presented on the importance of multidisciplinary teams in cancer treatment, and on the issues that are holding back their development. In the past, the two-stage decision on treating patients with colorectal cancer was to operate or not, and if not, whether to use chemotherapy, radiation, or other treatments.

Once it was understood that these can work together with sequential treatment, the benefits of cooperation became apparent.

Trials began, to determine the ideal order of treatment, and Dr. Law's team worked to improve communications between surgeons, radiotherapists, and chemotherapists. That led to new technologies and better communication of clinical impacts, and improved understanding of issues such as steatohepatitis and chemotherapy-associated hepatotoxicity. The resulting solutions included coordinating neoadjuvant medications, providing adequate staging, and

timing medication cycles to surgery. These practices led to increased survival, shorter wait times, and more appropriate treatment plans.

The GI team at Sunnybrook Cancer Center developed an algorithm from their trials that can act as a system for team communications and for the planning of treatment timing.

There are still problems to overcome, such as resource constraints, legal implications, questions about selection and compensation, decisions about who should participate, and challenges in moving practitioners from “comfortable offices into unfamiliar areas.” There are also differences to consider in how team management can work within academic centres and in community centres, which can be harder to organize.

Multidisciplinary protocols require coordination, and changing habits is difficult and initially expensive, but the work to develop teams is necessary to ensure advancement and to save more lives.

The Evolution and Future of Radiation Therapy in the Treatment of Patients with Rectal Cancer

Dr. Té Vuong
Radiation Oncologist
Rosalind and Morris Goodman Cancer Centre
McGill University

Better imaging technologies and new developments in targeted radiation therapy are allowing practitioners to customize treatment for patients with rectal cancer, improving outcomes and reducing incidence of negative side effects such as toxicity, incontinence, and impotence. At present, external beam radiation therapy (EBRT) is standard, and while effective, it is not particularly sensitive to differences among those being treated, which are becoming increasingly understood thanks to improvements in imaging technology.

The concept of targeted radiation arose in the 1950s, with the Papillon method of treating very small tumours with little toxicity. In 1998, Dr. Vuong’s team began working on a targeted treatment for cases that the Papillon method excludes. Brachytherapy is extremely specific, allowing radiologists to spare the bladder, sphincter, skin, and other non-targeted areas. In 10 years of testing, it has shown fewer complications, and it can be given over four days, rather than the 28 days required for standard treatments. It is also considerably more affordable.

Additionally, intensity-modulated radiation therapy (IMRT), allows radiologists to design treatment and shielding specific to each patient; for example, radiologists can shield the bladder and scrotum while giving high doses to the tumour and low doses to areas it may be invading.

“The end goal is to improve the patient’s quality of life and reduce costs.”

Planning for Reimbursement for Tailored Treatment

Dan Rego
Vice-President, Healthcare Services
Shoppers Drug Mart, and
DrugCoverage.ca

A 2008 survey showed that 70% of Canadian medical oncologists were not giving ideal treatment to colorectal cancer patients, owing to a lack of funding or private insurance. "This is a horrifying statistic to the Canadian on the street." Only 20% of provincial plans cover Avastin, Erbitux, or Vectibix, in part because the provinces require open plans and because insurance companies restrict payment for infusible drugs.

To note, civil servants who chose not to include these drugs in provincial plans personally have access to them through the federal workers' health plan.

Some provinces fund MSI testing, but none fund KRAS testing. Neither is covered in most private insurance plans. A 2008 "report card" on the payer distribution of oral chemotherapy agents, hormone therapies, and take-home medications showed that public payers paid more per case, but their per-instance case was lower than that of the private payers.

This lack of funding is disappointing and negatively impacts the standard of care. The report also showed much greater increases in private payments over public payments, and wide discrepancies between provinces.

Cancer drug prescriptions are subject to greater discretion than prescriptions for many other diseases. The accessibility of medications for HIV/AIDS is responsible for it becoming "a chronic condition instead of a death sentence," and the cholesterol-lowering drug Lipitor is prescribed widely, with hundreds of millions of dollars in public reimbursement. While the "sticker price" of new cancer agents is perceived to be high, the lower volume means the cost is comparatively modest. Political pressure and awareness of this fact could open access to new cancer medications.

Tailored Treatment Stream

Workshop Discussions and Recommendations

Participants in the Tailored Treatment represented a mix of regions, professions, and areas of expertise. Over the two days of the conference participants were presented various future tailored treatment concepts and took part in four focused discussion workshops. The purpose of the workshops was to create a list of best practices, critical success factors, and recommendations for the following areas:

- Timely access to and integration of medical breakthroughs
- Integration of evolving approaches to multidisciplinary team care

- Future innovations and infrastructure that will improve care
- Management of reimbursement barriers

Summary of Workshop Discussions

Discussions in each of the four workshops were far-reaching, touched on many key issues and topics, and led to significant recommendations. What follows is a summary of those in-depth discussions that gleans the key emerging themes.

Workshop 1

Timely Access to and Integration of Medical Breakthroughs

PANELLISTS:

Dr. Anthony Fields
Alberta Cancer Board

Dr. Brent Schacter
Cancer Care Manitoba

Dr. Calvin Law
Odette Cancer Centre, Ontario

Discussion outcomes

Participants made numerous points and recommendations relating to timely access to and integration of medical breakthroughs including:

- Education of and communication to practitioners and patients
- The establishment of efficient timing systems and sample collection processes to streamline testing
- The creation of and role for a centralized body, such as a pan-Canadian institution for biomarker development
- The re-evaluation of the current quality-adjusted life year (QALY) guideline to better suit oncology terms and the current understanding of biomarkers
- Translational research must be encouraged and accelerated
- Policy makers must be better informed at much earlier development stages

Cooperation

Participants also discussed the need for improved cooperation outside the colorectal cancer field for faster development, better policy-making, and improved advocacy. **Dr. Anthony Fields** noted the lack of appropriate tools to make decisions in the current era—the number of fields competing for limited funding has created immense pressure.

Funding

Funding was a recurrent issue: participants indicated that funding should be streamlined and kept under one umbrella, to reduce competition for research dollars, prevent “cherry picking,” and bring in a higher level of quality control. Dr. Fields added that in a climate of restricted spending, decision makers will look at such factors as evidence, the economic indications, and benefits.

Other key themes emerged in the table discussions, including:

- Physicians and institutions must be well-versed in current scientific advances, and must be aware of the best research and data before they give recommendations.
- Establishing a working group, based either provincially or nationally, to act as an advisor and watchdog.
- Collecting and promoting evidence is critical, and can be achieved through the use of medical databases and population-based application of new approaches such as electronic medical records.
- Tissue collection and biobanking networks play a key role in the continued evolution of treatment.
- Ethical concerns must be considered, such as the implications of widespread MSI testing.

Other outcomes and recommendations

- Create bodies or mechanisms for quality control and for assessment of breakthroughs.
- Streamline surgical sampling so that upfront collection can serve multiple uses in clinical pathology and biobanking.
- Accelerate translational research and testing to keep pace with scientific advancement, and build awareness and support for translational research platforms.
- Include genomic teams in cancer centers, to connect, in both directions, clinical medicine and fast-evolving scientific developments.
- Employ pharmacoeconomics and statistics experts at the local level to interpret data on new tests and treatments.
- Work with provincial health ministries to ensure policy and testing methods are up to date.

Workshop 2

Integrating Multidisciplinary Team Management

FACILITATOR

Shaniah Leduc
CancerInsight

PANELLISTS:

Dr. Anthony Fields
Alberta Cancer Board

Dr. Brent Schacter
Cancer Care Manitoba

Dr. Calvin Law
Odette Cancer Centre, Ontario

Discussion outcomes

Participants' discussion focused on the importance and role of multidisciplinary tumour boards. All agreed that such multidisciplinary teams should be adopted as a best practice, and they should be made a standard approach for colorectal cancer care. In support of this recommendation, participants noted numerous non-financial benefits of tumour boards, including:

- Individualization of patient care
- Ability of patients to obtain several opinions about and participate in the debate over their treatment during one clinic visit
- Significant role patients could play in education and research
- The facilitation of decisions on inoperability. One member of each board must take responsibility for communicating fully and honestly these decisions to the patient. This person should not only convey a decision of inoperability but also the option for a difficult and costly plan of treatment
- Prevention of complications, education, relationship building, improved sense of community, saving time for physicians and patients, and more opportunities to seek funding.

Participants also discussed several key enablers for tumour boards:

- Inviting community centers to participate in tumour boards, and disseminating research to community and academic centers
- Communicating with regional centers—tools enabling this communication should be funded by government
- Videoconferencing technology for off-site tumour board members, and extensive communications between them and with the patient, to allow for a big-picture

discussion and efficiently plan a course of action

- An influential champion from each discipline must get buy-in on tumour boards from the larger medical community.

Participants discussed several practice models for tumour boards and made the following recommendations:

- The ideal tumour board would include clinical specialists and pathologists, and accommodation for pathology review.
- A wider range of practitioners such as dietitians and those trained in psychosocial support.
- Standardized care maps that include technology elements, as this and other mobile technologies could help smaller centres conform to the care maps used by larger ones.
- The use of electronic medical records housed in databases could also support team efforts.

Participants noted it can be difficult to get acceptance for tumour boards, due in part to the potential for large patient backlogs and insufficient compensation. Issues such as billing and team member time and resources must be addressed to enable tumour boards to function optimally.

