The more things change, the more they stay the same

...and so it is with cancer control in Canada. We have made significant steps forward in innovative new treatments and advanced diagnostic tools and research, yet we fail to adopt this knowledge.

Leadership is emerging under the banner of the Canadian Partnership Against Cancer, even under the Joint Oncology Drug Review, to rethink old problems. But the baggage of institutional, jurisdictional and fiscal self-interest has overwhelmed such attempts in the past. Meanwhile the needs grow in size and number: for more relevant research; much better planning for and utilization of health human resources; improved access to innovative treatment and diagnostic tests, multi-payer cooperation to protect vulnerable patients from the cost of their cancer drugs; and seamless, comprehensive supportive care.

Benjamin Franklin once said, “the definition of insanity is doing the same thing over and over and expecting different results.” Continuing to apply the same policies and attitudes toward cancer control will produce the same outcomes. The current environment is ripe with opportunity; it would be disgraceful to fail.
Special thanks to many organizations for their help in defining and researching cancer priorities for this publication: Advocacy Solutions, Best Medicines Coalition, Brogan Inc., Canada’s Association for the 50 Plus, Canadian Association of Provincial Cancer Agencies, Canadian Association of Nurses in Oncology, Canadian Breast Cancer Foundation, Canadian Breast Cancer Network, Canadian Breast Cancer Research Alliance, Canadian Cancer Action Network, Canadian Cancer Society, Canadian Hospice Palliative Care Association, Canadian Partnership Against Cancer, Canadian Prostate Cancer Network, Colorectal Cancer Association of Canada, Colorectal Cancer Resource and Action Network, Kidney Cancer Canada, Lung Cancer Canada, National Cancer Institute of Canada, Ontario Institute for Cancer Research, Royal College of Physicians and Surgeons of Canada, Wellington’s World Health Advocacy, Wyatt Health Management, cancer agencies and government officials across the country and individuals in many other cancer groups. Your advice and cooperation are greatly appreciated.

BOARD OF DIRECTORS
Jack Christley BA, MD, MSc, FRCP, is one of the founding members of the CACC. He practiced Internal Medicine and Medical Oncology for 25 years in the Interior of British Columbia before joining the BC Cancer Agency as a Vice President leading the provincial Communities Oncology Network.

James L. Connors, Q.C., is a graduate of Memorial University of Newfoundland and the University of British Columbia and is Vice President, Regulatory Affairs of Emera Inc, an energy company headquartered in Halifax. In May 2006 he was diagnosed with metastatic colon cancer leading to surgery and chemotherapy.

Dauna Crooks RN, DNSc, is currently the Dean of the Faculty of Nursing, University of Manitoba as well as an Associate Professor at both the University of Toronto and McMaster University. Dauna is also a member of seven professional organizations and has numerous grants and publications.

Geoff Eaton a graduate of Memorial University of Newfoundland’s business faculty, is a two-time cancer survivor, professional speaker and founder of RealTime Cancer. He lives in St. John’s, NL with his wife Karen and daughter Adia.

Douglas Emerson has spent the last decade working in communications, public affairs and government relations. He lost his father to cancer in 2005.

James Gowing (Chair) BA, MB, BS, FRCP, founded the community cancer clinic in Cambridge, ON and established the National Conference on Community Cancer Clinics. He has been an advocate for community cancer care and cancer control throughout his 40-year medical career.

William Hrynkiw (Past Chair) MD, FRCP, has practiced in Canada and the US as a medical oncologist, taught at medical schools, developed and directed major cancer centres and regional cancer control programs. He remains active in basic and clinical research and is currently Medical Director of CAREpath Inc.

Linda Jaibert is a breast cancer survivor and hotel industry consultant, now living in Toronto. She has been an active advocate on behalf of cancer patients and survivors with a special interest in services that meet the emotional needs of breast cancer patients and their families.

Darwin Kealey (Vice Chair) BA, MA, is a former executive public servant and international entrepreneur with extensive advocacy experience.

Kong Khoo (Vice Chair) MD, FRCP, is a medical oncologist based in the Southern Interior of British Columbia in Kelowna.

Eric MacEwen is a recent cancer survivor and is also a founding director of the East Coast Music Awards and has been a singular voice for the music of Canada's East Coast through his weekly syndicated radio program.

Robert Pearcey MA, MBBS, FRCP, is a practicing academic Radiation Oncologist and Professor of Oncology in Edmonton. He also has 14 years of previous administrative experience in Radiation Oncology and is the current chair of the specialty committee in Radiation Oncology for the Royal College of Physicians of Canada.

Joseph Ragaz MD, FRCP, is a Clinical Professor, Medicine & Oncology, McGill University, Montreal, Quebec. He is an outgoing Director, Oncology Program, McGill University Health Centre (2003–2007); prior to this, he spent 27 years as a senior Medical Oncologist and an Internationally recognized Breast Cancer Researcher at the BC Cancer Agency, Vancouver, British Columbia (1977–2003).

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Jack Shapiro Order of Canada, is presently the Co-chair of the Canadian Cancer Action Network and Board Member for the Canadian Cancer Research Alliance.

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Colleen Savage is a public affairs and communications consultant serving as President & CEO for the CACC.

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The opinions expressed in the Report Card are those of the individual authors of individual articles and material. Their views do not necessarily reflect the views of CACC.

WARNING: CACC’s Report Card should not be used for the purpose of self diagnosis, self treatment or as an alternative to medical care. If you have any concerns arising out of the information contained in CACC’s Report Card, you should consult your own physician or medical advisor. If you suspect you have cancer, seek professional treatment immediately.

About the Cancer Advocacy Coalition of Canada

The CACC is Canada’s only full-time, registered, non-profit cancer group dedicated exclusively to advocacy. The CACC is not a charity and operates on unrestricted grants from sponsors based on guidelines that ensure the organization’s autonomy. The CACC publishes Canada’s only independent evaluation of cancer system performance, the annual Report Card on Cancer in Canada. The Board of Directors is comprised of unpaid volunteer oncologists, health sector executives and patient advocates from across the country.

Our Vision for the Cancer System

An effective, comprehensive, evidence-based cancer system that offers Canadians the best chances for preventing and treating this disease, and addresses the emotional, physical and financial needs of patients and survivors.

Our Goals: to benefit cancer survivors and all Canadians

• Consistent adherence to best practices in cancer care and prevention, making best use of financial and human resources
• Accountability to patients, survivors and taxpayers
• Transparency of decision-making, priority-setting and performance measurement
• Reduction of the emotional, physical and financial distress associated with a cancer diagnosis
• Access to best practices in disease prevention and timely, effective treatment options
• Increased awareness of prevention choices
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EDITORIAL

As usual, this was an eventful year. The Canadian Partnership Against Cancer (CPAC) has become organized. Its aim is to control cancer by finding ways to apply what we know now. The CPAC Prevention Action Group and the Research Action Group were planning to team up for a population-based study of the interaction between genes and carcinogens in the environment. This, despite the evidence that environmental carcinogens contribute only one per cent to cancer risk, compared to up to 60 per cent contributed by unhealthy lifestyles. Somehow this does not look like finding out how to apply what we know now. The much-maligned Common Drug Review is now sharing its responsibility for adjudicating cost-effectiveness of cancer drugs with a newly-created Joint Oncology Drug Review (JODR). It was decided the newly-created JODR would be run by the province with the most restrictive record for providing access to and paying for cancer drugs, Ontario. Perhaps we shouldn’t be too surprised. The decision was made by the ministers of health and their deputies who run the provincial health plans and who are de facto insurance executives.

An additional fourteen effective, but expensive, cancer drugs have appeared on the scene. Many haven’t even been approved yet by Health Canada so that cancer patients must get them on the compassionate-use program requiring time-consuming documentation by the attending oncologists in every case, at a time when oncology manpower shortage is a serious problem.

Some problems remain largely untouched: we aren’t doing very much to apply what we know now about cancer prevention, research is still preoccupied with genes instead of behaviour, and the limited access to costly cancer drugs continues.

Meanwhile, problems seem to be getting worse. In three years, cancer will be the number one killer of Canadians. Two-tier medicine has arrived, especially evident in provinces east of the Manitoba border, and is developing in an ad hoc fashion. Private pay for cancer drugs is rising sharply, and at the moment is up to ten-fold higher in the eastern provinces compared to the western provinces. In Ontario and Quebec the private payout doubles every two years. Private insurance payouts are being limited by plans which in turn are specified by what employers can accommodate. Both parties are struggling to define their next step.

Perhaps we should be thankful that at least some things are not changing. Access to PET scans in Ontario didn’t get worse. It couldn’t. Ontario has just recognized the value of PET for staging early lung cancer five years after a large randomized trial proved it could reduce futile lung surgery by half.

We still don’t have a set of national guidelines for cancer treatment and the CPAC Guidelines Action Group seems to be preoccupied with describing how to write guidelines rather than actually writing them.

Canadian oncologists still aren’t advocating in an organized fashion to get patients better access to new drugs and, despite our entreaties to them, it looks like they aren’t going to. Mind you, to be fair, they are working very hard treating the steadily rising number of cancer patients for whom they spend inordinate amounts of time accessing care for the individual. Unfortunately, in several provinces the treatments they prescribe are frequently outmoded or, for lack of adequate diagnostic facilities, all-too-often not entirely appropriate.
Cancer research supported by your tax dollars (our federal government) continues to be largely focused on the mysteries of the cancer cell instead of preventing the external forces driving it to distraction and mayhem.

Oncology nurses are the main providers of supportive care which begins the day the patient enters the health care system. Yet an inordinate amount of their time is spent nursing doctors and clinics instead of cancer patients.

But we shouldn’t point fingers at just the health care system. When we survey the broader landscape to determine what is being done about drug access and cost, we also don’t find too much to cheer about. Everyone, not just doctors, legislators or bureaucrats, seems to be running away from the two problems instead of toward a conjointly crafted solution.

As eternal optimists, we look for positive signs. And we do see glimmerings of hope.

CPAC action groups are just getting started, so let’s give them a chance. They are moving ahead on a broad front as described elsewhere in this Report Card. For example, the CPAC Action Group on Rebalancing the Focus is studying ways to incorporate improved supportive care seamlessly into the cancer system, and help patients find their way through the silos of the public cancer care system. Hopefully, nurses will then be able to play a greater role in supporting and navigating cancer patients. The CPAC Cancer Surveillance Action Group (arguably the most important one) has well thought-out plans to redress serious deficits in Canadian cancer statistics. We may yet get phase IV data (impact of new treatments on cancer mortality in the public at large) so that provinces in addition to BC can craft better control strategies.

The Canadian Cancer Society in partnership with the National Cancer Institute of Canada (NCIC) has announced a strategic plan to advocate channeling cancer control efforts into more promising avenues. Perhaps the Clinical Trials Group supported by NCIC will now introduce more studies on how behaviour modification can prevent recurrence in cancer survivors.

The newly-created Ontario Institute of Cancer Research (OICR) appears to be making real efforts to tie laboratory research directly to clinical research in order to solve diagnosis and treatment problems more efficiently and rapidly.

The Canadian Cancer Action Network (CCAN) has entered into a formal affiliation agreement with CPAC. This will ensure a strong voice for cancer patients whenever CPAC plans its activities. Hopefully, researchers and providers will become more focused on meeting the needs of patients and survivors.

All good intentions.

But the major players still appear to be the elected members of federal and provincial governments. Will they lead or, to paraphrase Ralph Klein the former premier of Alberta, will they just watch which way the parade of voters is marching and then join it? If so, change will be up to the voters. And that is us. Maybe Pogo was right when he said “We have met the enemy..... and he is us”

James D. Gowing, Chair, CACC
William Hryniuk, past Chair
If you met her, you are not likely to forget Suzanne Aucoin. Lively does not describe her, she was bursting with ideas, plans, questions, strategies and news. Bright, insightful and wired for problem solving, she stayed alive against daunting odds when her colorectal cancer returned. Quite a few Ontario politicians, reporters and the Ombudsman could tell you about Suzanne’s determination. Like a teacher who refuses to let a lazy student fail, or make excuses, or hide, Suzanne kept after the provincial government to provide the treatments she needed. Wrap those qualities inside an engaging, and compassionate personality and you start to understand why Suzanne had such a powerful impact.

Cancer is intensely personal, ripping at the sense of self, bruising human faith in a higher power, perforating all the envelopes we create to manage our lives. Suzanne turned it all into pixie dust. She created a website (helpsuzanne.com) and organized dozens of fundraising events to pay for her cancer treatments in the US. She became a friend and advocate for hundreds of other cancer patients, trying to make their journey less painful than hers. She talked to reporters and looked into television cameras describing the government decisions that put her life in jeopardy.

Suzanne challenged OHIP and filed a complaint with the Ombudsman to initiate an investigation, spoke at public functions and press conferences, questioned Cancer Care Ontario’s proposal for private pay and said, “It puts the responsibility on cancer patients to pay for unfunded drugs. This is essentially the situation I just went through with OHIP. It is grossly unfair and unjust.” She demanded that her government treat cancer patients as if they matter.

As a relatively young patient, maybe Suzanne had more energy for the bureaucratic battles but maybe all the rest of us just hoped that was true. The toll was visible at times. Her huge army of friends and supporters, not to mention a loving family who dropped everything to help her, often dragged her away for holidays, lunches, little trips and fun events. Afterward, Suzanne propelled herself back into advocacy, knowing time was short and many others were too sick to fight for themselves. There was so much she wanted to do about accessibility and accountability, transparency, efficient decision-making and appeals processes.