Other outcomes and recommendations

- Increase awareness of the benefits of tumour boards for both clinicians and patients.
- Institute systems and policies that will facilitate the change required. Enablers can include the following:
 - Hospital accreditation bonuses
 - Billing codes for patient review to prevent lost income
 - Full-time dedicated administrative assistance
- Invite community clinicians onto tumour boards.
- Improve external and internal communication with electronic medical records, video- and teleconferencing, and improved image transfer technology.

Workshop 3

Future Advancements and Patient Care Paths

FACILITATOR

Dayle Acorn
Executive Director
Canadian Foundation for Pharmacy

PANELLISTS:

Dr. Scott Berry
Cancer Care Ontario

Dr. Hagen Kennecke
BC Cancer Agency

Discussion outcomes

A number of key themes emerged from the discussions in this workshop, including the following:

- Individualized medicine should become the gold standard.
- While the integration of targeted therapies, surgeries, and psychosocial support is necessary to promote individualized care, these innovations must be built on consistent national management policy.
- Transparency is needed in the decision process for approving treatments for reimbursement, and for frequently reviewed and consistent national guidelines and policies.
- A more formalized body should be created, with the role of assessing new technologies, drugs, and diagnostic products.
- Wider use of screening and current surveillance methods is an important step in improving care.
- The clinical trial program must be changed to improve recruitment and refine patient selection.
- Biomarker testing should be incorporated into the trial system, to prevent the need for retrospective work later on.
- A robust evidence collection bank network is another critical element for improving care.
- Current evaluation systems should be re-examined to take not only economic but also moral benefits of saving lives into account.

Funding

Participants raised the critical issue of funding several times.

- Funding must be made available before any work can begin on defining appropriate

national policies.

- Specific areas that require better funding and more availability include biomarker testing and tissue assays, therapy trials and research infrastructure, and research for tumour tissue banking.

Participants also discussed flexible funding systems and greater use of partnerships between the private and public sectors. They discussed allowing private elements to creep into funding plans to help offset the stress on the public system; they also talked about having same-source funding for treatment and diagnosis.

For organizations such as the CCAC, the current funding model — with funds issued at the federal level but distributed provincially — is restrictive. A national colorectal cancer strategy will require staggering funds, and advocacy efforts must focus on making the federal level assume the funding delivery role.

Patient support systems

Participants also reinforced the need for patient support systems, with an emphasis on the patient perspective. More work is needed in the area of patient support, and access to information should be improved. In addition, patients should be assisted in the process of navigating an increasingly complicated range of care pathways.

One part of the solution could be to better capitalize on the potential of the Internet, creating web-based tools for disseminating information. Organizations like the CCAC are vital for patient support, and will play a large role in developing improved information and support delivery systems.

In their discussions, participants referred to other issues that will drive future advances, including:

- An accelerated review process so that patients can benefit sooner from innovative treatments
- The formation of a national body for effective lobbying, evaluation, and accreditation based on the best practices of similar existing bodies
- The need to find other low-cost innovations and lifestyle interventions, such as exercise after resection

Other outcomes and recommendations

- Advance individualized assessment and treatment
- Formalized assessment for molecular diagnostics
- Improved patient selection and risk stratification in both the adjuvant and the metastatic

setting consistent across provinces and academic/community centers

- Consider continued research into circulating tumour cells as a method of avoiding repeated biopsies
- Re-evaluate and adapt current infrastructure to streamline priorities and prepare for innovation
- Test agents active in metastatic disease in adjuvant settings
- Consideration of legal and ethical questions surrounding tissue banking

Workshop 4

Managing Reimbursement Barriers to Integrate Tailored Treatment into Cancer Care

FACILITATOR

Dayle Acorn
Executive Director
Canadian Foundation for Pharmacy

PANELLISTS:

Dr. Scott Berry
Cancer Care Ontario

Dr. Hagen Kennecke
BC Cancer Agency

Dan Rego
DrugCoverage.ca

Discussion outcomes

Participants in this workshop discussed a number of issues including advocacy, funding, and the need for a national strategy. In the area of advocacy, participants suggested educating decision makers so that they understand the value of extra months of life, with its potential to bridge patients to the next emerging therapy.

National funding strategy

Discussions on a national funding strategy yielded several recommendations:

- Siloed funding— separate drug budgets, hospital budgets, research budgets, and so forth— makes it difficult to advocate change and enact efficient policies. Since funding silos across different agencies in each province could create inconsistencies regarding which take-home drugs are covered, funding should be aggregated.
- Consensus should be sought regarding the affordability of drugs relative to their medical value.
- The current complex funding structure should be streamlined to allow funders to investigate each individual agent, its costs, and its capacity to extend life, particularly when

they are weighing all those factors against other priorities.

- A fund is set up for the development of new biomarkers and for existing biomarkers that show proven benefit. Funding decisions can then be made within that pool of money.

Participants agreed that consensus is needed, along with a national Pharmacare strategy that looks at the larger picture and has a consistent plan for funding cancer drugs, whether oral, subcutaneous, or intravenous. The body responsible for these decisions must act in a timely and transparent manner, its policies must be portable and universal, and the provinces must be bound by its decisions.

Opportunities and concerns with private funding were discussed. Health economic calculations must improve if they are to be a part of decision making. An opportunity to fund treatment coverage could lie in qualifying patients for catastrophic drug coverage.

Describing a Quebec policy in which employers are required to offer a drug plan with coverage at least as good as the government plan, Rego suggested that a similar policy could be instituted in other provinces.

Other outcomes and recommendations

- Initiate a debate at the federal level, involving the *Canada Health Act*, to create a definition for “medically necessary” treatment.
- Advocate coverage for new medications. Include the argument that federal civil servants have access to these drugs, so other Canadians should as well.
- Examine the potential for manufacturers and payers to form cost-share frameworks for biomarker testing.
- Form a national body for reimbursement decisions that are timely, transparent, and most important, binding.
- Resurrect efforts to create a national Pharmacare strategy to reduce interprovincial discrepancies in cancer care.

Tailored Treatment Stream

Wrap-Up

Several recurrent themes emerged in the four breakout discussion workshops for the Tailored Treatment stream. Participants agreed that individualized care and multidisciplinary tumour boards should become standard, as should tissue banking, biomarker testing, and electronic records. Biomarker research should be accelerated, and cooperation with research bodies and practitioners in other medical and scientific areas must be improved.

A national infrastructure is needed to streamline funding, educate government, inform policy, resolve ethical and legal issues, advocate change, and raise awareness of the value of new treatments. Improved and more flexible funding is required to accelerate research and integration of treatment innovations, and patients need faster and wider access to these treatments. Finally, patients must be empowered through improved support systems, increased help with system navigation, and broader access to information.

Screening Stream

Opening and Breakout Presentations

Primary Research Methods of Colon Cancer Screening, & Overview and Focus on the Future of Colorectal Screening

Dr. David Ransohoff
Professor of Medicine
Division of Gastroenterology and Hepatology
University of North Carolina at Chapel Hill

“With the screening tests available in 2009, colorectal cancer screening is more effective than almost any other cancer screening.” There have been advances in screening as well as issues that policy makers must consider when forming guidelines for colorectal cancer screening.

The fecal immunochemical test (FIT) represents a significant advancement that has yet to garner much respect. Virtual colonoscopy offers good sensitivity and a low false-positive rate, but professionals need specialized training to perform it. “It can’t be undertaken lightly.”

Colorectal cancer screening is already highly effective, and more improvements are coming. Implementation and anticipating the future are the current concerns. Critical considerations include the team’s composition, identifying appropriate systems and responsibilities, training, reimbursement, and performance monitoring. Provincial responsibilities may simplify implementation and help Canada avoid the “Wild West” situation in the United States.

Dr. Ransohoff said that guidelines must be critically analyzed and agreed on before infrastructure is considered. It is a political process, because money and clinical activity are attached to each decision. All guidelines must consider screening and surveillance together in their development and recommendations, and be examined for future implications.

There is also a need to conduct prospective randomized clinical research in screening on new testing methods compared to current practice. Such research will provide the necessary evidence for better guideline review and recommendations.

Blending Future Science Breakthroughs with Innovative Approaches The Tailored Treatment Revolution

Dr. Shana Kelley
Director
Division of Biomolecular Sciences
University of Toronto

Dr. Shana Kelley described new developments in nanotechnology – the design and manipulation of materials on a molecular scale – and their applications for improving diagnostic instrumentation.

“By shrinking a sensor to the size of the thing you are trying to detect, you can see much smaller amounts of it.” Diagnostic technologies include semiconductor quantum dots used in imaging, and nanowires and metallic nanoparticles used in biosensing.

Current assays, such as fluorescent in situ hybridization (FISH), can be difficult or expensive. An ultrasensitive, multiplex, high-throughput technology for protein and nucleic acid detection that is truly cost effective and completely automated is needed. Her team has been working to develop this technology for tumour profiling and biomarker detection, with the goal of making it standardized, universal, and useful in diagnostic settings.

Dr. Kelley’s team chose electronic signals as a platform model, based on the cheap and easy-to-use glucose meter. The sensor technology they developed took the form of an electronic chip printed on a silicon wafer. Nanostructures are grown on the chip and engineered for sensing a range of markers. With this type of technology, future screening will be more efficient and easily accessible at the bedside as well as more precise and affordable than current invasive screening methods. Dr. Kelley noted that use of nanotechnology in future screening technology will detect cancer, as well as screen for lifetime risk of developing disease, with just a finger prick of blood.