Suzanne’s personal motto was to LIVE LIFE LARGE. You did that, Suzanne. We loved you for it.
January 2008

Dear Cancer Advocacy Coalition of Canada members,

As the end of the first year of the Canadian Partnership Against Cancer approaches, I am pleased to report we are making progress implementing the strategy to improve cancer control in Canada.

Am I satisfied with the progress in cancer control?
No. None of us working in this arena should be satisfied until cancer is under control – preventable cancers are prevented, quality of life is a central pillar in caring for all patients and the likelihood of dying of cancer is greatly reduced for all Canadians.

Am I satisfied with the progress of the Canadian Partnership Against Cancer nine months into its first year?
Yes. A tremendous amount has been accomplished as the concept of a national cancer control organization has become a reality.

PROGRESS

Board of Directors – We have an outstanding governance team. There is an unrivalled depth of expertise in our Board of Directors, including medical experts, cancer survivors, government and community representatives. No matter what their background, each of them brings dedication, commitment and passion to their role. Watching our board in action – seeing that passion – is inspiring.

Advisory Council on Cancer Control – The collective experience of the Advisory Council is also truly impressive. We are able to draw on a wealth of knowledge that spans our country and beyond, and cuts across a multitude of cancer specialties and community linkages. This resource will be invaluable as our work progresses.

Management Team – I was privileged to join the Partnership as chief executive officer in October 2007. Since then I have recruited a four-person leadership team with the experience and vision to skillfully guide the organization in a dynamic, professional and accountable way. The people drawn to the organization are here because they believe in the need for a national strategy and can see the payoff for all of us as Canadians. It’s more than a job; it’s a commitment.

Action Groups – The Action Groups established under the Canadian Strategy for Cancer Control became part of the Partnership in April. The cancer control work continues under their direction, but now as part of the CPAC organization. Project management systems and support resources are now available so they can move forward efficiently on implementing cancer control initiatives. You can see examples of some of that work in the table included with this report.

I have had the opportunity to attend many Action Group meetings and I can’t speak highly enough of the calibre of individuals committing time to this work while, in many cases, juggling a host of other responsibilities. The value of their collective efforts is the backbone of the Partnership’s strategy.
THE FUTURE
While we recognize that progress is being made, we also recognize a need to make a real and measurable impact on cancer. We must lead where appropriate and support where appropriate. We must not duplicate. We must add value. We must be focused.

Over the past several weeks we have been engaging in strategic renewal. We need to be certain that the strategy is current and will deliver the impact that Canadians rightfully demand.

The overall strategic planning process continues and it would be premature to tell you specifically what that will mean. What I can tell you is that we are mindful of the work that got us to this point and our mandate.

I can promise you that when the strategy renewal is complete we will be eager to communicate to all stakeholders inside and outside the cancer community. I invite you to visit our website www.partnersagainstdcinCanada.ca for updates and to sign up for our newsletters. You can also find out more about our Board of Directors, Advisory Council, leadership team and Action Groups on the website.

PARTNERS ARE THE KEY
The Canadian Partnership Against Cancer will continue to build relationships with federal and provincial governments, patient and survivor groups, and cancer organizations, such as CACC, to share a common vision and direction in implementing the strategy.

We recognize the rich history inherited from the Canadian Strategy for Cancer Control and the years of work dedicated by many, many stakeholders.

We also recognize that the goals of cancer control are not just goals of the Partnership, but are shared by the entire cancer community. The Canadian Partnership Against Cancer’s role is to leverage our strengths, work in partnership with experts across the country and facilitate the adoption of best practices.

In the few months since I became CEO, I have had the opportunity to meet and learn from many stakeholders in this community. Some are medical or scientific experts, some represent arms of government, while others have come to this arena because cancer has touched them personally as patients, survivors or family members.

No matter how they got involved, the dedication, passion and vision are clear. This is the same vision that propelled the strategy from an idea to reality. I understand that we are implementing a strategy drawn from the experience and wisdom of many people. We owe it all of you who worked so long and hard to get to this stage – and to all Canadians – to ensure that the work we do is focused and has a demonstrable impact. That is what drives us. We look forward to our ongoing dialogue with CACC and its members as we work together on our common goal.

Sincerely,
Jessica Hill
Chief Executive Officer
CANADIAN PARTNERSHIP AGAINST CANCER

CURRENT STRATEGIC INITIATIVES

The initial work underway is significant. I hope these examples give you a sense of both its breadth and scope.

Attributable Risk (Phase 1)
Assess the strengths and weaknesses of existing attributable risk models to guide the development of a new model to calculate the proportion of cancers attributable to specific risk factors in Canada.

Collection of Occupational Histories
(1) Investigate the feasibility of an occupational cancer related registry similar to the one currently available in Quebec for other Canadian jurisdictions; (2) develop online education module to recognize the importance of occupational and environmental exposures and potential disease.

Status report on Cancer Prevention (Phase 1)
Consult with the provinces and territories on the scope and indicators for a national status report on cancer prevention.

Public Awareness
Communication needs assessment based on: 1) Poll of Canadians’ cancer prevention knowledge, attitudes, behaviours 2) Consensus among cancer control organizations on key public messages on cancer prevention.

National Community of Practice
Knowledge exchange and transfer forum to build cancer prevention capacity through health promotion, research, surveillance and policy.

Family Physician Survey
Knowledge translation plan based on a recently completed family physician survey to address needs/gaps to better engage the family physician communities in primary prevention.

Develop a National Skin Cancer Prevention Community of Practice
Establish a national network to mobilize a broad range of health promotion practitioners on the topic of skin cancer across the country, and disseminate timely information on this issue.

Develop key messages for skin cancer prevention
Develop a set of current, evidence-based skin cancer prevention messages targeting the general public & selected subgroups (e.g. children, outdoor workers).

Disseminate Results of the Sun Survey (NSS2)
Ensure Sun Survey results are appropriately analyzed and broadly disseminated. Evaluate the process to inform future similar surveys.

Vitamin D Exposure Estimates
Use current knowledge to estimate the amount of sun exposure required in different parts of Canada and during each season.

National Symposium on Sun Safety
Share current evidence (including results of Sun Survey), best practice, research needs, and develop consensus on Sun Safety messages for use at national, provincial and regional levels.

Infectious Agents and Cancer Literature Review
Complete a comprehensive, systematic review of cancer and infectious disease, and other health-related literature concerning viral, bacterial and other infectious agents and cancer.

Cancer Screening National Indicators
Define a set of common national indicators for monitoring cancer screening programs Screening Impact and Planning Model Development (SimPMod).

  Develop a computer model for screening in the Canadian population, containing general components to capture characteristics of Canadian and provincial populations, with different modules for specific cancer sites.

Baseline Prevalence of Colorectal Cancer (CRC) Screening
Acquire the best available information nationally of the prevalence of appropriate CRC screening prior to the implementation of organized screening programs.

Patient and Provider Educator Tools re: Screening Benefits and Limitations
Create educational tools to assist patients in making more informed decisions about cancer screening, including clarifying common misconceptions. Materials to be distributed to frontline professional staff (primary care physicians, screening program staff).

Colorectal Cancer (CRC) Screening Network
Establish pan-Canadian CRC screening network and knowledge exchange and transfer forum to foster development of organized screening programs, facilitate best practice, assess CRC screening, support CRC screening policy, etc.

National Conference on Maximizing the Impact of Screening Programs
Convene a national conference on how to maximize the impact of screening programs, with international speakers to describe best practice in other jurisdictions.
Guideline Adaptation Tool
Support guideline developers in how to locate, evaluate, select and synthesize key information from existing guidelines to develop locally relevant, evidence-based guidance (Bone pain guideline work underway as is dissemination of advanced ovarian cancer guideline).

Synoptic Reporting Tools Project
Encourage and facilitate the use of uniform reporting templates that optimize the incorporation of evidence into practice through good reporting

Cancer Knowledge Resource Website
Within CPAC portal initiative, develop interactive public website for use by health professionals, guideline and standards developers, decision makers and researchers across Canada to exchange information on guidelines, standards, indicators and related documents.

Capacity Enhancement
Establish a sustainable network of national clinical practice guidelines training partners; develop, execute, and evaluate a comprehensive curriculum and training enterprise; provide tailored educational support for CPAC-supported guidelines

Measuring the Function & Performance of Networks/Communities of Practice
Produce tools/processes for monitoring the evolution of CG-AG’s network structures, functions and performance over time, and to transfer such knowledge for use by other Action Groups

Supportive Care Human Resources
(1) Prepare a report containing standards and formulas for budgeting comprehensive and supportive cancer care services for use at provincial levels; (2) monitor the status of human resources available to provide biopsychosocial care across the cancer continuum

Awareness activities
(1) Consult with stakeholders on rebalanced cancer system vision; (2) build awareness among provincial counterparts of the benefits of a rebalanced cancer system; (3) develop Canadian Cancer Patients Rights & Responsibilities document

Improving Access to Person-Centred Care
(1) Disseminate the Educational Framework for Promoting Person-Centred Care; (2) design a learning kit for volunteers based on required competencies of person-centred care; (3) design a webbased portal for education modules, links and tools

Integration (Accreditation/Standards,Guidelines)
(1) Build a community of practice to share knowledge, best practices on patient navigation; (2) Develop screening for pain and emotional distress (5th & 6th vital signs) in cancer centres and community settings; (3) Foster appropriate use of technology to increase access to biopsychosocial care (e.g. peer- and professionally led online support)

Knowledge Exchange activities
(1) Accreditation: Work collaboratively with partners to incorporate biopsychosocial criteria into cancer standards and create learning kits; (2) Standards/guidelines: Conduct a quality review of existing guidelines and develop practice guidelines & standards for identified gaps

Bridging to the community
Through tailoring and providing access, improve cancer care support services to specific populations that are:
(1) located in rural/remote locations
(2) Aboriginal/First Nations
(3) Multicultural

Improved Data Collection Quality and Management
Coordinate efforts with partners to improve data quality and examine areas of enhancement for national cancer surveillance in Canada (i.e. staging data)

Strengthening Analytic Capacity and Surveillance Information Products
Increase the quality, breadth, relevance and timeliness of pan-Canadian analysis, interpretation and production of information products based on data from cancer registries

Networking, Communication and Knowledge Translation
Facilitate the dissemination, diffusion and uptake of evidence-based surveillance information by the public, patients, health care providers, policy and decision makers, researchers and the media

Modeling Framework/Model Development
Following the international Burden of Cancer modeling workshop (Oct. 07), and based on a peer review of existing models, develop a population-based modeling framework to forecast trends in cancer incidence and mortality, and measure the impact of cancer control interventions on those trends

Outcome Indicators
Develop key outcome indicators to inform model development Targets for Cancer Control Develop set of targets to monitor progress in reducing disease and burden of disease

NOTE: This table is a sample of Action Group activities and does not represent all the work underway at the Canadian Partnership Against Cancer.
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Where do our research dollars go...still?

WILLIAM HRYNIUK and DANIEL GILLESPIE

“research: careful, systematic, patient study and investigation in some field of knowledge, undertaken to discover or establish facts or principles”

—Webster’s dictionary

Introduction

Historical precedents abound proving that “an ounce of prevention is worth a pound of cure”. For example, control of “Red River Fever” in Manitoba was achieved by separating the water supply from disposal of sewage carrying the typhoid bacillus. Throughout the world, malaria due to the mosquito-borne parasite was largely controlled by swamp drainage. In neither case was study of the respective offending micro-organism a major contributor to disease control. So it will be with cancer control.

To date, major advances in cancer control have come from epidemiologic research and serendipitous clinical observations. Thus, reduced use of tobacco, reduced exposure to cancer-causing chemicals, radiation, and ultraviolet light, eradication of cancer-causing protozoa and bacteria, and immunization against viruses, have all been effective maneuvers derived from epidemiological studies, and have been very effective in preventing cancer. According to the World Health organization up to 50 per cent of all cancers could still be prevented if we just applied what we know now. As is shown in Table 1, fully 62 per cent of cancer risk is attributable to lifestyle choices, all of which might be changed.

It is true that systemic treatment and screening have made substantial contributions and we must continue these efforts strongly. But we can not afford to keep going in that direction without at the same time making much stronger efforts in prevention. Strategies, based on sound research, must be devised to reverse the factors listed in Table 1.

Given this scenario, our interest has been piqued by the discordance between current directions of cancer research versus the directions in which cancer control solutions are likely to be found. Our initial analysis was largely restricted to the two granting agencies which account for over two thirds of national expenditure on cancer research: the National Cancer Institutes of Canada (NCIC), and the Canadian Institutes of Health Research (CIHR). The NCIC is supported by the Canadian Cancer Society (CCS) which in turn receives voluntary public donations, while the CIHR receives its money indirectly from the public, i.e., through grants from the federal government.

As evidenced in our 2004 Report Card, we found that 70 per cent of cancer research dollars allocated by these agencies went to support studies of the offending organism (the cancer cell) rather than the exogenous factors leading to its creation and external forces driving it to destroy the host. We found that only 13 per cent of the dollars went for prevention research and that the amount of money spent on studies of fruit flies, chickens, and yeast was equivalent to that spent on studies to improve supportive care for cancer patients and survivors.

Three years later we revisit the issue to determine if there has been any change in allocation of research dollars to more closely accord with societal priorities, namely preventing cancer, improving treatment and taking better care of cancer patients and survivors. Or, does research money continue to be allocated according to priorities largely set by the researchers themselves?

Methods

In an attempt to detect changes in patterns of research, we included only the new grants which took effect in 2006, that is, we excluded automatic continued funding of grants into 2006 which had been approved before 2006. Therefore, the total dollar amounts shown will be less than the amounts reported in our previous analysis. The exception to this is the data from the Cancer Research Society (CRS) where the dollars are for new grants awarded for 2005.

In the present study we included additional research agencies, based on the possibility this might affect the picture. Thus, we now account for approximately 80 per cent of new cancer research grants.

We used the same classification of research categories as in the previous report (see sidebar). The classification stipulates that for research to be classified as prevention, diagnosis, or treatment, it must involve humans or material taken directly from humans as tissue or blood
DEFINITIONS

BASIC RESEARCH: studies of cells, bacteria, yeast etc. in tissue culture or in animals. Excluded from this category are in vitro studies of blood products or tissues directly removed from humans. Also excluded are studies of human behavior or screening or psychosocial events or mathematical models for epidemiology, risk assessment etc. (see prevention research).

DIAGNOSIS RESEARCH: includes technology development or assessment, marker discovery in a clinical setting, or support of resources related to diagnosis or prognosis. Excluded were screening studies.

TREATMENT-RELATED RESEARCH: includes the testing, development, or clinical application of localized or systemic tumour-directed therapies, or their combinations. Complementary therapy is included if it is tumour directed. Also included were studies of blood products or tissues directly removed from humans in connection with therapy trials. Excluded were all other studies in model systems (see basic research), and psychosocial interventions (see supportive care).

SUPPORTIVE CARE RESEARCH: includes studies in patients undergoing active treatment and aimed at improving quality of life, symptom control, or enhancing patient caregiver interactions and decision-making.

PALLIATIVE CARE RESEARCH: as in supportive care research above but in patients who are no longer on active treatment and who are expected to die soon.

PREVENTION RESEARCH: studies involving epidemiology, demographics, genetics, family studies and risky behaviours in people with no symptoms of cancer, i.e., primary prevention, screening studies, secondary prevention, and studies to prevent recurrence or second primaries in cancer survivors who have completed treatment for their initial primary tumour i.e., tertiary prevention. This is in contradistinction to the definitions in the Common Scientific Outline (CSO), a research classification which places some types of laboratory research in clinical categories even though that research does not involve humans or human material. In our previous study we found that all too frequently laboratory research projects allocated to these CSO categories were only remotely related to clinical problems. As we shall see, that is a critical distinction when comparing our findings with those of others.

In our previous study we also found that a computer scan of the words in the abstract describing the various research projects did not accurately classify each project. Therefore, in the present study to be certain that projects were accurately placed in our classification, we again carefully perused each of the 718 abstracts describing the individual newly-funded projects.

Results

Table 2 shows the agencies included in the present study, the total dollar amounts allocated for new grants and the percentages allocated to each category of research. The pie charts in Figure 1 compare the overall distribution of grant funding from the previous study with the present study. There appears to have been no overall material change in allocation of research dollars since the last study three years ago. Most of the money continues to go for basic research. However, some important details deserve attention.

Table 3 compares the percentage of funding allocated to each research category by NCIC and CIHR, the two largest agencies included in the previous period, with the present period. There has been a significant shift in the allocation by the NCIC: proportionately more money was allocated to treatment and prevention research in 2006 compared to 2003. The figures for CIHR have changed relatively little from the previous analysis, except for a modest decline in percent of new dollars allocated for prevention and a slight increase for diagnostic research.

Many of the dollars allocated by NCIC for treatment research are given to the NCIC Clinical Trials Group (NCIC-CTG), which conducts large clinical trials testing various methods of cancer control. At the time of this analysis 46 of 50 ongoing trials were testing innovative cancer treatments, three were testing supportive care strategies, and one large trial was testing an agent to prevent breast cancer.

Also noteworthy is the program of the Ontario Institute for Cancer Research (OICR), an entity supported by the Ontario government. The focus of this agency is supposed to be on prevention, early detection, diagnosis, and treatment. Nevertheless, Table 2 indicates that almost two thirds of the new grant money awarded in 2006 was for basic research as we have defined it, i.e., it did not directly involve humans or human tissue or blood.

Discussion

As has been succinctly stated in the report of the Canadian Cancer Research Alliance (CCRA), “The burden of disease is
only one factor that drives the direction of research. Scientific opportunity, the introduction of new technologies, the researchability of a tumour type, the size and level of expertise in the research community, and the strategic priorities of research funders all shape the direction research will take."\(^1\) Given the results of the present survey of research dollar allocation, and the one undertaken three years ago, it would appear that the factors driving research continue to be predominantly those of the researchers themselves.

Regarding scientific opportunity, it is not as if we do not know what was contributing to the cancer epidemic. As shown in Table 1, 62 per cent of cancers can be attributed to smoking, inappropriate diet, lack of exercise and resulting obesity, excessive use of alcohol and unprotected sun exposure. The problem is how to apply this knowledge.

Despite the evidence indicating which factors promote cancer, the research priorities of CIHR do not appear to have changed by 2006, the emphasis on research of the offending organism continues. Changes in research allocation have been relatively minor and could simply have been due to the vagaries of year-over-year comparisons.

It should be noted that the CIHR recently announced that $10-million will be allocated over five years to research which will enable Canadians to "better detect, treat, and survive cancer". This is most welcome and is an improvement over the previous announcement of $2.4-million over six years. The most recent grant is worth 7.5 cents per Canadian per year, compared to the previous grant of one cent per Canadian per year. Meanwhile, the allocation for new basic research by CIHR is in the order of $2.61 per Canadian per year.

Of note is the fact that a relatively small amount ($300,000) was allocated for studies which cannot reasonably be related to cancer. One might regard this amount as trivial, and perhaps due to an internal administrative error in reporting. But the fact remains that it is larger than that allocated by CIHR for research in palliative care of cancer patients ($187,000).

Hopefully, since the 2006 grant period, the CIHR has continued to change its research emphasis in a material way. If so, we look forward to documenting that change in future analyses.

In contrast to the relatively small changes in CIHR funding, the NCIC appears to be refocusing its efforts in a major fashion. According to the results shown in Table 3, considerably more emphasis is being placed on treatment and prevention compared to previous grant periods. The increase from 16 per cent to 39 per cent in grants allocated for treatment research is particularly noteworthy. Grants for treatment research have traditionally flowed to the NCIC-CTG. This consortium of Canadian clinical researchers continues to be strongly led. It is in the first rank of international clinical cancer research groups and the results of their research change cancer treatment policies worldwide. Up to this point, the NCIC-CTG has emphasized tests of new cancer therapies, only four of the 52 active trials are in prevention and supportive care. Hopefully, these categories will receive increased emphasis.

The NCIC and the Canadian Cancer Society (CCS) have recently entered a new era of collaboration as evidenced by the 10 year strategic plan of NCIC noted on the CCS/NCIC websites. According to the plan, “NCIC will take informed risks in developing new programs that...improve cancer control.” NCIC is also “…proposing to undertake, among other activities, an expanded version of the Canadian Cancer Statistics publication and the creation of a policy paper series on priority topics in cancer control to be developed in consultation with CCS.” NCIC does not propose to assume the responsibilities of governments, but will advocate for governments to do their jobs. This welcome change in strategy could have a major impact on cancer control in Canada.

Special mention should be made of the program of the Ontario Institute for Cancer Research (OICR). As noted earlier, despite its mandate, most of the money has gone for studies which we have categorized as basic research. However, even though the newly-funded studies are conducted in non-human model systems, most of the abstracts describe research which is sharply focused on solving clinical problems in humans. This is in contradistinction to the more fundamental themes in the other agencies’ basic research portfolios. Furthermore, OICR is already participating in prevention research via grants awarded prior to 2006. It remains to be seen what impact OICR studies will have on cancer control but the effort is clearly in that direction. As long as collaborations ensure that bench findings are translated directly to the bedside in a well organized fashion and that clinical results are fed directly back to the lab, we can be optimistic about the

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**TABLE 1  RISK FACTORS FOR CANCER**

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Attribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>24%</td>
</tr>
<tr>
<td>Tobacco</td>
<td>22%</td>
</tr>
<tr>
<td>Genetic predisposition</td>
<td>20%</td>
</tr>
<tr>
<td>Infections</td>
<td>10%</td>
</tr>
<tr>
<td>Family history</td>
<td>8%</td>
</tr>
<tr>
<td>Alcohol</td>
<td>6%</td>
</tr>
<tr>
<td>Occupation</td>
<td>6%</td>
</tr>
<tr>
<td>Obesity</td>
<td>5%</td>
</tr>
<tr>
<td>Physical inactivity</td>
<td>4%</td>
</tr>
<tr>
<td>Sunlight</td>
<td>1%</td>
</tr>
<tr>
<td>Environment</td>
<td>1%</td>
</tr>
<tr>
<td>Ionizing radiation</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

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REPORT CARD ON CANCER IN CANADA, 2007 13
returns for the effort.

The Canadian Cancer Research Alliance (CCRA) has recently published the results of a study of cancer grant distribution in the year. The CCRA study differs from our study in two respects. Firstly, CCRA included more of the cancer research agencies extant in Canada than we did. Secondly, their final results are different from ours: they indicate that only 45 per cent went for “biology—research, compared to the 68 per cent which we report herein for essentially the same category, namely “basic” research.

It is unlikely that the difference in years studied, 2006 in the present study versus 2005 in the CCRA analysis, explains the difference reported in distribution of research funding. Research funding allocations would not have changed so drastically in one year. It is also unlikely the more inclusive coverage of agencies by the CCRA explains the difference in distribution of research funding. The additional agencies included by CCRA compared to the present survey were relatively small (in the aggregate accounting for only 10 per cent more research dollars) and their pattern of funding largely followed the same pattern as the larger agencies, namely an emphasis on biology or basic research.

The reason for the discrepancy is more likely explained by the different classifications of research categories that were used in the two analyses. Our classification stipulates that research classified as prevention, diagnosis, and treatment must either involve humans or material taken directly from humans. As explained earlier, the CCO classification allows certain types of basic laboratory research to be categorized as clinical research.

Close perusal of Table 6 in the CCRA publication reveals that fully 19 per cent of the money judged by CCRA to be directed to diagnosis and treatment was for the sub-categories of discovery and development (codes 4.1, 4.2, 5.1, and 5.3). Most, if not all, of this research would have been conducted in animals and cultured cells, not in humans or using human tissue or blood products. Such studies we would classify as basic research. Our experience has consistently been that studies classified in these sub-categories are frequently only very loosely related to problems relevant to humans, but are crucial to problems relevant to other species.

### Table 2: Research Funding Allocation in 2006 (New Grants)

<table>
<thead>
<tr>
<th>Agency</th>
<th>Total ($)</th>
<th>Basic (%)</th>
<th>Treatment</th>
<th>Prevention</th>
<th>Diagnosis</th>
<th>Supportive</th>
<th>Health Service</th>
<th>Palliative</th>
<th>Not Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRS</td>
<td>$5,371,623</td>
<td>98.9%</td>
<td>1.1%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>CIHR</td>
<td>$27,330,860</td>
<td>75.9%</td>
<td>4.6%</td>
<td>6.2%</td>
<td>8.3%</td>
<td>1.6%</td>
<td>1.6%</td>
<td>0.7%</td>
<td>1.1%</td>
</tr>
<tr>
<td>PROSTATE</td>
<td>$980,000</td>
<td>75.0%</td>
<td>6.3%</td>
<td>0.0%</td>
<td>18.8%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>OICR</td>
<td>$13,729,296</td>
<td>64.9%</td>
<td>25.0%</td>
<td>0.0%</td>
<td>10.1%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>NCIC</td>
<td>$23,738,000</td>
<td>58.5%</td>
<td>28.8%</td>
<td>9.8%</td>
<td>0.7%</td>
<td>0.2%</td>
<td>1.2%</td>
<td>0.8%</td>
<td>0.0%</td>
</tr>
<tr>
<td>CBCRA</td>
<td>$4,909,000</td>
<td>44.6%</td>
<td>8.2%</td>
<td>17.1%</td>
<td>31.1%</td>
<td>26.2%</td>
<td>0.0%</td>
<td>0.9%</td>
<td>0.0%</td>
</tr>
<tr>
<td>TOTALS</td>
<td>$76,058,779</td>
<td>68.0%</td>
<td>15.85%</td>
<td>6.40%</td>
<td>5.46%</td>
<td>2.34%</td>
<td>0.92%</td>
<td>0.56%</td>
<td>0.39%</td>
</tr>
</tbody>
</table>

#### NCIC

<table>
<thead>
<tr>
<th>Agency</th>
<th>Total ($)</th>
<th>Basic (%)</th>
<th>Treatment</th>
<th>Prevention</th>
<th>Diagnosis</th>
<th>Supportive</th>
<th>Health Service</th>
<th>Palliative</th>
<th>Not Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>TFF</td>
<td>$6,661,000</td>
<td>96.1%</td>
<td>3.9%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>CCS</td>
<td>$17,077,000</td>
<td>43.9%</td>
<td>38.5%</td>
<td>13.6%</td>
<td>1.0%</td>
<td>0.3%</td>
<td>1.6%</td>
<td>1.1%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

**CRS** Cancer Research Society  
**CIHR** Canadian Institutes of Health Research  
**PROSTATE** Prostate Cancer Research Foundation of Canada  
**OICR** Ontario Institute for Cancer Research  
**NCIC** National Cancer Institute of Canada  
**CBCRA** Canadian Breast Cancer Research Alliance  
**TFF** Terry Fox Foundation  
**CCS** Canadian Cancer Society

### Table 3: Research Funding Allocation

<table>
<thead>
<tr>
<th>Type of Research</th>
<th>NCIC 2003-4</th>
<th>NCIC 2005-6</th>
<th>CIHR 2003-4</th>
<th>CIHR 2005-6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic</td>
<td>65%</td>
<td>44%</td>
<td>73%</td>
<td>76%</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>3%</td>
<td>1%</td>
<td>3%</td>
<td>8%</td>
</tr>
<tr>
<td>Treatment</td>
<td>16%</td>
<td>39%</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Supportive care</td>
<td>3%</td>
<td>&lt;1%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Palliative care</td>
<td>2%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Prevention</td>
<td>10%</td>
<td>14%</td>
<td>14%</td>
<td>6%</td>
</tr>
</tbody>
</table>
in which case they rarely lead to timely advances in cancer control. Hence, the 19 per cent allocated to these categories by CCRA, when added to the 46 per cent they allocated for “biology” research yields 65 per cent essentially the same as the 68 per cent we report herein for “basic” research.