Colorectal Cancer Screening: The Future is Now False-Negatives in Immunochemical FOBT Screening due to Delayed Return of Fecal Samples

Leo van Rossum
Epidemiologist
Radboud University Nijmegen Medical Centre
The Netherlands

Leo van Rossum presented new developments in Fecal Immunochemical Test (FIT). In Canada, colorectal cancer rates are rising, and despite new diagnostic and treatment techniques, costs and mortality rates are still too high. Increasing screening is the only effective plan.

Colonoscopy is the current “gold standard,” but it is expensive and burdensome. The guaiac-based fecal occult blood test (FOBT) has proven mortality reduction, but it is messy, has low

participation by the general public, and is not sensitive enough. FIT takes one day, and is specific, automated, and quantitative.

Van Rossum's group conducted comparison trials showing statistically significant improvements in participation and sensitivity for FIT over FOBT. In comparing FIT screening on apparently healthy populations against symptomatic populations, FIT showed an 85% survival rate among those with colorectal cancer (vs. 59%), and 27% did not require surgery (vs. 3%).

Cost-effectiveness models showed a savings of 12,043 life years over FOBT and 20,963 life years over no screening. "Colorectal cancer screening can start now, and we can trust it will be effective."

Planning for FIT should include increased colonoscopy capacity for polypectomy follow-ups, although there would be a decrease of indications for "symptomatic" colonoscopies. Citing results from a field and laboratory study that highlighted some limitations of FIT, van Rossum recommended that screening programs use both FIT and colonoscopy. His study showed that fecal specimen haemoglobin can degrade over time. As the delay in fecal sample analysis from initial sample collection increases to a few days, minor adenomas can go undetected; after six days, some colorectal cancers are not detected.

Can Genetics Enable an Individualized Approach to Colorectal Cancer Screening?

Alan Coley
VP Regulatory Affairs
Arctic DX

In at least one third of patients, sporadic colorectal cancer progression is due to genetics. "Can we identify patients at risk of progressing and increase surveillance of those?" If the group of mutations associated with progression could be identified, screening could be more accurately targeted. The objective is to identify the patients at the highest risk of developing the disease.

The Assessment of Risk for Colorectal Tumors in Canada (ARCTIC) project focused on single-nucleotide polymorphism, a DNA sequence mutation. Patients' DNA was collected and compared with non-patients' DNA, to find associated polymorphisms. The strength of the study lies in the number of times it was replicated with different databases around the world. It isolated two mutations associated with colorectal cancer.

Since the study was published, it has been replicated to consider different odds ratios. Eight other mutations identified by other groups were then combined to identify eight polymorphisms that were used to model risk.

Patients were divided into eight categories of polymorphic structure, each with a different lifetime risk of cancer.

In collaboration with McMaster University and the University of Ottawa, Arctic DX is working to develop the Colo-Risk™ test. Studies are expected to demonstrate that with the use of genetic structures, patients can be placed into a category that should improve the management and screening of those patients.

ColonSentry™: Blood-Based RNA Profiling

Dr. Wayne Marshall
Chief Clinical Scientist
GeneNews

Given the critical importance of early diagnosis, the standard recommendation is that people with average risk and no family history of colorectal cancer begin regular screening at age 50. But only a low percentage of people – 15%–20% in Canada – actually undergo screening. Reasons include lack of access and the discomfort of the screening test.

A blood-based approach, such as mRNA expression, would resolve many barriers to screening. Cells that circulate throughout the body respond to the various micro-environments they move through.

This approach is not cancer specific—it involves tapping into a host response to the presence of a pathology.

GeneNews' ColonSentry™ test could be used for risk stratification, to divide the average risk population over age 50. Those with higher risk would be encouraged to get a colonoscopy. This test could also be used to identify those with very low risk.

Dr. Marshall stressed that unlike genetic screening that is life long, ColonSentry captures a point in time: it identifies the *current* risk of colorectal cancer.

The blood-based test has the potential to improve compliance, to provide enriched information that should assist with colorectal cancer screening decisions, and to help identify populations with high risks of cancer whose aversion to colonoscopy should be overcome.

Population-Based Strategy for Reducing Colon Cancer Mortality Using a Metabolite-Based Blood Test (the Phenomenome gTA Test)

Dr. Dayan Goodenowe
President and CEO
Phenomenome Discoveries

To reach the objective of reducing colorectal cancer mortality within a defined geographical region, possible mechanisms include better treatments, early detection, and prevention.

Metabolites have been discovered that are specific to colorectal cancer, a low level of which indicates a problem. Studies have determined that gTA deficiency is an acquired phenomenon

and not an inborn genetic error; but once acquired, it is stable. In five independent case-control studies, the Phenomenome gTA test showed good sensitivity and specificity at all stages of colorectal cancer.

Screening Stream

Workshop Discussions and Recommendations

FACILITATOR

Dr. Robert Hilsden
Associate Professor
University of Calgary

Participants discussed and evaluated screening tests and programs, from initial development to implementation.

Participants considered a number of new screening tests, as well as new ways to deliver existing tests. Patient compliance emerged repeatedly as a central concern, along with a strong desire for information-sharing and collaboration.

Participants stated often that screening tests cannot be evaluated in isolation; preventive measures such as diet and exercise and psychosocial impacts must be considered. The significant infrastructure that is being created to support screening programs should be used to assess innovative approaches and maximize the value of the work put into it.

In the flurry of new tests that are emerging, it should not be forgotten that the existing tests are very effective. The problem is that they are not being used.

Recommendations

Clinical Trials, Programs, and Collaborations

- Research should be built into the program from the beginning.
- Guidelines tend to focus on one specific aspect of screening, but peripheral implications must also be considered. For example, a guideline for population screening for colorectal cancer could affect the guideline for symptomatic colonoscopy.
- Research should be conducted on preventive measures such as diet and exercise.
- An information-sharing mechanism, like a website or a hotline, is needed. An organization such as the former Canadian Task Force on Preventive Health Care would have been well positioned to look at the changing evidence and keep it updated.
- National standardization would be beneficial but challenging, as health care is provincially regulated. Participants suggested evaluating the Health Canada-approved kits to determine which one has the best characteristics for population-wide application. It would be feasible

to perform a national clinical trial to test one FIT product. Van Rossum said all tests perform the same, but offer different balances between sensitivity and specificity.

- False-negatives resulting from FIT sample degradation could have a severe impact if patients who receive a negative result are less likely to continue to return for a retest after two years, as the guidelines state. Consideration should be made, as in the case of some provinces, to use a “dry kit” in the hope that it will be less resistant to fluctuations in temperature and that samples will degrade less.
- Participants suggested creating a national registry of studies that would provide meaningful information including the investigator’s name, the variables collected, and independent and dependent variables. Such a registry would facilitate resource sharing.
- Current screening infrastructure could be used to evaluate emerging technologies. Communities should identify resources and collaborative opportunities such as piggybacking onto existing studies and making use of existing infrastructure.
- The CPAC screening network is a positive step, but there are some gaps: educational resources and social marketing campaigns are not shared and should be.
- The support needed by patients’ families should be examined.
- Family doctors should be involved in the testing process, as their endorsement can increase response rates to test invitations. Return rates may be low for initial invitations, in part due to lack of information and cultural barriers, so several communication strategies should be employed to ensure that people who learn in different ways are able to absorb the material.
- Behavioural studies could help assess reasons for low response rates; once the reasons are understood, targeted approaches such as social marketing can be used to encourage participation.
- The two-year interval between screening tests may discourage involvement. Although this approach is used on the basis of cost effectiveness, it is not a good strategy if people are not being tested. Instead, a high number of tests, performed in a short period, could be more popular with patients.
- Gastroendocrinologists should be involved in assessing potential new tests to evaluate how a new test would work in a clinical setting.
- The distribution of left and right cancers and the stage distribution determined by the screening process should be analyzed.
- Participants provided several suggestions for data outcomes and validation studies including: Knowledge and evaluation of the resources involved in administering both the test and the associated colonoscopies, in terms of implementation and the reduction of morbidity
- The use of tests for risk stratification, such as Colo-Risk™, which could be used to stratify

the population by levels of risk. Unlike blood-based tests, the results will not change over time

- The collaboration between researchers and existing large-scale screening studies, such as Canadian cohort studies looking at risk etiology, to enable long-term analysis of screening tests
- An understanding and consideration of the impact of the screening test itself on patients' quality of life

Infrastructure Support

- Participants reiterated the value of using existing infrastructure and collaborating to share resources.
- Primary care physicians are the gatekeepers to screening, and they should be engaged as leaders in the process. As an example in Ontario, where only primary care physicians provide testing kits, and 13 regional primary care leads dedicate one day a week to talk to colleagues about screening.

Cancer Support Stream

Opening and Breakout Presentations

The Future of Cancer Support and Its Impact on Outcomes, and Implementing the Distress Thermometer by Reaching All Newly Diagnosed Patients

Dr. Linda Edgar
Director of Support
CCAC

Distress among patients is consistent and not linked to gender; thus, cancer care has two pillars: treatment and psychosocial care.