Basic research is important and should not be neglected. It has yielded fascinating biological insights which will ultimately translate into practical applications. Already an abundance of new and effective (and very expensive) cancer drugs is entering the clinic. Important new knowledge is evolving regarding genetic variations of either tumor susceptibility to drugs or individuals’ ability to metabolize cancer drugs. Especially important from the viewpoint of cancer prevention, is the possibility that individuals’ susceptibility to carcinogenic influences is genetically determined. However, these results have yet to have a material impact on cancer incidence and mortality. One must look at what has been their influence on the cancer epidemic, to date it continues unabated.

Canadian laboratory researchers rightfully enjoy an international reputation for excellence. We must continue to support them. But we also need a large cadre of new researchers to study cancer prevention.

To be more specific, studies should be greatly increased to find better ways to prevent cancer in otherwise healthy individuals (primary prevention), to improve screening for early cancer (secondary prevention), and ways to prevent cancer from recurring in cancer survivors (tertiary prevention).

Studies could focus on the following:

**Prevention**

2. Enhanced methods for detecting and reducing risky behaviors in “normal” individuals or in cancer survivors.
3. Improving adoption by doctors and patients of proven methods for preventing cancer.

**Treatment**

6. Strategies to reduce waiting times.
7. Identification of patients most likely to respond to new cancer drugs.
8. Pharmacogenetic reasons for failure to respond to cancer drugs.

**Supportive Care**

9. Enhancing the role of nurses in supportive care.
10. Ways to reduce increased utilization of health care systems by cancer survivors.

**Conclusions**

Cancer research priorities are too important to be left to the sole discretion of the researchers. In the 2004 Report Card we suggested that Canada needed an all-party parliamentary committee to ensure alignment of research priorities with societal priorities. The newly-formed Canadian Partnership Against Cancer (CPAC) Research Action Group, combined with the change in strategy of the NCIC/CCS, may help achieve this goal. But there still needs to be ongoing public scrutiny of cancer research objectives and results.

Daniel Gillespie BSc, is a graduate of the University of Toronto. He has been a consultant and research assistant to the Cancer Advocacy Coalition of Canada for the past three years.

Dr. William Hrynuk is a Medical Oncologist in Dundas, ON and past Chair of the CACC; he is currently Medical Director of CAREpath Inc.

**Reference**

A Critique of the Breast Cancer Clinical Research Process

SAVE TIME, MONEY AND LIVES BY REDUCING REPETITIVE TESTING OF NEW AGENTS AGAINST PLACEBO

JOSEPH RAGAZ

This article summarizes a study presented to international cancer specialists at the 29th Annual San Antonio Breast Cancer Symposium in December 2007. The study calls for a major overhaul of the clinical trial process testing breast cancer treatments. The present system is becoming obsolete due mainly to the rapid emergence of many new, potentially curative cancer drugs outstripping the capacity of the present system to test them in a timely fashion.

The recommendations aim to markedly reduce the time for a drug to find its way “from the bench to the clinic,” which is currently as much as a decade or more.

The proposals require a fundamental change in cancer drug testing, specifically how randomized trials are conducted in the adjuvant setting. While based on an evidence-based review and common sense, they might be considered drastic to some members of the present cancer establishment. Although the current system has produced a marked reduction of breast cancer mortality over the last 30 years, it could be more efficient and less expensive.

In order to understand the proposed reforms, two factors require review:

1. Clinical trials of new cancer therapeutics, an important step governing the eventual approval of new drugs into clinical use, with process delays affecting human lives.
2. The biology of metastases of human cancer, specifically the difference between “macrometastases” of advanced Stage IV disease versus the “micrometastases” of subclinical early stage disease, the adjuvant setting.

Human Clinical Cancer Trials

At present, it takes a minimum of 10 to 15 years for a new agent to reach the clinic from the laboratory bench, in many cases 15 to 20 years to become fully characterized, because a sequence of at least four, and usually five types of trials are required for each new drug.

Randomized placebo-control trials – those which take time and are most costly – are done first in the advanced stage IV, and then in the same design, for the adjuvant setting.

If results are flexibly applied from stage IV into adjuvant setting, for those new agents when effect is seen beyond reasonable doubt, the complex second set of randomized trials in the adjuvant setting could be skipped. Also, with other suggested reforms calling for enhanced efficiency the time period of testing could be reduced from the present 10 – 15 to less than five years.

Biology of Human Cancer Metastases

Typically, as the tumour becomes more advanced, more resistance to therapeutic agents is seen. Therefore, killing tumour cells with drugs and prolonging patient survival is more difficult in advanced disease. As a corollary, tumour sensitivity to a new cancer agent in advanced disease should predict even greater sensitivity in early disease. This observation may permit skipping the repeat testing of a new agent against placebo in the adjuvant setting.

Are Results of Stage IV Trials Applicable to the Adjuvant Setting?

In order to establish if this complex sequence could be simplified, we reviewed all principal randomized breast cancer trials testing hormones, chemotherapy and biologicals, first in the advanced stage then, in an identical design, in the early adjuvant setting.

In every trial in our analysis, starting from Tamoxifen, (the first hormone studied in human breast cancer 2,3,11), to the new generation of hormones (the aromatase inhibitors), and from early types of chemotherapy regimens 3,4 to the most recent combinations including the biological Herceptin 5–9 the results were consistent. While responses were seen in Stage IV, there were no cures; but when agents were moved to the adjuvant setting, each one produced a much more powerful clinical benefit. The result was not only a signifi-
cant reduction of recurrences (metastases), but also
durable cures, equated with a significant reduction of
breast cancer mortality.
Furthermore, the analysis showed that a profound
population-based breast cancer mortality reduction was
identified in parallel with the introduction of these
agents into the adjuvant setting. This was true both in
rural and urban areas. However, in the provinces where
adjuvant therapy was delayed, or not given uniformly
across the whole population, the mortality reduction
did not materialize, or was seen at a slower pace.
Specifically, in some provinces in Canada breast mortal-
ity reduction trends became apparent as early as the
1980s, while in other provinces, as in the majority of
western countries, the mortality reductions were record-
ed as much as a decade later. The irregular timing of
decreases in mortality probably represents the uneven
transfer of early results from clinical trials into routine
practice.

**Consequences of Delaying Curative Treatments**

If routine use of effective systemic therapy is curative,
than we must ask the obvious question, does delay in
use of curative agents delay the reduction of mortality?
This issue provides the core of our arguments against
delays in activating effective cancer treatments. Consider
the consequences of delaying use of Tamoxifen and Herceptin.

**TAMOXIFEN**

Tamoxifen, the most commonly used hormonal ther-
apy against breast cancer, is now credited with saving the
lives of hundreds of thousands of women since it
moved into routine adjuvant treatment in the mid-
1980s. Yet its effectiveness in producing significant
responses in Stage IV advanced disease had been rec-
ognized five to 10 years earlier. How many more lives
could have been saved had Tamoxifen been used in
the adjuvant setting immediately after its effectiveness
became evident from the Stage IV trials? The estimates
indicate that, worldwide, up to 20,000 additional lives
could have been saved annually or 100,000 lives for
every five additional years that it took to conduct all the
trials of Tamoxifen in the adjuvant setting.

**HERCEPTIN**

In 1999, randomized trials showed that Herceptin
would double the response rate and significantly
prolong life in advanced Stage IV disease, (i.e., when
added to conventional chemotherapy in patients whose
tumors over-expressed the HER2/neu gene).

Herceptin was then tested in early disease between
2001 and 2005 in four large simultaneous adjuvant ran-
domized trials in North America and Europe. Each
trial produced a benefit that could have been expected
from the original 1999 advanced disease study, namely
a 50 per cent reduction of recurrences as a surrogate for
preventing breast cancer death. As a result of such a
high degree of proof of efficacy and after intense politi-
cal lobbying, and despite its cost and complexity of
delivery, the drug was approved in North America with-
in six months as part of standard adjuvant therapy for
patients with tumours positive for HER2/neu. It took
another two years for similar approval in the rest of the
western world.

Rather than waiting until 2005/2006, had the drug
been introduced into routine use in the adjuvant setting
in 2000–2001 when it was shown to be highly effective
in advanced Stage IV disease, an estimated 5,000
women’s lives could have been saved in Canada and ten
times as many in the US. As it is, these breast cancer
recurrences were not avoided and we are only now
determining the optimum duration of treatment with
this very expensive agent.

**Delay of Curative Treatments – The Present Situation**

As documented elsewhere in this Report Card, we are
faced with a dilemma. More than 40 new agents/indica-
tions are waiting in line for further action either in clin-
ical trials or approval for general community use. Drugs
such as bevaczizumab (Avastin) shown, as early as 1999,
to significantly prolong life in Stage IV colorectal can-
cer are still not used in the adjuvant setting. The same
drug was shown to produce a similar benefit in breast
cancer in 2005 yet only a handful of patients are
receiving it in Stage IV, and not a single patient in the
adjuvant setting. The first trial testing Avastin as adju-
vant treatment of breast cancer started only months
ago. Its results will not be available for another five
years.

The most recent example is lapatinib (Tykerb), a drug
Killing tumour cells with drugs and prolonging patient survival is more difficult in advanced disease. As a corollary, tumour sensitivity to a new cancer agent in advanced disease should predict even greater sensitivity in early disease.

that inactivates the HER2/neu molecule like Herceptin but by a different mechanism. A large North American trial showed two years ago that lapatinib, added to chemotherapy in patients with advanced Stage IV breast cancer who had relapsed on Herceptin, produces a response rate of more than 40 per cent and a median survival twice as long as patients not receiving lapatinib. One might ask “How close are we to offering this highly effective non-toxic drug to Canadian patients with aggressive, advanced Stage IV disease?” The first adjuvant European trial testing adjuvant lapatinib is only just starting, with at least three to five more years before results will be documented. Yet as indicated by the evidence already available, lapatinib in conjunction with Herceptin will almost certainly increase survival in women with early breast cancer.

Conclusion
• The narrowly defined balance between underinvestigation and overinvestigation of new agents has swung too far in the direction of overinvestigation. Both are examples of poor science. This report suggests balance can be restored, with specific proposals for breast cancer.
• If we persevere with the status quo, testing new agents as we have always done, new and potentially useful therapies will be increasingly caught in the log jam, and lives will be lost unnecessarily.
• On the other hand, speeding up the process by which new drugs reach a defined population who could benefit from earlier treatment would save thousands of lives, at much lower cost to society.

See the CACC Website for detailed proposals
www.canceradvocacy.ca

Dr. Joseph Ragaz is a Medical Oncologist in Montreal, QC and a Director of the CACC.

References
15. Details of the proposals presented by Dr. Ragaz in San Antonio, December 2007, can be found with Background Documents to this Report Card on the CACC website www.canceradvocacy.ca.
The past year has seen some progress in the availability of Positron Emission Tomography (PET) imaging technology to Canadian patients with cancer, although there remain significant regional differences. This overview will provide background to availability of FDG, the radioactive drug required to image most cancers; clinical PET scanning; medical cyclotron facilities; and research sites.

**Availability of Fluoro-deoxyglucose (FDG)**

One of the major factors limiting the rapid diffusion of PET imaging was the regulatory position of FDG. Health Canada regulations required that each centre producing FDG be considered an independent manufacturing site and that all patient studies had to be performed under a clinical trial application. Over the past year, four centres have made new drug submissions with respect to FDG and have received formal Notice of Compliance documentation from Health Canada. These centres are: IPET in Vancouver, McMaster University in Hamilton, BMS in Sherbrooke and Alberta Cancer Board in Edmonton.

Once the inspection processes have been completed, these four sites will be able to supply FDG for clinical imaging use for the specified indications without a CTA arrangement. In addition, off label use will also be permitted. This will be very helpful in situations where an oncologist believes that a PET scan may be valuable in the management of a less common malignancy. For example, although PET scans will be approved for the staging evaluation of patients with cervical cancer, a less common cancer like vaginal cancer may not appear on the list of approved indicators. In the future it will be possible to order PET scans for patients with less common malignancies provided that the oncologist can justify the request based on his or her ability to show how the result will influence patient treatment and provided that the nuclear medicine physician performing the scan agrees.