"Every patient should have a right to the care and support he [or she] needs; it should be accessible, low-cost, available soon after diagnosis, and followed through to survivorship,"

Dr. Linda Edgar said.

In the past, psychosocial oncology has not been recognized as a critical part of care. "'Why worry about a patient's psyche?'" Dr. Edgar said, was a common sentiment less than 20 years ago. Rigorous research, particularly that conducted by Dr. Mary Vachon and Dr. Jimmie Holland, broke that mould. Now some major cancer centres conduct screening for distress and offer good support systems, but patients still report inadequate levels of support. Although the situation has improved, much remains to be done.

A third or more of all patients are clinically distressed at diagnosis, but only major specialized cancer centres are likely to screen for distress and offer support. There is a lack of buy-in from staff, and a persistent fear that support resources are inadequate: clinicians report insufficient time and a lack of tools to screen for distress, and inadequate resources and time to provide follow-up.

Studies have found that psychosocial interventions can reduce emotional stress, improve a patient's quality of life, improve treatment efficacy, and lower medical costs.

Patients need to be assessed for distress within the first four months: "what happens by then affects survival and outcomes at one year," said Dr. Edgar. She has been involved with the distress thermometer for 10 years, and it can be a good first-stage screen. Using this tool, patients rate their distress level, and then identify the causes of that distress.

Dr. Edgar presented her vision of psychosocial care five years from now. Every patient, not only those being treated in major centres, should be screened for distress on a regular basis. Soon after diagnosis, all patients should be linked with someone who can answer questions, screen for distress, and provide first-line access.

Cancer survivors are an untapped source of knowledge and sympathy and could provide support to patients without significantly increasing costs or taxing health care system resources.

The Institute of Medicine in the United States has stated that standard care must include psychosocial care. "Survival is an outcome," Dr. Edgar said, that is "linked to positive psychological well-being."

The Princess Margaret Hospital Distress Screening and Response Program

Dr. Madeline Li
Psychiatrist
University Health Network
Princess Margaret Hospital

The rationale behind standardizing distress screening is both to increase the detection of unrecognized distress and to reduce the stigma surrounding distress, said **Dr. Madeline Li**.

The distress treatment guidelines written by the U.S. National Comprehensive Cancer Network state that all patients should be screened at each visit and that clinicians must link that screening to multidisciplinary treatment pathways.

When designing a distress screening program, said Dr. Li, the creators must consider a number of elements. Before choosing a screening tool, they must establish the program goal, as each tool meets different goals depending on variables such as length and sensitivity. Screening tools that capture all domains, including physical distress and quality of life, lack specificity and usually

require a two-step process: “they can rule out distress, but they can’t rule it in,” she said. How screening will be linked to clinical follow-up should be considered.

The Princess Margaret Hospital Foundation’s tool is the Personal Well-Being Survey along with the Edmonton Symptom Assessment System, administered with a touch screen. Patients are screened in the waiting rooms of oncology clinics at their second visit, longitudinally during treatment, and six months after treatment. Volunteers, many of whom are cancer survivors, are trained to work the front desk and administer the tool. The results are electronically scored and linked to the patients’ electronic records. The output sheet serves as the referral form.

The Distress Screening and Response Program also educates volunteers and medical staff on how to talk to patients and what appropriate actions to take when distress is identified.

Cancer Support Stream

Workshop Discussions and Recommendations

FACILITATOR

Shaniah Leduc
CancerInsight

Participants discussed the importance of psychological support and considered options for implementation. The most frequent issue raised was the under-reporting of distress.

Stigmatization presents a significant barrier to psychosocial care. Distress must be destigmatized and normalized. Different communication methods must be used to meet different needs and reach across cultural barriers.

Standards of care are needed for psychological support; everyone, from clinicians to volunteers to cancer coaches, is responsible for delivering emotional support. Coordination and communication between teams within health care and between non-profits and hospitals must be improved.

Nevertheless, participants were encouraged by the current state of cancer care. Psychosocial care is becoming widely recognized as an essential element. Participants offered a number of recommendations to keep the forward momentum; including using technology to improve the accessibility of information and resources, and using volunteers to deliver support.

Recommendations

Integrating new tools, innovations, and concepts in supportive care

E-Health Technology

- Patients should be provided with printed information and also made aware of available

online resources. Online resources could include information on issues such as chemotherapy pain or a checklist in the style of the distress thermometer.

- In clinics, a large-screen TV would display information covering such areas as myths about cancer, common questions, and coping mechanisms.
- An electronic book could be available in waiting rooms with information for patients and their families. For those patients who prefer a personal approach, volunteers could be identified in a cancer clinic with a button: “Ask me. I’ve been through cancer myself.”
- The best approach for each patient – person-to-person, over the phone, or online – must be identified. “We’re looking to new innovative approaches, but that doesn’t mean we throw away what’s already worked.”
- A multimodal screening tool could respond to such issues as language barriers, cultural sensitivity, and gender.

Psychosocial Care—Referral Process Change

- All patients need information, support, communication, and good symptom management. Ideally, a standardized approach would allow people to obtain the help they need at the right point in the cancer journey.
- Because needs vary and change over time, the process should be in place from the moment of screening. Some patients need support before they are diagnosed.
- Valid, reliable ways of identifying distress are needed. It should be explained to patients that the score on a screening test is a tool for further communication.
- Myths and misconceptions about distress and psychosocial workers need to be addressed. Sharing information through a repository would be one effective way to combat this. Health care professionals should be armed with information on the available resources, and those resources need to be easily available.
- Participants also suggested evaluating referral efficacies by providing health care providers with scripts referring patients to support services. The number of patients taking advantage of the services would indicate if referrals are more effective when they are received from certain individuals. The study could also evaluate if invitations to access support services are more effective when received anonymously.
- In addition, the study could analyze what the support service should provide to the patient: what information should be given, what assessments should be done, and how trust should be established. A checklist could be developed to determine what resources patients should be linked with. It would also be beneficial to provide feedback to the referring source about what actions were taken, what referrals were made, and what the outcomes were.

Integrated Non-Profit Organizations and their Resources

- Non-profits have a responsibility to reach out to institutions and form relationships with many people at different levels in the organization.
- Critically, non-profits need to connect with nurses. Nurses have the most direct contact with patients and are able to engage them constantly about the available resources.
- Cancer coaches need to not only know about the support resources available to patients, but also be aware of the warning signs of suicide and the actions they can take. Coaches also require support themselves, especially if one of the patients they are supporting dies.
- A marketing campaign could be targeted to those who deliver diagnoses, to convince them of the need for adequate support and information.
- New forms of handouts, resources, and information binders could be explored. Some existing information kits are overwhelming and provide so much information that the most useful elements are overshadowed. A pilot project could explore the feasibility of creating different binders to respond to different patient needs.
- Another pilot project could deliver appointments to patients receiving curative planned chemotherapy in a group model. All the patients who are due for treatment in the same week would meet with a health care professional, a cancer coach, and potentially a third facilitator. The patients would drive the care they want delivered that week and raise the issues they need addressed. Patients at different stages of treatment would learn from each other, and patients who are too shy to ask questions in one-on-one situations would still have their questions answered. This model would be cost- and time effective, and would provide the benefits of peer leadership and cancer coaching, and it would use the leverage of a group to deliver care to everyone.