Notices of compliance for these four manufacturers will, over the course of 2008, significantly improve the availability of PET scanning and reduce the complexity of the procedure from the patient point of view. Previously patients were required to agree to be part of a research protocol in order to obtain a scan. The process of giving consent for participation in a clinical trial is significantly more time consuming for both patients and staff. Since in all provinces, except Ontario, most PET scans will be performed as part of routine clinical practice, the process will become as simple as consent to a CT scan or MRI scan.

**Clinical PET Imaging**

PET imaging continues to be available across the country with Ontario remaining the province with the most limited access (compare Table 1, Ontario, with Table 2, Alberta).

![Table 1](image)
The gap between Ontario and the rest of Canada appears to be getting wider.

In Ontario there remains very limited access to PET scanning for patients with cancer. There is a movement away from enrollment in Ontario clinical trials, to registration of patients undergoing PET imaging in a specific tumor type registry which will allow evaluation of efficacy at some later date.

Gradually the barriers to cancer patients being able to access PET scanning for approved indications are being lowered in provinces across Canada. For example the indications for PET scanning in Alberta are quite wide-ranging (Table 2).

In contrast, access is very much more limited in Ontario. Access to PET scanning in Ontario continues to be limited to those patients who are either eligible for entry into one of the formal clinical trials, or those patients eligible for being included in the registry. Table 1 outlines those entry points. The gap between Ontario and the rest of Canada reported in last year’s Report Card appears to be getting wider.

PET scanners for clinical imagining are available in the following locations:

<table>
<thead>
<tr>
<th>Location</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vancouver</td>
<td>2 (1 private)</td>
</tr>
<tr>
<td>Calgary</td>
<td>1</td>
</tr>
<tr>
<td>Edmonton</td>
<td>2</td>
</tr>
<tr>
<td>Winnipeg</td>
<td>1</td>
</tr>
<tr>
<td>Ottawa</td>
<td>2 (one of these scanners is mainly dedicated to research but does perform some clinical cardiac imaging under the myocardial viability registry).</td>
</tr>
<tr>
<td>Toronto</td>
<td>4 (1 private)</td>
</tr>
<tr>
<td>Hamilton</td>
<td>1</td>
</tr>
<tr>
<td>London</td>
<td>1</td>
</tr>
<tr>
<td>Quebec</td>
<td>12 (2 private)</td>
</tr>
</tbody>
</table>
While most PET imaging studies are currently performed under the CTA regulations, there will be an increasing move away from this in all provinces, except Ontario, as the manufacturing sites make their approved products available.

Most PET scanners across the country are performing between 1000 and 1600 images annually.

Clinical scanners are planned for Thunder Bay and Halifax. It is anticipated that these scanners will be installed and operating within the next 18 months.

It is important to note that in Ontario (McMaster), Quebec (BMS), Alberta (Cross Cancer Institute) and British Columbia (IPET), Health Canada product approval for FDG for PET imaging has been obtained. The indications are outlined in Table 3.

With these Health Canada approvals there is no requirement to use the previously required CTA process to perform PET scans with these four products on patients for any indication if, in the opinion of the referring physician the test is important to the care and management of the patient, and of course, if it is funded by the provincial government.

Medical Cyclotron Facilities
Medical cyclotrons are currently installed and operating in the following cities: Edmonton, Ottawa, Hamilton, Toronto (almost entirely dedicated to research use), Sherbrooke, and Montreal. Cyclotron installations are planned over the next one to two year time frame in the following cities: Vancouver, Winnipeg, Toronto, London, Quebec, Halifax and Thunder Bay. Each of these cyclotrons will require the construction of glucose monophosphate (GMP) manufacturing facilities for the production of FDG and for other PET imaging tracers that may be required by the oncology communities.

<table>
<thead>
<tr>
<th>Medical Cyclotron Facilities</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Health Canada FDG NOC</th>
<th>Non-Small Cell Lung Cancer</th>
<th>Small Cell Lung Cancer</th>
<th>Colorectal Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>McMaster</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMS</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCI</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>IPET</td>
<td>+</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

There continues to be considerable activity on the research front across the country

Research Facilities
There continues to be considerable activity on the research front across the country and many of the cyclotron sites that will be installed over the coming years will support both clinical research and research facilities. PET scanners dedicated to research have been installed in the following sites: Vancouver (UBC), Edmonton (Cross Cancer Institute), Ottawa (Ottawa Heart Institute), Toronto (Princess Margaret Hospital, Centre for Addiction and Mental Health), Montreal (Montreal Neurological Institute), Sherbrooke (CHUS).

There continues to be a dialogue across the country about ways in which the research activities of the various PET groups can be integrated and enhanced.

Since last year there has not been a significant enhancement of PET imaging capability across the country, but this has been largely due to no significant change in the access of PET imaging to Ontario patients. There have been a number of new scanner installations and several more are planned which have the potential to increase the availability of this technology to patients with cancer in each province.

**Dr. Alexander J.B. (Sandy) McEwan** is a Nuclear Medicine physician and Director of Oncologic Imaging at the Cross Cancer Institute, and is Professor and Director of the Division of Oncologic Imaging, Department of Oncology at the University of Alberta in Edmonton, Alberta. Dr. McEwan is also President of the Society of Nuclear Medicine.

**Dr. Robert Pearcey** is a Professor in the Dept. of Oncology, Division of Radiation Oncology at the University of Alberta. He has a busy clinical practice in addition to academic responsibilities.
Diagnostics
James D. Gowing

Positron Emission Tomography (PET), invented in Montreal as a gift to the world with its many innovative derivatives (PET/CT, PET/MRI) and applications, is revolutionising the detection and tracking of many diseases, especially active cancer. The fact is while PET is widely available in many countries around the world and in other provinces in Canada, it is not widely available in Ontario. In this province, clinicians are severely restricted in accessing this modality to the detriment of their patients’ welfare.

POINT
Represents the perspective of those in a position to make far-reaching health care decisions for Ontarians and who are currently opposed to the clinically guided use of PET in this province.

COUNTERPOINT
Represents the perspective of a clinician who deals, on a daily basis, with cancer patients who need access to this modality.

POINT
There is no high quality evidence to support the use of PET.

COUNTERPOINT
Most patients present with a unique set of problems and hence Phase III trials of imaging are extraordinarily difficult to conduct. A wide variety of indications for PET have been established based on good evidence from well-designed comparative, but not randomized, studies. Among the studies that justify its use is one large randomized trial that showed pre-operative PET scanning can cut in half the instances of futile surgery in lung cancer patients headed for thoracotomy. The results of the study were published more than five years ago in a prestigious medical journal yet it was not until late in 2007 that Ontario approved pre-operative PET scanning in this situation.

As additional evidence of the widely recognized value of PET, physicians training in diagnostic imaging must now get experience interpreting PET scans in order to qualify for the Canadian Fellowship Examination. Trainees in London, Ontario, however, had to leave the province to get this experience because of restrictions in access to PET scans.

The limited trials in Ontario are ostensibly to establish the utility of PET in oncology. They are not randomized and are of questionable quality given the lack of documentation required in each case. The Ontario trials are also quite restrictive, leaving PET scanners in the province lying idle or used to study animals. Meanwhile, high quality innovative research of a vastly different nature in the use of PET is proceeding rapidly in numerous other jurisdictions.

POINT
Inappropriate factors (are) driving the number of diagnostic tests in Canada.

COUNTERPOINT
By inference, access to PET scanning should be curtailed to prevent theoretical, future overuse. Where is the evidence, based on randomized trials, that Ontario oncologists and haematologists are ordering unnecessary imaging tests for their patients? Is it fair to penalize cancer patients when, for example, cardiology patients are also subjected to expensive isotope studies based solely on clinical indications?

POINT
PET scanning is too expensive.

COUNTERPOINT
A major cost of PET is in the production and transportation of the short-lived isotope. This cost can be greatly reduced by producing cyclotrons centrally and in large quantity. By adopting this tactic, the cost of a PET/CT in South Korea has been reduced to $775 Canadian, compared to current costs of $1300–$2000 in Canada. In Seoul, patients with lymphomas are assessed before chemotherapy, after two rounds (treatment is altered if there has been no response) and again three to four months following treatment. If the last scan is negative, it is repeated every two years but no other follow-up or examinations are conducted.

POINT
The exceptional use protocol does provide clinicians with access.

COUNTERPOINT
In fact, an anonymous panel of three people adjudicate requests for exceptional use. They turn down many requests because of the “lack of high quality evidence.” The panelists require Phase III trial evidence to justify use, but such trials will rarely be conducted. McMaster University in Ontario has had 12 years of experience in PET, yet the expertise at this centre is largely ignored by individuals guiding government policy. The implication, it seems, is that experienced imaging physicians, oncologists, and haematologists are less capable of making appropriate recommendations for the benefit of their patients than the ministry’s anonymous “expert” committees.

POINT
The appeal mechanism from the expert panel decision will provide another opinion.

COUNTERPOINT
Appeals to the Health Services Appeal and Review Board (HSARB) although suggested by the Ministry, would be a waste of time and money. The HSARB stated in a judgement on October 17, 2006, that “Since the Schedule of Benefits does not include PET scans, they are not an insured service under the Act and the Appeal Board cannot order the General Manager to pay.”

Summary
Ontario limits cancer patient access to a tool that can help to achieve early diagnosis and accurate follow-up in individual patients. If used widely and appropriately, PET could ultimately lead to better cancer control.

References
Health Human Resources for Cancer Control in Canada

ANDREW PADMOS

Cancer comprises a family of malignant diseases that places a heavy burden on patients, families, communities, and the health system. Cancer incidence continues to rise annually in Canada by two to three per cent, while prevalence is growing at least twice that rate. Because the prevalence is rising quickly, cancer control is evolving to a system of chronic disease management with attendant challenges of complexity, comprehensiveness, coordination of care and control of costs. In the meantime, patient awareness and expectations are rising, in large part, because of better communication and access to information.

Over the last twenty years, shortages of health human resources in the cancer workforce have been chronic, recurrent and widespread. While some of these shortages are the result of inadequate supply of cancer health professionals in the face of increased caseload, other shortages exist because of inter-provincial migration, retirement and technological change affecting service delivery models. The results of shortages in the cancer workforce include longer wait times for important and essential services to prevent, diagnose, treat and support cancer patients as well as frustration and disgruntlement on the part of cancer health professionals.

In 1999, a process to monitor and respond to workforce shortages and concerns began with the creation of the Human Resources Policy Advisory Committee (HRPAC) of the Canadian Association of Provincial Cancer Agencies (CAPCA).

Around the same time, the Canadian Strategy for Cancer Control (CSCC) was under development as a grassroots volunteer organization of several-hundred cancer care providers, consumers, and institutions led by the Canadian Cancer Society, the National Cancer Institute of Canada and CAPCA with support from Health Canada’s Cancer Secretariat. In its initial organizational model instituted in 2000, the Canadian Strategy for Cancer Control identified Health Human Resources as a priority theme and created the Human Resources Action Group (HRAG) to manage this component of the strategy development.

As initially drawn, the membership of the HRPAC for CAPCA generally followed geographic lines with individual representatives from each of the provincial cancer agencies and programs. In contrast, the membership of the HRAG for the CSCC generally represented professional disciplines and job categories in the cancer workforce. Soon it was apparent that it was more practical, efficient and cost effective to operate both committees as a single group sharing meetings, conferences, information, infrastructure and expertise.

The early work of the combined HRAG centered on snapshot surveys of key job categories in cancer treatment centers across Canada. The data collection was initially limited to the disciplines of (a) medical oncology, (b) radiation oncology (c) medical physics and (d) radiation therapy. These categories were chosen because the professional staff were identifiable and their data and opinions accessible, since all were appointees or usually employees of provincial cancer agencies and programs. The three national surveys completed all had the same weaknesses: incomplete data due to lack of response from some reporting centers; the short shelf life of the data, since changes to the work force in these job categories took place on an almost weekly basis; and the data were of limited use because decision makers and system managers viewed the information as suspect and self-serving.

Despite their weaknesses, these initial surveys were helpful to describe the problem set and create interest among cancer system managers. It was recognized, however that there was a clear need to shift the focus of the HRAG to develop a mechanism or tool for reliable, accurate, timely and comprehensive data collection, storage and analysis. This tool was called the Human Resources Planning Information System (HRPIS) and was intended to support functions of an HR ‘observatory’ and provide capabilities of modeling at local, provincial and national levels.

The value proposition for the HRPIS was the theoretical advantage that cancer, unlike other sectors of
There was general recognition that, at this rate of support and development, the Human Resources Planning Information System was unlikely to move beyond the prototype stage.

the Canadian health system, could provide the requisite data for true population needs-based planning for health human resources. This is because the Canadian Cancer Registry has long provided accurate, population level data about cancer incidence that, when linked to the available data about the HHR supply and service delivery models through the HRPIS, could create a unique tool to address needs; rather than the utilization or demand for services. Thus, the cancer control system would be in a position to proactively address the chronic HHR shortages that have long plagued the country.

The organizational model for the HRAG evolved to include four working groups or sub-committees each charged with a different aspect of cancer workforce planning, including HRPIS. The four working groups were assigned the following tasks: 1) to describe the nature and severity of cancer workforce challenges; 2) to investigate and document the supply chain of cancer health professionals from educational institutions, training programs and immigration; 3) to review, document and analyze different models of cancer service delivery; and 4) to develop the HRPIS as a workforce and service modeling tool and database.