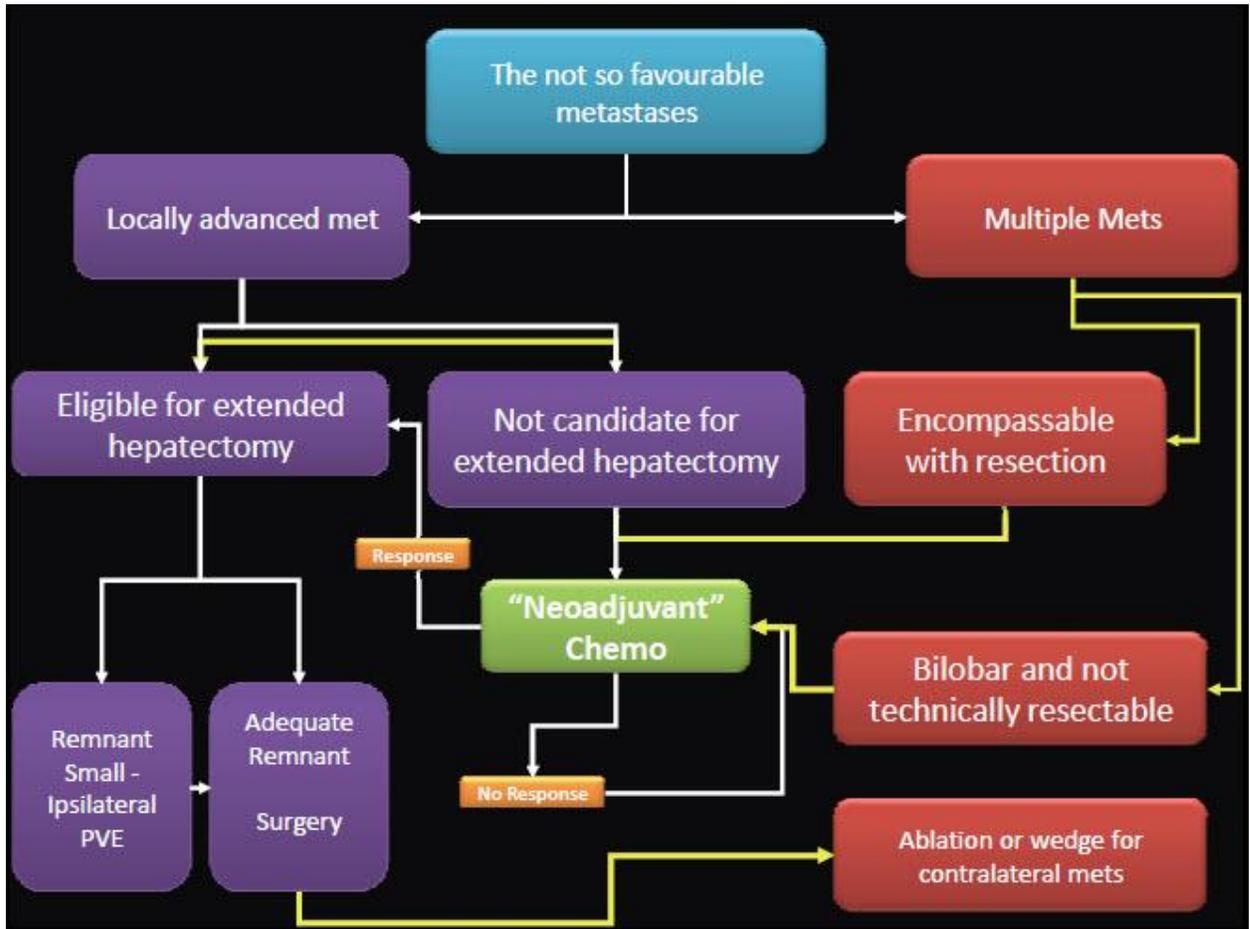
Roundtable Conclusion

Barry Stein
President
CCAC

Barry Stein thanked participants for their input over two days at the Colorectal Cancer Roundtable.

Stein said that the two-day roundtable proceedings will be published, and that document will form CCAC's plan of action for tailored treatment, screening, and cancer care. "We more than value your input – we're going to act on it as well," he said.

Appendix 1
Algorithm per Dr. Calvin Law's presentation



Appendix 2

Detailed Outcomes of Each Tailored Treatment Workshop

Workshop 1

Timely Access to and Integration of Medical Breakthroughs

FACILITATOR

Shaniah Leduc
CancerInsight

PANELLISTS:

Dr. Anthony Fields
Alberta Cancer Board

Dr. Brent Schacter
Cancer Care Manitoba

Dr. Calvin Law
Odette Cancer Centre, Ontario

Shaniah Leduc introduced the panel members who would oversee the first discussion workshop of the conference, and asked participants to “get into the meat” with recommendations from an advocacy perspective that could help launch the change that must occur. The wide range of expertise across the tables would bring in different perspectives, and areas of overlap would help identify critical points. Leduc asked the discussion groups to consider two questions:

- What are the critical success factors to enable timely access to molecular testing and targeted treatment?
- What can we do to pre-plan for future breakthroughs and innovations, such as genomics?

Discussion outcomes

Education and communication

Educating everyone involved about the importance of proper timing is critical, said a table representative. Information acquired by clinicians must be disseminated to all practitioners, and patients should be empowered with knowledge so they can become their own advocates. Participants said promoting education and public awareness is also a good way of building political pressure, particularly in the area of KRAS and other biomarker testing.

Timing standards

Establishing efficient timing systems and sample collection processes would streamline testing, said participants. Taking upfront samples that could be used for diagnosis, therapy, and biobanking would lighten the burden on patients, speed the process, and prevent needless

testing on patients who would not require treatment. For example, more work is needed on logistics, for example, to get the turnaround on KRAS testing down to an ideal 14 days.

National infrastructure

Participants said a centralized body, such as a pan-Canadian institution for biomarker development, could play a large role in developing public awareness, streamlining priorities, and creating political pressure.

Improved cooperation

Dozens of other medical fields could be holding meetings just like the Colorectal Cancer Roundtable on implementing biomarkers, said a participant. "It's a more generic problem, and we have to look at it with that view," he said. Cooperation outside of the colorectal cancer field could lead to faster development, better policy-making, and improved advocacy.

Dr. Anthony Fields agreed, adding that there is a lack of appropriate tools to make decisions in the current era, and the number of fields competing for limited funding has created immense pressure. He said that although sanctioned bodies exist for making technology assessment decisions, they have been ignored in the discussion.

Re-evaluation of cost-effectiveness models

A table representative said that the current quality-adjusted life year (QALY) guideline of \$50,000 per year of life saved needs to be reassessed. He said the figure is a 25-year-old model that comes from renal analysis, not oncology. Cost-effectiveness models must be revised to suit oncology terms and the current understanding of biomarkers.

Funding

Participants said translational research must be encouraged and accelerated. Policy makers must be better informed at much earlier development stages, to speed patients' access to new drugs. **Barry Stein** said improving this area would prevent the need to "react, rather than act." Participants said that funding should be streamlined and kept under one umbrella, to reduce competition for research dollars, prevent "cherry picking," and bring in a level of quality control.

Dr. Fields said decisions should not be made "in an ivory tower, insulated and opaque to the people who live with them." Progress was once led by scientific and professional champions, but now information is available to a much wider range of people, and there is a proliferation of tests with increasing effectiveness.

“What is the path to get them fully integrated into the system?” asked Dr. Fields. He said governments are asking, “What is the science? What is the evidence? What are the economic indications and benefits?” This is particularly true in a climate of restricted spending. People who make funding decisions must look at these questions too.

Awareness of new research

Dr. Joseph Ragaz said his table agreed that physicians and institutions must be well versed in current science and be aware of the best research and data before they give recommendations. Optimal integration of working groups and thorough evidence-based homework are prerequisites. He added that a combination of advocacy and oversight was needed to advise the professionals.

Dr. Ragaz recommended establishing a working group, based either provincially or nationally, to act as an advisor and watchdog. Existing groups could be aligned and “beefed up” to form this body. Leduc said the Canadian Partnership Against Cancer (CPAC) could help bring this idea to the national table.

Participants said that having provincial agencies follow other new scientific developments, such as the rapid advances in genomic medicine and molecular biology, was also a necessary part of a communications plan.

“It’s astounding what’s happening in genomic medicine right now,” said **Dr. Brent Schacter**. “There may be another level of control that we don’t know about.”

Electronic records and evidence collection

Medical databases would increase efficiencies, and could help increase funding by facilitating evidence collection. Participants cited a need for population-based application of new approaches, including the electrification of patient management linked to the data around biomarkers. The collection and promotion of evidence were critically important, both for translational purposes and for funding.

“Money follows measurement,” said **Ronald Burkes**. Governments will ask, “Should we spend money on a new transit line, or save X amount of people by using drug Y with a biomarker attached?”

Biobanking networks

Participants said that tissue collection is critical for continued evolution of treatment. “It’s mind-boggling that we don’t collect this data every time we take a tumour out of a person,” said Dr. Law. “Somewhere in that specimen is a secret.” Funding for bionetworks could build the evidence to help speed biomarkers into clinical trials.

Ethical concerns

A participant said her pathology department had concerns over the ethical implications of widespread MSI testing, and over the need to bring patients back for genetic testing after therapeutic testing. Dr. Fields thanked her for raising the issue, and said that questions on ethical clarity need to be kept in the discussion.

Recommendations from Workshop 1

- Involve funders and policy makers early on in planning for anticipated medical breakthroughs.
- Create bodies or mechanisms for quality control and for assessment of breakthroughs.
- Create a provincial or national working group to assess new tests and advise on new integration pathways.
- Utilize bionetworks.
- Streamline surgical sampling so that upfront collection can serve multiple uses in clinical pathology and biobanking.
- Ensure that tests are done at the appropriate time, with consideration to clinical options, trials, and logistics.
- Accelerate translational research and testing to keep pace with scientific advancement.
- Include genomic teams in cancer centers, to connect, in both directions, clinical medicine and fast-evolving scientific developments.
- Employ pharmacoeconomics and statistics experts at the local level to interpret data on new tests and treatments.
- Work with provincial health ministries to ensure policy and testing methods are up-to-date.
- Re-evaluate the current QALY threshold of \$50,000, to ensure it is appropriate for current and future colorectal cancer care.
- Utilize web-based educational programs.
- Improve publicity and education efforts toward government and the public, to build awareness and support for translational research platforms.

Workshop 2

Integrating Multidisciplinary Team Management

FACILITATOR

Shaniah Leduc
CancerInsight

PANELLISTS:

Dr. Anthony Fields
Alberta Cancer Board

Dr. Brent Schacter
Cancer Care Manitoba

Dr. Calvin Law
Odette Cancer Centre, Ontario

Leduc referred participants to the presentation given by Dr. Law on multidisciplinary teams and asked the discussion groups to consider the following questions:

- What is your feedback on multidisciplinary team management, and your recommendations for integrating this evolving approach?
- What is the role of academic centers and community centers? Can technology help?

Discussion outcomes

Individualization of care

The opportunity for a patient to meet with and ask questions of members of the entire treatment team is a great benefit of multidisciplinary tumour boards.

“It’s like getting a second and third opinion all at once,” said a participant. Another said that in addition to the patient hearing several opinions; there is value for the patient in the debate over their treatment being transparent.