The work of the Human Resources Action Group, particularly the project to create the HRPIS received considerable attention and support. CAPCA funded the work of a part-time project manager. The BC Cancer Agency provided technical support for the design of the HRPIS in an Access database as an in-kind contribution to CAPCA. Development milestones included a privacy impact assessment based on extensive work in collecting provider datasets from provincial cancer agencies and programs to populate the HRPIS.

There was general recognition that, at this rate of support and development, the HRPIS was unlikely to move beyond the prototype stage. Therefore a case for support was presented to the Health Human Resources sub-committee of the Federal Provincial Territorial (F/P/T) Advisory Committee on Health Delivery and Human Resources (ACHDHR). The presentation was well received, but the proposal for a labour market sector study for the cancer workforce and the development of a HRPIS was only partially successful. Ultimately, the funding enabled a “scoping study” or environmental scan, intended to determine if the cancer work force data could be obtained reliably and sufficiently collected to operate an information system. Members of the scoping study team intended to create a research plan to form the basis of an application for a labour market sector study for cancer. In late 2006, the scoping study team received approval and funding from the Public Health Agency of Canada, for implementation over eighteen months, with anticipated completion by mid 2008.

In the meantime, the Canadian Strategy for Cancer Control, slowly and often painfully accrued support and encouragement that culminated in November of 2006 with the announcement of the Canadian Partnership against Cancer (CPAC), by Prime Minister Stephen Harper. Envisioned as a bold new approach to health planning and system management, CPAC is a non-governmental organization operating as a pan-Canadian coordination mechanism based on the collaboration model that included significant volunteer, professional and institutional representation.

In 2007, CPAC established its corporate identity. Headquartered in Toronto, it has recruited both a governing board and an executive team. CPAC has established an advisory council on cancer control, which includes representation from the chairs of the nine action groups, each representing a different topic or theme in cancer control, including human resources. Most important has been the dedication of operating funds to support the work of the action groups, according to work plans and budgets approved by the CPAC leadership and board.

The creation of CPAC and provision of operating budget to action groups provides a stimulus to rethink, refocus and, where necessary, restructure the activities
of working groups including the HRAG. The overarching purpose and vision for the HRAG of CPAC, is to become a credible, leaderful, influential and impactful team in the domain of health human resources for the cancer workforce. To do this, we (the HRAG of CPAC) will channel the 2008 work plan to support the following objectives:

• Collaborate and partner with relevant provider and stakeholder groups for cancer health human resources (HHR).

• Create, sustain and enhance a network of committed individuals and institutions to advance the work and understanding of HHR in cancer control.

• Create, sustain and enhance a bibliography and body of work in cancer HHR and provide helpful and relevant information digests and data to partners and collaborators.

• Develop, maintain and enhance an inventory of cancer health professionals as an observatory to monitor the workforce, predict problems and shortages.

• Gather information, conduct expert analysis of cancer service delivery models, and assess technological change in cancer control to determine the effects on HHR and identify optimal approaches for service delivery models across the cancer continuum.

• Provide guidance, facilitation and support for relevant targeted research and development projects in cancer workforce management.

• Compile, analyze and disseminate solutions, best practices, guidelines and indicators to improve cancer control through optimization of health human resources and business process reengineering.

The tools at the disposal of the HRAG of CPAC include: travel and meetings to develop partnerships and promote collaboration resulting in stronger more active networks of stakeholders, researchers, managers, analysts and professionals; the organization of conferences and workshops to foster collaboration, stimulate research development and data analysis; and knowledge management and the transfer of expertise and technologies used to create bibliographies and bodies of work as repositories of knowledge and data. Ongoing communications will support the work of the HRAG, providing regular updates to its working groups and other action groups, in addition to forging a formal linkage between the HRAG and CPAC.

Current projects underway include the aforementioned cancer workforce scoping study, which is expected to be complete by July 2008. Another project is currently canvassing provincial cancer agencies, programs and centres; as well as professional associations and other cancer stakeholder organizations to determine the nature and number of existing health human resource shortages and concerns in the cancer system. Operating support for the HRAG is now provided by a project director and support staff based in Ottawa at the Royal College of Physicians and Surgeons of Canada.

While much of the work in monitoring and responding to cancer workforce shortages and concerns has until recently been thanks to the efforts of dedicated volunteers, we have now been funded to create a solid foundation on which to build. I am confident that with the direction, support and funding provided by CPAC, the HRAG will make significant progress in the year ahead. We will augment and strengthen our network, collaborate effectively with stakeholders and decision makers, develop and share a body of work in cancer HR; including service delivery models, develop an inventory as an observatory for cancer HHR, promote research and development projects and create a mechanism to compile, assess and disseminate leading practice solutions for cancer workforce shortages and problems.

The HRAG is committed to improving the country’s capacity to reduce cancer cases, lengthen survival and lighten the burdens of cancer by ensuring that necessary and sufficient resources are in place. Canadians deserve no less.

Andrew Padmos, MD FRCPC is Chair of the Human Resources Action Group for the Canadian Partnership against Cancer and Chief Executive Officer of the Royal College of Physicians and Surgeons of Canada.

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The Cost of Cancer in Perspective

Cancer has been the leading cause of premature deaths for many years and will soon surpass cardiovascular disease as the leading cause of all deaths in Canada. The two diseases are familiar to all Canadian families.

In a special report for the CACC, Wyatt Health Management compared the hospitalization costs associated with cancer and cardiovascular disease. The intention is solely to initiate research about the burden these two killers place on health budgets. It is hoped that as the research continues, some degree of clarity will emerge about an appropriate level of funding to support the treatment needs of cancer patients. Much more information is needed about the cost per person over several years, for example and the costs of a wide range of healthcare interventions.

Excerpts from the Wyatt report are reproduced below. The full report, including appendices with additional data, can be found on the CACC Website with the background materials relating to this Report Card.

Cancer patients often have their treatment as outpatients in Cancer Centres, without being admitted. Cardiovascular patients are more often hospitalized. The question to be answered is how do hospital costs compare between cancer and cardiovascular care?

Hospitalizations Across Canada
Discharge data indicated for 2000/2001 there were a total of 2,889,586 discharges from Canadian hospitals. Of those 215,493 (7%) were for cancer diagnoses and 472,376 (16%) were for cardiovascular diagnoses. When looking at all diagnosis, the average stay was 7.2 days, more than it was in 2006. The average stay for cancer patients was 9.6 days and for cardiovascular patients was 8.7 days. From this, we can calculate the Hospital Resource Consumption Index (% diagnosis X length of stay) for cancer patients as 0.672 and for cardiovascular patients as 1.392. The ratio is 0.48 to 1, meaning cardiovascular patients consume more than twice the hospital resources that cancer patients do; a factor of 2.07.

Top 50 Diagnoses on Hospital Admittance
Admittance for cancer stands at 9% whereas admittance for cardiovascular disease is 33%, with the top three of the 50 reasons all being cardiovascular disease. The data was sorted by the Dx code. This accounts for only the top 50 admittances, which does not include all admittances to hospital. Other admittances would also include other cancers and other cardiovascular disease.

Top 50 Surgeries in Hospital
Cardiovascular related surgeries account for 42% of the top 50 surgeries, accounting for 3 of the top 4 surgeries. Cancer related surgeries account for approximately 8% of the top 50 surgeries. This accounts for only the top 50 surgeries, which does not include all surgeries in hospital. Other surgeries would also include other cancers and other cardiovascular disease.

Comparison of Cancer and Cardiac Care in Ontario
There are a number of factors to compare when looking at cancer and cardiac care in Ontario. An important factor is hospital stays and length of stay. For 2006, there were 30,127 hospital stays (total of 342,907 days in hospital) for cancer patients compared to 131,969 hospital days (total of 842,491 days in hospital) for cardiac patients that include cardiology and cardio thoracic care. In comparison, there are 4.4 times more hospitalizations for cardiac care than for cancer care.
HOSPITAL STAYS FOR ONCOLOGY, CARDIOLOGY AND CARDIO/THORACIC PATIENTS IN ONTARIO

HOSPITAL STAYS FOR ONTARIO RESIDENTS FOR
ONCOLOGY, CARDIOLOGY AND CARDIO/THORACIC PROGRAM CLUSTER CATEGORIES
– 2005, 2006 FISCAL YEARS

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td></td>
<td># Dschg</td>
<td>Total LOS</td>
<td># Dschg</td>
<td>Total LOS</td>
</tr>
<tr>
<td>ONCOLOGY</td>
<td>33,307</td>
<td>370,461</td>
<td>30,127</td>
<td>342,907</td>
</tr>
<tr>
<td>CARDIOLOGY</td>
<td>99,162</td>
<td>558,462</td>
<td>95,009</td>
<td>547,166</td>
</tr>
<tr>
<td>CARDIO THORACIC</td>
<td>37,862</td>
<td>325,168</td>
<td>36,960</td>
<td>300,325</td>
</tr>
</tbody>
</table>

If we compare Intensive Care Unit (ICU) stays, there were 1,437 ICU stays (total of 156,969 days in ICU) for cancer patients compared to 49,379 ICU stays (total of 3,929,224 days in ICU) for cardiac patients. This ratio is an astonishing 34.4 times more ICU stays for cardiac patients than for cancer patients. In ICU days, the difference is 25.0 times more for cardiac patients.

COST OF ICU BED IN ONTARIO NOT INCLUDING REHABILITATION HOSPITALS

<table>
<thead>
<tr>
<th>Size of Hospital</th>
<th>Average</th>
<th>Median</th>
<th>Range</th>
<th>Average</th>
<th>Median</th>
<th>Range</th>
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<tbody>
<tr>
<td>&lt;50 Beds</td>
<td>$1,995</td>
<td>$1,977</td>
<td>$438-3084</td>
<td>$1,971</td>
<td>$1,968</td>
<td>$438-3084</td>
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<tr>
<td>51-200 Beds</td>
<td>$2,253</td>
<td>$2,148</td>
<td>$1107-4452</td>
<td>$2,238</td>
<td>$2,148</td>
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<tr>
<td>201-350 Beds</td>
<td>$2,436</td>
<td>$2,460</td>
<td>$1935-2901</td>
<td>$2,436</td>
<td>$2,460</td>
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</tr>
<tr>
<td>&gt;350 Beds</td>
<td>$3,150</td>
<td>$2,901</td>
<td>$719-1,555</td>
<td>$3,159</td>
<td>$2,895</td>
<td>$719-1,555</td>
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</table>

INTENSIVE CARE UNIT STAYS FOR ONTARIO ONCOLOGY PATIENTS (PROGRAM CLUSTER)

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2005</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Care Unit</td>
<td># Special Care Stays</td>
<td>Spec. Care Hrs</td>
</tr>
<tr>
<td>Cardiac Intensive Care Nursing Unit Surgery</td>
<td>17</td>
<td>935</td>
</tr>
<tr>
<td>Combined Medical/Surgical Intensive Care Nursing Unit</td>
<td>1,035</td>
<td>108,382</td>
</tr>
<tr>
<td>Coronary Intensive Care Nursing Unit Medical</td>
<td>134</td>
<td>9,942</td>
</tr>
<tr>
<td>Medical Intensive Care Nursing Unit</td>
<td>199</td>
<td>17,092</td>
</tr>
<tr>
<td>Surgical Intensive Care Nursing Unit</td>
<td>71</td>
<td>6,383</td>
</tr>
<tr>
<td>Total ICU Stays And Hours For Oncology</td>
<td>1,456</td>
<td>142,734</td>
</tr>
</tbody>
</table>

Note: patients may have multiple stays in intensive care per inpatient stay
### INTENSIVE CARE UNIT STAYS FOR ONTARIO CARDIOLOGY PATIENTS (PROGRAM CLUSTER)

<table>
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<tr>
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<th>2006</th>
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<tbody>
<tr>
<td>Special Care Unit</td>
<td># Special Care Stays</td>
<td>Spec. Care Hrs</td>
</tr>
<tr>
<td>Cardiac Intensive Care Nursing Unit Surgery</td>
<td>623</td>
<td>41,722</td>
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<tr>
<td>Combined Medical/Surgical Intensive Care Nursing Unit</td>
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<td>830,326</td>
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<tr>
<td>Coronary Intensive Care Nursing Unit Medical</td>
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<tr>
<td>Medical Intensive Care Nursing Unit</td>
<td>4,450</td>
<td>283,269</td>
</tr>
<tr>
<td>Surgical Intensive Care Nursing Unit</td>
<td>82</td>
<td>6,061</td>
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<tr>
<td><strong>Total ICU Stays And Hours For Oncology</strong></td>
<td>27,113</td>
<td>1,779,385</td>
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Note: patients may have multiple stays in intensive care per inpatient stay

### INTENSIVE CARE UNIT STAYS FOR ONTARIO CARDIO/THORACIC PATIENTS (PROGRAM CLUSTER)

<table>
<thead>
<tr>
<th>FISCAL YEAR</th>
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<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Care Unit</td>
<td># Special Care Stays</td>
<td>Spec. Care Hrs</td>
</tr>
<tr>
<td>Cardiac Intensive Care Nursing Unit Surgery</td>
<td>7,510</td>
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<tr>
<td>Combined Medical/Surgical Intensive Care Nursing Unit</td>
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<tr>
<td>Coronary Intensive Care Nursing Unit Medical</td>
<td>8,079</td>
<td>531,571</td>
</tr>
<tr>
<td>Medical Intensive Care Nursing Unit</td>
<td>425</td>
<td>106,332</td>
</tr>
<tr>
<td>Surgical Intensive Care Nursing Unit</td>
<td>1,165</td>
<td>107,751</td>
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<tr>
<td><strong>Total ICU Stays And Hours For Oncology</strong></td>
<td>24,481</td>
<td>2,387,829</td>
</tr>
</tbody>
</table>

Note: patients may have multiple stays in intensive care per inpatient stay
With apologies to Charles Dickens “it was the best of care, it was the worst of care.”