In cases where team members are at different sites, videoconferencing technology can be used to allow a big-picture discussion and efficiently plan a course of action. Communication within the tumour board and with the patient allows for a more refined and individualized treatment, particularly for unique cases. **Dr. Scott Berry** listed several examples of complicated cases where team discussions resulted in specialized treatment plans with successful outcomes.

Education and career growth

Tumour boards could play a significant role in education and research. The board could be responsible for recruiting students and finding research candidates. Several discussion groups proposed establishing recognitions systems, and being able to earn continuing medical education (CME) credits through the tumour board.

Community rewards

Dr. Berry said that even if providers such as radiologists are not paid for the team consultations, the non-financial rewards are huge. Participants listed alternative benefits such as prevention of complications, education, relationship building, and improved sense of community. A participant said the team approach not only saves time in the long run for both the physician and the patient, but also creates more opportunities to seek funding.

Practice models

The ideal tumour board would include clinical specialists and pathologists, and accommodation for pathology review. Clearly stated expectations and accountability should be included in the practice model. Participants proposed establishing standardized care maps that include technology elements. A participant with experience using mobile magnetic resonance imaging (MRI) and positron emission tomography (PET) scanning suggested these and other mobile technologies could help smaller centres conform to the care maps used by larger ones.

Dr. Schacter asked all attendees to send on examples of tumour boards they consider effective, so they can be included in an examination of ideal models that CPAC is conducting.

Electronic records and databases

Electronic medical records housed in databases would support team efforts by allowing all members to add notes to a case, even if they have no direct contact with the patient. Electronic systems must have standardized and up-to-date technology, with the ability to read and transfer films and to teleconference nationally or locally with other specialists.

A participant described a Quebec system that requires tumour boards to produce formal letters for their recommendations, which are then added to a database. Another participant suggested a system in which patients hold copies of their own records, to improve efficiencies when they move or change doctors.

Workload and compensation structures

Several participants noted difficulties in getting acceptance for tumour boards, despite the rewards. "You have to get them to the water before you can persuade them to drink," said a participant. Multidisciplinary rounds can be time-consuming, meaning providers may only be able to see a few patients. This could lead to large patient backlogs, as well as insufficient compensation. A participant said his centre was moving to salaries to compensate for the loss of fees and to prevent the need to "push patients through the system."

The need for more space should also be considered, and time-saving measures such as providing lunch to team members would balance the extra time needed for team discussions.

“Low-level” changes like holding meetings in more convenient settings can also add up to significant time savings.

“We have to resolve the issues around billing, time, and resources so we can get these teams going,” said a participant. Another participant suggested including low participation figures in reports, to create a “negative incentive” that may encourage action from administrators.

Staffing

Several participants recommended expanding teams to involve a wider range of practitioners, such as dietitians. Hiring clerical staff to support the physicians and practitioners with bookings, time management, and paperwork is “an obvious enabler,” said a participant. A discussion group representative noted that recruiting a wide enough range of practitioners could be problematic.

Community centre outreach

Inviting community centres to participate in tumour boards is important. Participants said that while including some centres was necessary, it would be too difficult to coordinate with all of them. Site-specific “navigators” who can help with community outreach would be a benefit. Tumour boards should have systems for disseminating research, so the progress of community centres and academic centres can be uniform. Videoconferencing, tele-health, and other communication technologies are crucial tools for communicating with regional centres, and so governments should fund these tools.

Decisions on inoperability

A participant noted that patients who were not resectable through their first round of chemotherapy would be unlikely to be resectable afterward. “Someone has to say to the patient, ‘We can’t operate.’ At what point does this happen?” he asked. Dr. Law agreed that it can be easier to recommend further chemotherapy than have that discussion. But by meeting and talking as a group, the board can hold these arguments and decide the course of action.

“Once the alternatives have been tried, then they can tell the patient no,” he said. Dr. Berry said it can be easier to sit with your colleagues and make decisions, but “someone has to walk out of the room and tell the patient treatment will no longer be curative.” In each board, someone must take responsibility for that.

Dr. Law added that there was a “flip side,” in which a difficult and costly plan of treatment could potentially work but the patient does not think they have the endurance for it. “Surgeons are often not trained for these difficult conversations.”

Champions for multidisciplinary systems

An influential champion from each discipline is needed to get the buy-in on tumour boards from the larger medical community. “If the nurses, for example, see someone influential joining in, then the whole team will go,” said a participant. Having an entertaining speaker disseminate information on tumour boards could also increase participation.

Recommendations from Workshop 2

- Adopt multidisciplinary teams as a best practice, and make them a standard approach for colorectal cancer care.
- Increase awareness of the benefits of tumour boards for both clinicians and patients.
- Institute systems and policies that will facilitate the change required. Example enablers are as follows:
 - CME credit for attending tumour boards
 - Hospital accreditation bonuses
 - Billing codes for patient review to prevent lost income
 - Full-time dedicated administrative assistance
 - Provision of lunch to tumour board members
- Invite community clinicians onto tumour boards.
- Improve external and internal communication with electronic medical records, video- and teleconferencing, and improved image transfer technology.
- Evaluate and research tumour board approaches to creating a standardized care map.

Workshop 3

Future Advancements and Patient Care Paths

FACILITATOR

Dayle Acorn
Executive Director
Canadian Foundation for Pharmacy

PANELLISTS:

Dr. Scott Berry
Cancer Care Ontario

Dr. Hagen Kennecke
BC Cancer Agency

Dayle Acorn explained that the focus of the second day of workshops was on the ethics surrounding the care of cancer patients and the funding of cancer care development. For the third workshop of the Tailored Treatment stream, he asked participants to consider both the

talks they had heard so far on current and future science breakthroughs and the plenary presentation from the Cancer Support stream before discussing two sets of questions.

For the first part of Workshop 3, participants were asked to create a “wish list” relating to two questions:

- What approaches and advancements do you envision for improving care?
- Where do you see these innovations fitting in the care path of a patient?

For the second part of Workshop 3, participants discussed two further questions:

- What are the critical success factors for paving the way forward?
- What are your recommendations on building the infrastructure required for implementing these approaches?

Discussion outcomes, Part 1

Individualized care

“What stood out as the main issue for us is that individualized medicine should become the gold standard,” said **Natalie Savoie**, presenting for her discussion group. Several tables agreed that work needs to be done in streamlining priorities, to make room for these advanced treatment methods and to allow physicians to prescribe treatments in the manner that they consider is needed for their patients.

Funding

Participants said funding needs to be made available before any work can begin on defining appropriate national policies. Therefore, a “buy-in” is needed on the consensus, on both the provincial and the national level.

Specific areas that need to be better funded and made more available include biomarker testing and tissue assays, therapy trials and research infrastructure, and research for tumour tissue banking.

Other participants said it might be necessary to be open to considering flexible funding systems. Greater use of partnerships between the private and public sectors might be required to give patients access to the increasingly complex products on the market. A participant said that while allowing private care is a controversial idea, the “creeping in” of private elements into funding plans could help offset the stress on the public system.

A table representative said her group would like to see funding for treatment and diagnosis come from the same source. “Keeping them in different pots can make treatment impossible,” she said.

National infrastructure

A table representative said that while the integration of targeted therapies, surgeries, and psychosocial support is necessary to promote individualized care, these innovations “must be built on a backbone of consistent management policy, created on a national level.” There are currently no national mechanisms to form these policies, though some provinces do have local processes.

Another participant said that provincial cancer agencies have varying success at defining management policies. Work needs to be done to bring them in line, as well as to strengthen the national body that coordinates them. National consensus is needed.

Other issues concerning oversight and policy-making that participants raised included a need for transparency in the decision process for approving treatments for reimbursement, and a need for consistent national guidelines and policies that are frequently reviewed and that reflect current systems. Many participants thought that a more formalized body should be created, with the role of assessing new technologies, drugs, and diagnostic products.

Multidisciplinary teams

Dr. Kennecke referred to the earlier discussion on interdisciplinary tumour boards and said that they were just as important to the discussion on improving care. Psychosocial support elements should be included in the team makeup.

Screening

Wider use of screening and surveillance is an important step in improving care.

“The infrastructure is outdated,” said a table representative. “It needs to be changed to allow for current surveillance methods.”

Trials and evidence collection

Participants said the clinical trial program must be changed to improve recruitment and refine patient selection. More focus is needed on early detection and treatment.

A table representative said his group would like to see biomarker testing incorporated into the trial system, to prevent the need for retrospective work later on.

A robust evidence collection bank network is another critical element for improving care. Participants said banks could be based within each province and integrated nationally. “Cost is always an issue,” said a participant. “You can’t convince any level of government that they need to spend more money without an evidence base. Canada should be doing better at this.”

Patient support systems

Participants expressed strong support for the themes presented by the opening speaker in the Cancer Support stream. The patient perspective needs to be considered, and more work is needed in the area of patient support. Table representatives reported recommendations from their groups on offering improved access to information; help with understanding it, and assistance with navigating an increasingly complicated range of care pathways.

Capitalizing better on the potential of the Internet by creating web-based tools for disseminating information could be a part of the solution. A participant named the CCAC as an example of an organization that is vital for patient support. It and organizations like it will likely play a large role in the development of improved information and support delivery systems.

A table representative said that circulating tumour cells among departments could also ease the burden on patients by preventing the need for additional biopsies.