In May 2006, my company doctor called and said to go immediately to the Emergency Department of our local hospital for a blood transfusion. He said I was in imminent danger of having a fatal heart attack.

I had been feeling poorly. A few days previously at his request I had had blood drawn. He had just received the results, indicating my red blood count was dangerously low. He insisted I not drive. My wife had to do that, just in case.

That day I had several blood transfusions. I stayed in hospital and within 24 hours was diagnosed with metastatic colon cancer. Life as I knew it had changed.

A professional and corporate executive, age 50, with three university age children I now found myself traveling through the health system. My journey illustrates some of what is working well and not so well in cancer care.

Let’s turn the clock back a few months before May 2006. I had started to feel extremely tired. A walk-in clinic ordered blood tests and forwarded the results to my family doctor. He called to say I was “chronically anemic.”

I saw him and that’s when things started to go awry. There was no physical examination. He simply announced I had a stomach ulcer. He prescribed an ulcer medication, said he would book an “upper GI exam” several months down the road and opined the drug would likely clear up the ulcer by that time.

I knew I didn’t have a stomach ulcer. So I had the same blood results reviewed by my company doctor.

His approach was a universe apart. He looked at the results and said I didn’t have an ulcer. He examined me very thoroughly. He indicated my blood count raised questions about the colon. I needed immediate referral for colonoscopy, CAT scan, etc. and he set those up.

He insisted I have more blood taken. In the following week, it was the results of my next blood test that prompted his fateful call to go immediately to the Emergency.

Subsequently, I suggested to the doctor who misdiagnosed an ulcer that he should have colleagues in his practice “peer-review” my file. I expressed fear that if uncorrected, his practice “may result in other individuals being similarly misdiagnosed when there is still time to successfully address their cancers.”

When he ignored my letters I wrote the College of Physicians and Surgeons. Making it clear I was not seeking disciplinary action, I only sought assurance that “knowledgeable medical professionals would look at this, and if there was merit to my concern” they address it with the doctor “so that his future care of others would be better than it seems to have been in my case.”

The College did as asked and “identified a number of areas of concern with the care provided” to me by my original doctor. They directed him to take actions including attending a program to “update his knowledge and develop an appropriate approach to the investigation of anemia.”

1. **Doctors need to be more aware of cancer symptoms and, having identified those symptoms, be more timely and aggressive in referring patients for further investigation.**

My company doctor, who took over as my family doctor, referred me to a surgeon who specializes in the colon. He had trained and practiced at the Mayo Clinic
before deciding to return home to Canada. This surgeon put me on his “emergency list.” He also told me that when he first returned home he was promised five surgery days every two weeks. But shortages of anesthetists and other cutbacks reduced this to three days every two weeks. His waiting list became huge, and he had to stop accepting referrals of complex cases from other provinces.

2. Resource constraints are preventing extremely competent specialists from being fully productive.

Let’s return again to when I was first diagnosed. It is the second day of my hospitalization. I was told I had colon cancer which spread to my liver. I’m now on a gurney about to be pushed through the donut hole of a CAT scan.

A doctor I had never met before suddenly loomed over me. Without any preliminaries she said. “I’m Dr. N——. I’ve looked at your scan. You have at best six to nine months so I’m not recommending surgery.”

Wow! Talk about a lack of bedside manner. And leave aside the fact that, as of the time of writing this, I have lived three times as long as her grim and off-the-cuff prognosis.

Of more importance was not letting what that doctor said deter me from seeking other doctors’ opinions and finding out that there were the other options (including the surgery she wasn’t “recommending”). These have kept me alive and generally well, in spite of my still having very serious cancer.

One should be very troubled by the question: “How many other folks, less assertive than me, would have just taken what she said as the final word, pursued no other treatment, given up, gone home, and made ready to die?”

3. Carelessly giving premature and incomplete information contributes to some cancer patients not seeking the care they need to significantly prolong their lives.

Let’s jump ahead few months. I have now had successful surgical removal of cancer from my colon, but I know the real fight is in my liver. I have a great oncologist. Several months into chemotherapy he recommended a targeted therapy, Avastin, which, while not a cure, might shrink the tumors and further sustain my life.

The trouble is that while the oncologists here and elsewhere have all agreed this drug should be included as standard medical care for patients with precisely my condition, it is very expensive (on average $35,000). It is not funded by my province. Here’s the real kicker. If I lived in BC, or in Quebec, or next door in Newfoundland and Labrador, the drug is provincially funded.

Fortunately I have the means to pay for this drug. So I began taking it at a private clinic, still under my oncologist’s care.

But I got angry as I became aware that in any given year, of about 100 Nova Scotians who should be taking and potentially benefiting from this drug, only a handful, for financial reasons, actually receive the drug.

This is the worst of two-tier health care. It starkly demonstrates the unfairness of a system that allows one standard for the wealthy and a lower standard for everyone else. Those who have the financial means to obtain the drug will probably live longer while those who do not will probably die sooner.

4. Canadians should not live or die of cancer by reason of their province of residence.

I responded reasonably well to chemotherapy. The tumors in my liver shrank to the point where a surgeon said, if I was prepared to be aggressive, he “might” be able to get it all.

But some annoying little spots were showing up in CAT scans of my lungs. A PET scan was required to determine if they were cancerous. We don’t have a PET scan in Nova Scotia. (One is under construction, thank goodness.)

The closest PET scan is in New Brunswick, a five hour drive away. But Nova Scotia, engaged in a silly bureaucratic disagreement, will not pay for PET scans in New Brunswick. Instead Nova Scotians must travel a far greater distance to Quebec where the government will pay for scans.

Travel costs (none of which government pays) were not an issue for me. But again, let’s think of all those Canadians, in tighter financial circumstances, who need this important test which would determine if they could undergo life-prolonging surgery, but cannot pay for it, or cannot access it much closer to home.

5. Inequitable access to cancer diagnostics means some Canadians will do without and suffer unnecessarily.

Then I encountered an example of how waiting times become much longer than necessary. The office of the surgeon who ordered my PET scan waits until the results have been received before contacting the patient to book the follow-up consultation.

A suggestion to medical booking staff: determine how long it usually takes to receive the report for each diagnostic test. Then book the follow-up appointment
This is the worst of two-tier health care. It starkly demonstrates the unfairness of a system that allows one standard for the wealthy and a lower standard for everyone else.

with the patient at the same time you book the patient’s diagnostic test. This might shorten the time to the next doctor’s visit by only two to three weeks, but it will make a huge difference for patients worrying about the progression of their disease.

6. Wait times can be shortened by better schedule management and doing so will make patients feel better.

Speaking of feeling better, here’s a tale of two nurses. The day I was diagnosed with cancer, I was lying in my hospital room when an older nurse came in and introduced herself as just coming on midnight shift. She said she knew I had had some bad news. She offered that it might be a long night and if I was awake and needed someone to talk to or sit with, I should press the button and she would be there.

A few weeks later, I was just out of surgery. Once again alone in a hospital room, this time looking at pictures of my three beautiful children, I must have been feeling sorry for myself for another nurse appeared, sat down, and gave me a hug.

I don’t recall the names of either nurse but they are the closest I have ever met to angels. God bless them.

The only other health professional who has asked about emotional or non-physical issues was my company doctor. People with cancer face practical issues that have nothing to do with their treatment options. They and their loved ones face tough decisions and experience a range of strong emotions. There may be economic pressures, sexual issues and certainly a whole host of other stresses with which to cope.

You cannot fully treat a cancer patient without being aware of the other non-medical stresses in the life of a cancer patient and his family that may negatively affect the outcome of treatments.

7. Failure to address the emotional and practical issues confronting the cancer patient can negatively affect treatment of the whole person.

By nature I am not a critical person. I look for the positive in any situation. Likewise as we consider shortcomings in cancer care (including the criticisms I have made) it is important to view the big picture. An older oncologist told me that when he started practicing 40 years ago, 80 per cent of children with cancer died. Today, 80 per cent live.

There have been huge advances. I have nothing but praise for the vast majority of the professionals who serve in the front-lines. But as with any large system, especially one over-burdened and under-resourced by government, there are always opportunities for improvement. The foregoing, though anecdotal, is, I hope, illustrative of a few of those opportunities.

We face a cancer crisis in this country. At current rates, one of every four persons will die of cancer. To return to Dickens, one might say in the face of such an ominous future “it was the worst of times.” But when we consider the array of resources and talents which we could potentially use to meet that challenge head on, surely we would want to be able to look back and say instead that “it was the best of times.”

James L. Connors is a lawyer and cancer survivor living in Dartmouth NS and a Director of the CACC.

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A New Day Dawns 
for Kidney Cancer Patients 

at least for those with the 
very best private drug insurance 

DEBORAH MASKENS 

Bill and Kim Dompiere have both enjoyed successful careers as teachers in Nova Scotia. After years of being active within their local community, they had a small army of loyal friends and supporters who rallied behind Bill when he was first diagnosed with renal cell carcinoma in 2001 and later in 2003 when he required surgery to his right lung.

In 2007 when Bill’s kidney cancer returned to his lungs, the Dompiere’s were shocked to learn that the one and only drug his oncologist could recommend was not covered by the province of Nova Scotia. As long-time teachers who have paid into a private health insurance plan for over 30 years, they anticipated full coverage for Bill’s oral cancer drug, Sutent. After Medavie/Blue Cross denied coverage for Sutent, Bill and Kim were left with no other option but to pay $7,800 every six weeks out of pocket.

“As a high school teacher for 31 years, I have paid literally thousands of dollars into Blue Cross,” says Kim. “I trusted the Nova Scotia Teachers’ Union to secure the best health coverage for me and my family.” The Nova Scotia Teachers’ Union joined the Dompiere’s in appealing the denial of coverage. All the while, Kim watched television ads for private health insurance in the Maritimes – commercials that advertise how, for $2 per day, a family could be saved from catastrophic drug costs – but clearly not if you have the misfortune to be diagnosed with kidney cancer.

Nova Scotians without private insurance have appealed to local MLAs and to the Health Minister. Few letters have been answered, but one letter from the Health Minister advised people like the Dompiere’s to access the financial needs office. As teachers and home owners who were looking forward to retirement in 2010, people like the Dompiere’s simply don’t qualify.

Instead, their small army of supporters planned a series of fundraising events to help pay for Bill’s cancer tablets. Kim pursued financial aid available from her employer and committed to do “whatever it takes” to make sure Bill has access to a life-saving drug. Finally, after three presentations to the Board of Medavie/Blue Cross and threatened legal action, the Dompiere’s received word in January 2008 that Bill’s cancer treatment would be covered.

Kim despairs at the choices other patients in the Maritimes must now face – whether to sell their home and pay for the drug, or accept an average one-year survival with metastatic renal cell carcinoma with traditional (and largely ineffective) treatments. “How can Canadians justify a patient being funded to receive Sutent in Quebec, but not in New Brunswick? Can we accept that patients’ home addresses may determine their eligibility to receive effective cancer therapy?”

International studies presented at ASCO 2006 and ASCO 2007 presented by Dr. Robert Motzer reference Sutent as the new reference standard for first-line treatment of metastatic renal cell carcinoma. These results have since been published in The New England Journal of Medicine and have been referenced in international
My plan is the same as current MPPs. If they are covered for this, then everyone should be covered.

Patients like Bob Eaton in Ontario hardly knew what all the fuss was about. “I pick up my prescription at my local pharmacy” says the retired Ontario MPP. “The slip says $8,676.13 but I’ve never paid a penny.” Bob’s private plan covers 90 per cent of the cost for Sutent and the manufacturer (Pfizer) picks up the ten per cent co-pay amount. “I was shocked when my doctor informed me that other Ontarians and other Canadians have to pay for this drug out of pocket” says Bob. “As a former MPP for 13 years, I have to ask – what on earth has happened to our provincial plans for catastrophic drug coverage? My plan is the same as current MPPs. If they are covered for this, then everyone should be covered.”

Diagnosed with metastatic renal cell carcinoma in October 2006, Bob was initially given a bleak prognosis. Dr. Peter Ferguson, the orthopedic oncologist treating the cancer in his hip and pelvis, put it plainly: “looks like you’ve got six months.” A year later, that same doctor calls Bob his miracle man.

Between Christmas and New Year 2006, Bob considered himself at death’s door. “I had accepted that I would never work again – that this was the end.” Down to 150 lbs then, he had surgery to remove the tumors and then started Sutent. Today, Bob is back to 180 lbs and CT scans show no evidence of disease. He suffers from very few side effects, just a few mouth sores in the last week of his four-week cycle of tablets. Now back to work as a real-estate broker operating four offices, Bob and his wife Pat recently joined his colleagues in Bermuda for the annual conference.

In his spare time, Bob is working with Kidney Cancer Canada, a new patient support and advocacy organization, to ensure that patients like him have access to lifesaving treatments such as Sutent. “I was an elected member of the provincial legislature for 13 years and served in Cabinet and Management Board of Cabinet, and so I appreciate the difficult decisions governments must make sometimes. But to deny someone a chance to try these remarkable new drugs is unthinkable. How can an elected member face a constituent and tell them that their life isn’t worth the cost of this drug?”