Ethical and legal considerations

While tissue banking is important, issues will likely arise in regard to genetics-related ethical questions and confidentiality, said a table representative. The legal considerations of these questions need to be discussed.

Discussion outcomes, Part 2

Acorn thanked participants for their comments and introduced the second set of discussion questions on critical success factors and recommended infrastructure development for improving care.

Acorn noted that the first part of the discussion on future advancements and patient care paths clearly indicated that participants thought the opportunities arising from new developments cannot be examined without also considering the barriers.

"I'm hearing a lot of 'This would be great, but . . .,'" he said. He suggested participants use this part of the discussion to address these barriers and to examine possible solutions.

Funding

The majority of workshop tables listed access to funding as a critical factor. Dr. Berry asked Barry Stein from the CCAC if the federal government listened to advocacy groups like his on issues about funding and resources. Stein responded that it is "a painful process," and that the model—in which funds are issued at the federal level but distributed provincially—is restrictive.

However, he said, the CCAC has seen amazing success after much hard work lobbying the federal health minister for improved screening. After listening to the association's arguments, the health minister agreed that screening should be made a priority in the Canadian strategy for cancer control, and a network was launched.

"Now virtually every province is a member," said Stein. "But that was totally unpredictable that we would find that support at that moment."

Stein said that a national colorectal cancer strategy will require "staggering" funds, and the provinces are going to "give the push back." As the federal government could invest in the strategy through many avenues, the advocacy efforts must be put toward making the federal level assume the role.

Another participant raised the issue of current evaluation systems, and said they must be re-examined. "Evaluating the economic benefits of saving a person is not enough," he said. "The moral benefit also needs to be taken into account." Awareness should be built around this issue and worked into funding arguments.

Measurement, research, and review

"We need outcomes measurement and translational research. We need them both, and they must be constantly driving each other," said **Dr. Stephan Larsson**, representing his workshop table. Dr. Kennecke said that his table agreed the review process must be accelerated so that patients can benefit sooner from innovative treatments.

National systems

An accreditation system, built on a national, professional level, needs to be formed to provide standards and feedback and to inform policy-making.

"The CCAC is a fine, powerful, important advocacy group, but that's not what we're talking about," said a table representative. "We need a professional body that will engage with national and provincial governments." The CCAC would in turn benefit from the support of such an agency.

Several workshop groups stated the need for a national body to assess new technologies and drugs, and agreed that the body must be well funded and empowered to make decisions. Dr. Berry said that his table thought the national body should also be tasked with lobbying for resources.

A participant said that other professional infrastructures could provide guidance in forming a national colorectal cancer agency. "Many disease areas have national bodies," she said. These

bodies can be examined and evaluated for best practices, to form a model for an effective lobbying, evaluation, and accreditation system.

Another participant said a national model would be ideal, but if it cannot be formed, then communications between the provinces must be improved.

Other participants noted the benefits of the BC Cancer Registry to care in its province, and said such a registry should be established nationally.

Lifestyle changes and other alternative recovery methods

Dr. Berry referred to an ongoing trial examining the effects of exercise on post-surgery colorectal cancer patients. “The hazard ratio reductions with exercise after resection are amazing,” he said. “We need to think outside the box to find other low-cost innovations and lifestyle interventions.”

Recommendations from Workshop 3

- Advance individualized assessment and treatment for patients. This recommendation will require the following infrastructure:
 - Funding, research, and resources for biomarker testing
 - Formalized assessment for molecular diagnostics
 - Improved patient selection and risk stratification in both the adjuvant and the metastatic setting
- Offer better patient support structures—including broader outreach, help with system navigation, and psychosocial support.
- Advance tissue banking by resolving privacy issues and building the infrastructure necessary to support translational research.
- Consider continued research into circulating tumour cells as a method of avoiding repeated biopsies.
- Re-evaluate and adapt current infrastructure to streamline priorities and prepare for innovation.
- Improve screening and surveillance.
- Include lifestyle and exercise effects in clinical trials, and consider other innovative ways to fight the incidence of disease.
- Test agents active in metastatic disease in adjuvant settings.
- Create national management policies for appropriate funding.
- Coordinate the efforts for all of the above recommendations through the support of a

national professional body endowed with appropriate resources for overseeing the following areas:

- Outcome measurements
- Translational research
- Accreditation and standards

Workshop 4

Managing Reimbursement Barriers to Integrate Tailored Treatment into Cancer Care

FACILITATOR

Dayle Acorn
Executive Director
Canadian Foundation for Pharmacy

PANELLISTS:

Dr. Scott Berry
Cancer Care Ontario

Dr. Hagen Kennecke
BC Cancer Agency

Dan Rego
DrugCoverage.ca

Dayle Acorn said the purpose of the final discussion workshop was to find ways to integrate tailored treatment into cancer care. He asked participants to consider what they had heard during Dan Rego's presentation on treatment reimbursement policy as they discussed the following question:

- Taking recent advancements plus future innovations into consideration, what are the critical success factors and recommendations to manage reimbursement barriers?

Acorn asked participants to address several points as they brainstormed with their workshop groups, but not to restrict their discussion to those points or guidelines:

- Who should pay – governments, employers, patients, the pharmaceutical industry – and what should they cover – testing, medication, infusions?
 - When should they pay for it?
 - How can we make it affordable?
 - What can we do now to ensure adequate future reimbursement?

Discussion outcomes

Advocacy efforts

Dan Rego noted that breast cancer groups have been very successful in getting public support, exerting political pressure, and gaining access to new medications like Herceptin. Another participant referred to Rego's presentation point on civil servants having access to drugs that are denied to the general public, and said that this would make a strong argument to funders. Participants agreed that policy makers do not understand colorectal cancer and its treatment. "They see a drug that will only give you a few months of survival, so they don't think it's important," said a table representative. She recommended sending advocacy groups to meet with policy makers and show them how a few months can lead to a few more months, which can lead to years.

Participants recommended increasing efforts to improve education around lifestyle and to build awareness of colorectal cancer screening. "Investing in better health education and screening to prevent some of these downstream costs is a good argument in tough economic times," said a participant.

A table representative said her group would like to see pressure on the federal government to re-evaluate the *Canada Health Act*.

"The Act is really putting people in a no man's land," she said.

National funding strategy

"Siloed" funding makes it difficult to advocate change and enact efficient policies. "Drug budgets are not looking at the hospital budget, which is not looking at the research budget, and so on," said Rego. A participant said that creating a measure of legitimacy to compare the different silos could allow funding to be moved across silos. Another participant said that funding silos across different agencies in each province—and in some cases, across each hospital within a province—creates inconsistencies regarding which take-home drugs are covered.

Dr. Berry said that the lack of agreement about what drugs are considered affordable in terms of their medical value further confuses the issue. "All of these drugs are funded in some places, but not others," he said. "None are considered so outrageously expensive and valueless that no one will pay for them." Dr. Berry said that in Ontario, the current criteria mean that if a drug is not funded it is therefore, by law, considered not medically necessary. "It's a good legal argument, but not a good medical one," he said.

Another participant said the current structure makes it too difficult for funders to investigate each individual agent, its costs, and its capacity to extend life, particularly when they are

weighing all those factors against other priorities. There is also a degree of rigour applied to cost-benefit analysis with cancer drugs that is not applied in other medical areas.

Participants agreed that consensus is needed, along with a national Pharmacare strategy that looks at the larger picture and has a consistent plan for funding cancer drugs, whether they are oral, subcutaneous, or intravenous. Dr. Berry added that his table thought the body responsible for these decisions must act in a timely and transparent manner, its policies must be portable and universal, and the provinces must be bound to its decisions.

Participants also discussed funding strategies for biomarkers. Dr. Ragaz recommended setting up a fund for the development of new biomarkers and for existing biomarkers that show proven benefit. Funding decisions can then be made within that pool of money.

Opportunities and concerns with private funding

Dr. Berry said health economic calculations needed to improve if they are to be a part of decision-making.

“There is good literature to suggest that pharma-sponsored health economic evaluations tend to come in under the perceived threshold, and those done independently come in above it,” he said. “It’s still an evolving field, and it needs to be done better.”

A table representative said that his group saw an opportunity to find treatment coverage by working to have patients qualify for catastrophic drug coverage. Rego also described a Quebec policy in which employers are required to offer a drug plan with coverage at least as good as the government plan. A similar policy could be instituted in other provinces.

Dr. Berry expressed dismay that private insurance had to be considered for treatments that are recognized as standard care. “How did Canada get to this position without people rioting in the streets?” he asked. Rego responded that part of the problem is that there has yet to be formal debate and consensus on the definition of standard care, so in the context of health care budgets, funders do not consider these drugs medically necessary. “Twenty years ago, there were few take-home cancer drugs, so we developed this system for funding in-hospital care. So that’s how the system is now, despite newer developments in outpatient care,” he said.

Interim measures

Acorn asked participants what measures could be taken in the immediate term, given that the national strategy they recommend will likely take a long time to come to fruition. A participant said that there had been previous movements to form a national mechanism, but they had “gone moribund.” He recommended pooling existing advocacy groups to reinvigorate the effort. “We have too fractured an approach,” he said. “Maybe it needs a new voice.”

Dr. Berry said he considered that an excellent idea. “We didn’t have trouble setting the priorities in our discussions; we had trouble figuring out how to get there from here. Advocacy groups are the way to do it,” he said. People who are adept at the political process are needed to build pressure behind colorectal cancer priorities and make them a reality.

Recommendations from Workshop 4

- Educate decision makers so that they understand the value of a few months more of life and its potential to bridge patients to the next emerging therapy.
- Initiate a debate at the federal level, involving the *Canada Health Act*, to create a definition for “medically necessary” treatment.
- Advocate coverage for new medications. Include the argument that federal civil servants have access to these drugs, so other Canadians should as well.
- Create a larger lobbying presence through a consolidated advocacy group, increased pressure, and better use of the political process.
- Examine the potential for manufacturers and payers to form cost-share frameworks for biomarker testing.
- Create a fund for biomarker development and new biomarker research.
- Form a national body for reimbursement decisions that are timely, transparent, and most important, binding.
- Resurrect efforts to create a national Pharmacare strategy to reduce interprovincial discrepancies.

Appendix 3

Discussion Outcomes of Screening Stream Workshop

During the workshop, participants answered a series of questions:

What are your recommendations for data outcomes and validation studies in colorectal cancer screening research?

Any novel test must have strong characteristics: it must be highly accurate, with good specificity and sensitivity, and the false-negative rate must be known. Overall validation of the effectiveness of a new test would be a decrease in cancer mortality.

In designing new tests, researchers must keep in mind the age bracket of the population involved, the variations of urban and rural settings, and the extreme weather in some parts of Canada. The test must be designed to be usable all over the country. The Canadian Partnership

Against Cancer (CPAC) has made significant progress toward creating a common data set, as well as toward producing guidelines for screening. There must be uptake among providers and patients. To facilitate uptake, the ideal test would be accessible, easy to use, inexpensive, and easy to report, with minimal laboratory error. Compliance rates are critical and need to be assessed for any new test.

Asked about the criteria that would be applied to select a novel test for study in a large population-based study, Van Rossum said the choice of test depends on the aim of the test. For instance, the genome project would be suited for a triage model, wherein the test would be performed first and then follow-up would be conducted according to risk level.

In a comparison of the different risk stratification tests, Van Rossum said, the cost of the test must be compared with the test's effect on the number of colonoscopies that are performed.

Van Rossum echoed the importance of standard test criteria, including compliance, sensitivity, and cost. He added that genome tests could affect patients' well-being: patients could feel guilty for having a genetic disorder.

Participants discussed novel test criteria in light of existing tests, making a number of key points.

- Good patient uptake is a critical aspect of a novel test.
- Although existing screening tests are reasonably effective, they are not being used extensively (e.g. FOBT); this is in contrast to breast cancer screening, which is widely implemented but is less effective.
- The choice of tests and strategies has been "arbitrary" and based on different criteria in each province. Only three provinces currently use FIT, and only two or three kits are approved by Health Canada. It is difficult to compare the widely varying programs that have resulted, but it would be valuable to learn as much as possible about these options.
- Novel tests should not be selected in isolation but should be compared with and complement—or be clearly superior—to the best existing tests. The screening test is only a part of the tool kit used for treatment—a tool kit that varies depending on the specific treatment goal.
- The critical element is not what people want, but what will induce them to act. Focus group testing has identified those aged 45–60 as most likely to come in for screening. Focus groups also identified that colorectal cancer is perceived as a male disease, and that most people are unaware there are no early warning symptoms. This underscores the need for education from an early age about the need to begin screening at age 50.

Dr. Hilsden asked, "Do we need a test that replaces colonoscopy or the FIT screening?" Unnecessarily searching for or evaluating alternatives can waste resources. Other elements of

the treatment tool kit could be explored. For instance, colonoscopies would be used “exponentially” more frequently if a better preparation method were developed.

Screening should not be seen in isolation from prevention. As exercise and diet can reduce colorectal cancer incidence, lifestyle behaviours could be tied in to the testing process so that patients would see testing as part of a holistic, healthy process.

Policy makers in provincial health ministries want certain key questions answered when they are presented with a potential new program:

- Is there strong scientific evidence that the suggested program will reduce mortality?
- Is there strong evidence that there will be uptake in the population?
- Is it cost-effective?

To patients, a blood test is more reassuring. But regardless of the test, a good bedside manner and candid conversation can help to make any test understandable to the patients, which is key to reducing their stress.

Appendix 4

Discussion Outcomes of Cancer Support Stream Workshop

During the workshop, participants responded to a number of questions:

“Where are we at today in supportive care referrals and program access, and why are we in this position?”

What are all the possibilities for supportive care access and programs for the future?

Cancer care is currently better than ever before; there are more support organizations and more information is available, and there is an awareness of the need for integrated psychosocial care and a person-centred approach.

But there is still a lack of coordination and communication. In the current system, there is no standard for how patients are informed about their diagnosis, what information they are provided with and how, and what resources they are connected with. Patients who rely on the Internet for information about their diagnosis can be overloaded with information: they have no way to judge or evaluate the information they find, and they are frustrated at having to seek out their own information.

Internet resources should be used to extend the reach of colorectal cancer support programs. Although some good support materials are available online, there are associated problems. Chat rooms could be moderated to prevent misinformation, but that is a huge task. Distressed

patients often do not know how to find online resources; some may not have access to the Internet at all.

- Sometimes care providers give new patients too much information, without any accompanying guidance. Information must be provided in a segmented, stepwise approach, to avoid “bombarding” patients.
- There is no broad understanding of whose job it is to communicate with patients about their diagnosis. Participants strongly supported the involvement of the entire medical team. To facilitate a holistic approach to cancer care, all members of the team—oncologists, social workers, and dietitians—should be located in the same physical space.
- Rather than conceptualizing two separate pillars of cancer care, the approach should be united, comprehensive, and patient-centered.
- Communications must be offered in different forms for different people. Some people like face-to-face communication, and other people would prefer to read written information. In some centers, patients have the initial diagnosis conversation recorded so that they can review it at a later time.
- Patients need individualized support, and cultural diversity must be respected and acknowledged.
- Support organizations are under-recognized, undervalued, and under-communicated to patients.
- The Canadian Council on Health Services Accreditation has recognized the importance of distress screening. Standards now include an embedded expectation that psychosocial distress is identified. Edgar said that the inclusion of distress screening in accreditation guidelines will not result in implementation unless patients are informed that it is part of cancer care.
- Participants agreed that the numbers of distressed patients are under-reported. Gender, religious, and cultural barriers prevent patients from self-reporting. Efforts must be made to raise awareness, and distress must be normalized.
- Some provinces have implemented a patient navigator system, in which a navigator nurse supports people with psychosocial distress. Navigators from various cultures can combine their personal experiences and the volunteer training to provide support in a culturally sensitive way. They could also help to overcome physical barriers such as travelling from one medical site to another. Evidence is needed to assess how well such systems are working.
- Lessons should be learned from the pediatric cancer model, which works effectively and collaboratively. Although it is widely acknowledged that children require distress screening, it is less well-known that adults also require that support.

- Participants urged better collaboration between non-profit organizations and cancer centers. Patients are most visible to those in hospitals and clinics during the acute treatment phase, but patients need support before and after that period. Non-profits should also be involved with the educational system.
- Early in the process, patients would benefit from being told that cancer and its treatment will have an impact beyond the physical.
- Participants also suggested a group discussion approach. A patient group could be formed to discuss such issues as how to maintain a good diet on a low budget and how to find time to exercise. Getting families involved through online diet and exercise planning programs could be another way of motivating patients.
- Many organizations are developing websites with a variety of approaches. One participant suggested posting a yoga routine online for people to use at home.
- Medical staff is slow to buy in to screening tools; they believe they can assess the patient accurately. But often more is revealed in a paper assessment than in a face-to-face interview. Patients can be connected immediately with onsite resources including Aboriginal navigators, social workers, and nutritionists.
- Physicians must be taught how to follow through after distress screening, and to understand that screening is a “hook” to engage patients in a conversation about what is important to them. Myths of the additional workload that will be created if distress is identified need to be dispelled. Identifying distress actually streamlines care and can be preventive.
- The nature of supportive care, including whether a volunteer, a professional, or a peer delivers it, should vary over time.
- Although many patients are unwilling to talk when support is first offered, often they want to access that support later on. Having the support offered initially is critical for enabling them to access support services once they are ready. They need to know that resources are available.
- Roles and responsibilities must be clearly defined, and patients should be involved as partners in the dialogue about the referral process. Better use should be made of decision aids, to help patients understand “the path ahead and how they can be guided along that pathway,” a participant said.
- Participants suggested creating a wallet-sized card with a simple message: “You’ve just been diagnosed. What do you do? Start with us.” The person delivering the diagnosis could provide this card to patients. This program should be branded so that when patients go to the website or call the phone number, they can easily follow the prompts for the “you’ve just been diagnosed” services.

- Lessons learned in the major cancer centers are not necessarily resurfacing in smaller communities.
- Patients should be seen as members of the team. The roles of various team members, as well as potential events and the ensuing activities, should be clearly communicated to the patient.
- Clinicians should be provided with summaries of psychosocial oncology research to help elicit buy-in from professionals. A participant said that there is significant research into what patients need, how their needs unfold over time, and what interventions are valuable and effective.
- Ontario is adopting the U.S. Institute of Medicine guidelines, which recommend developing a repository of information and a standard of care.