Bob’s oncologist, Dr. Mary McKenzie in London, Ontario plans to keep Bob on Sutent. Cases of other patients like Wally Vogel in Toronto are showing unprecedented long-term potential for these drugs in the fight against kidney cancer.
We are literally making history here – at least for those who can access the drugs

At 43 years old, Wally Vogel credits Sutent with saving his life. His prognosis in 2004 was extremely poor with extensive metastasis to his liver, spleen, and throughout his abdomen. Starting Sutent at the Cleveland Clinic gave Wally a head start before the drug was approved by Health Canada. Beginning in January 2006, he continued receiving Sutent in Canada under clinical trials at Princess Margaret Hospital in Toronto.

Sutent shrunk his tumours by 85 per cent, allowing surgeons to remove the remaining metastasis. Pathology proved that many of his tumors had necrotized and were no longer active. The final remaining met in the lumbar muscle was removed using RFA (radio frequency ablation) in May 2007.

In June 2007, Wally had CT scans that confirmed the words he never thought he would hear: he is now clinically free of any evidence of disease. He is back to work running his own software company and living a full and active life. Wally’s Medical Oncologist, Dr. Jennifer Knox, comments that with drugs like Sutent now available, “we are literally making history here” – at least for those who can access the drugs.

After the failure of the Common Drug Review (CDR) to review new cancer drugs, patients and oncologists rest their hope in a new process that will, in theory, bring about some standardization across Canada. A new national process, the Joint Oncology Drug Review (JODR), with representatives from each province (except Quebec), is being piloted. This body will review the efficacy of oncology drugs at a national and provincial level to develop uniformity and consensus.

So far, the jury is out. From Health Canada approval in August 2006, Sutent was first denied by the CDR seven months later in February 2007. Quebec was first to fund the drug in June 2007, followed by British Columbia in July 2007, and then Ontario in November 2007. Time will tell whether provinces with lesser health care budgets will adopt the JODR recommendation in favour of Sutent.

In the meantime, patients like Bill Dompierre will go on thanking the private fundraisers who organized fundraising events to pay for his drugs. “We never expected to be in this position” says Kim Dompierre. “We’ve worked all of our lives. We’ve paid our taxes in Nova Scotia, and we’ve paid into private insurance. If I had breast cancer, all of my drugs would be covered here. Why is that kidney cancer patients are being left out in the cold?”

Written by: Deborah Maskens, kidney cancer patient and Vice-Chair, Kidney Cancer Canada. Deb is clinically free of kidney cancer thanks to new targeted agents only available to rcc papillary patients through private insurance in Ontario.

Bill Dompierre lives in Bedford, Nova Scotia. Until his medical leave, Bill taught at Nova Scotia Community College (NSCC) for 31 years.

Bob Eaton lives in Dorchester Ontario. Bob is a former MPP for Middlesex County and currently works in real estate.

Wally Vogel lives in Mississauga Ontario where he is resuming his life after two years of successful treatments for metastatic kidney cancer.

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Young Adult Cancer Patients

GEOFF EATON

Each year in Canada, at least 6500 young adults in the age group 15–39 are diagnosed with some form of cancer. The most common malignancies in young females are cancers of the breast, cervix, and ovaries; while in young males testicular cancer is followed by non-Hodgkin’s lymphoma. For unknown reasons, some malignancies are increasing among young adults of both sexes including cancers of the thyroid, lung, brain, and non-Hodgkin’s lymphoma in young women and testicular cancer in young men. Young adults are also affected by the more common cancers.1

The numbers are relatively small, but do not give a true reflection of the potential years of life lost to society, nor the cost to each individual having to deal with cancer at this young age. The cost can be better estimated in terms of Potential Years of Life Lost or PYLL. This metric evaluates the societal impact of any given disease by calculating the lost potential of those dying between the ages of zero and 70. As shown in Table 1, the incidence of cancer in the age group 15–39 in 2002 was only 10 per cent of that in older age groups2 (9.1 per cent versus. 89.7 per cent) but the PYLL is 28.3 per cent of the total PYLL from cancer.

For many years the prognosis for adolescents and young adults with cancer compared favourably with that for both younger and older patients. However, over the period 1975–1997 not only did adolescents and young adults develop more cancer, but improvements in survival in this age group failed to keep pace with improved outcomes seen in children and older adults. The data are shown in Figure 1. There are several reasons for the disparity in survival between this age group and the others.

One factor generally recognized as contributing to the disparity is the paucity of age-specific clinical research. It is well recognized that survival rates among participants of structured clinical trials are uniformly higher than in the general population of cancer patients, and that clinical research in general improves survival. Approximately 30 to 50 per cent of cancer patients under the age of 15 participate in clinical trials, compared to only about one to two per cent of young adults.3

In 2006, the Canadian Institutes of Health Research, the National Cancer Institute of Canada (funded primarily by the Canadian Cancer Society) and the Terry Fox Foundation invested, in the aggregate, $76-million in newly funded research studies for that year, as documented elsewhere in this Report Card. A search for projects focusing on young adults with cancer identified exactly one grant, approved for $61,061 (0.08 per cent

<table>
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<tr>
<th>AGE RANGE</th>
<th>PYLL</th>
<th>% OF TOTAL PYLL</th>
<th>INCIDENCE</th>
<th>INCIDENCE %</th>
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<tr>
<td>0-14 years</td>
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*PYLL Potential Years of Life Lost
Adolescent and young adult cancer survivors indicate that a defining feature of their illness was a feeling of profound isolation

of the total). The proposal was to study preservation of fertility in female cancer survivors.

Notwithstanding the fact that results from other cancer research will at times benefit young adults, the group under consideration has unique problems that merit special attention. It is possible, for example, that treatments tested in older adults are not as well suited to the biology of the cancers occurring in younger adults. Some as yet unrecognized biological factors may well be operating which disadvantages young adults from the outset, for example, more aggressive tumor biology, different hormonal milieu, different rates of metabolizing drugs, etc.

Furthermore, young adults might benefit from and be able to tolerate more aggressive and more effective treatments than older adults. The therapy they currently receive from oncologists accustomed to treating older patients is generally less aggressive than that administered by pediatric oncologists to children with the same malignancies. International studies indicate that adolescents treated in pediatric centres have much better outcomes than if they are referred to adult treatment centres.4 Hopefully, the young adult oncology program pioneered at McGill University Health Centre under the direction of Dr. Petr Kavan will serve as the model for others to follow to see whether advantage can be taken of this aspect.

Thus a combination of factors may be conspiring against this patient group to tip the scales against their odds of survival. Inadequate participation in trials, lack of age-specific protocols, a cancer which may behave more aggressively, a different physiologic milieu, reduced treatment dose intensity, delays in diagnosis, and treatment inappropriate for their particular malignancies may all be operating.

A diagnosis of cancer also has important age-specific psychosocial ramifications for adolescents and young adults different from those seen in children or older adults. Young adult cancer patients report encountering systems at all levels geared to individuals two or three times their age, producing feelings of profound isolation. Compounding this is the small number of peer-support programs for young adults with cancer. For example, CACC could identify only four major cancer centres (Victoria, Vancouver, Winnipeg, and Ottawa) that had support groups open to young adults which met on at least a monthly basis. Even these were somewhat restricted. In Victoria the support group was for women only, in Vancouver the support group was only for patients with breast cancer while in Ottawa the support group accepted only cancer survivors treated at the Ottawa Regional Cancer Centre.

The survey uncovered three additional support programs: two offered sporadically throughout the year and one, at the Princess Margaret Hospital, offered daily childcare to patients receiving treatment. In contrast, the Princess Margaret Hospital has 23 support programs targeted at various segments of the adult population. The survey also revealed only five additional support groups run by community based organizations in Vancouver, Toronto and Montreal.

The personal challenges faced by young adult cancer survivors are also unique. Looming large, just as adult life supervenes, are issues related to fertility preservation and a struggle for physical and financial independence. Compounding these issues is the isolation of young patients from survivor peers who truly understand the challenges they face. In fact, a recent study revealed that young adults place a higher value on a connection with survivor peers than support from family and friends.5 With so little support designed to meet their unique needs, small wonder that adolescent and young adult cancer survivors indicate that a defining feature of their illness was a feeling of profound isolation.
FIGURE 1 CHANGE IN 5-YEAR RELATIVE SURVIVAL RATE OF ALL INVASIVE CANCER, SEER, 1975–1997

Source: Cancer in Young Adults, 2006

Recommendations
A shift of at least a subset of young patients to treatment in specialized centres is in order which, as mentioned earlier, is being undertaken at McGill University Health Centre. This would not only reduce delays in diagnosis and treatment, it might also lead to more appropriate treatment, and ultimately better survival if some of the following areas were investigated as they apply to individuals aged 15–39:

1. Age-specific differences in the biology of selected malignant diseases,
2. Barriers to development of and accrual to clinical trials,
3. The impact on survival, quality of life, and delayed side effects of treatment of specially tailored oncology programs, and
4. Unique psychosocial issues.

Acknowledgements
The author would like to extend special thanks to Dr. Anthony Miller, a former CACC Board member now chair of the CPAC Quality and Performance Assurance Action Group, Dr. Mark Greenberg at the Pediatric Oncology Group of Ontario, Karen Joblin and the various professionals in cancer centres across the county for the help they graciously extended in the research for this article.

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“Silencing the doctors will harm patients”

JOHN CROWN

The following, reprinted with permission of the author, Dr. John Crown, an oncologist in Ireland, describes what may happen when oncologists accepting guaranteed salaries from governments try to speak out on behalf of their patients’ welfare.

In the current climate, any senior medical specialist who expresses reservations about the patient care implications of any aspect of Health Minister Mary Harney’s proposed new consultant contract will be accused of obscuring financial self-interest behind a smokescreen of public advocacy.

Despite this, I hope that commentators who understand that the appointment of 1,500 new public-only consultants is very much in my self-interest will hear me out when I say that one aspect of the proposed new dispensation has great potential to undermine care and to harm patients.

I am referring to Minister Harney’s surprising attempt to do away with the traditional role of doctors as advocates for their patients, both as individuals, and in the collective, by gagging their right to speak out on health policy issues. Specifically, we should all be very alarmed that the proposed new contract seeks to limit the ability of consultants to state their views on matters which the Health Service Executive might deem to be “health service business”.

We should be reminded of Fintan O’Toole’s insightful description of a “corporate mentality” in the Department of Health, which makes it primarily loyal to itself, and not to its clients, or to the citizenry at large. While it will come as no surprise that these public servants will have included a medical muzzle on the wish list that they presented to Minister Harney, it is remarkable that she, undergoing an apparent death-bed conversion to Sir Humphreyism, is tamely and acquiescently ticking their box.

I have a personal perspective on this issue. When I returned to Ireland in 1993 as only the fourth medical oncologist in our entire country, I found myself working in what was clearly, palpably and measurably the worst cancer treatment system in Western Europe. I was simply flabbergasted at the grotesque departures from international standards of routine practice that applied here.

All four public sector medical oncologists worked in Dublin, with another oncology-trained doctor appointed as a haematologist in Galway. Radiotherapy was available only in Dublin and Cork. Many patients with highly treatable cancers were being under-treated or totally untreated.

Some died unnecessarily, or prematurely, or spent their last days in avoidable misery. Others were unnecessarily subjected to mutilating operations because proven, internationally recognised treatment alternatives, were not widely available here. Poor cancer care was not an equal opportunity visitor moreover, and public patients, and in particular female public patients, bore a disproportionate burden.

While individual doctors attempted to draw attention to this scandal, our profession, largely drawn from a spectrum of Irish society in which conservatism, begrudgery and schadenfreude jostle for primacy, was, through its omerta-like silence, and failure to support those who advocated change, too often complicit in the problem.

Approximately a year after my arrival (and before I was placed under Departmental Fatwah) I had occasion to meet with officials from the Department. One opined (in response to my complaints about deficiencies) that it was her opinion that there were actually too many oncologists in Ireland (perhaps she meant one too many). Thankfully, the press became involved, and after two years of media coverage, which had the desired effect of putting the cancer services on the national,
Muzzling is part of a larger culture war in medicine

and ultimately on the political agenda, a substantial belated service improvement took place.

Intimidation was the order of the day, however. Together with other colleagues, I was brought into the Department for a dressing-down because they were displeased with the adverse coverage. I was subsequently hauled in by senior colleagues in my own institution, and told that the Department had informed management that a failure to silence me might result in their reconsidering much needed investment in the hospital.

On another occasion, I was told that I was only saved from dismissal by the safeguards in the self-same contract that Minister Harney wants to abolish. These are the people who want to determine who has the right to speak out on health service business.

Similarly, under the new contract, would I have been muzzled when I blew the whistle on life-threatening religious interference in cancer clinical trials? Did anyone, by the way, notice the stunning silence on this issue from the HSE and the Department?

What of the ubiquitous public relations companies, many of whom appear to be rather well-connected, who have been awarded lucrative contracts by our hospitals? What exactly is their role? Who do they work for? Will it be the spin doctors, or the medical doctors who will be the patients’ information watch dogs in Harney-land?

Muzzling is part of a larger culture war in medicine. Eisenhower warned of the dangers of a “military industrial complex”. We now have an analogous situation in the UK and Irish health services, where a ‘hospital administrator/civil service complex (HACS)’ has taken firm control of hospital management. The HACS wish to remove the historical clinical leadership and advocacy roles of senior specialists, transforming us into mere technicians, therapists who would implement treatments not on the basis of scientific evidence or the needs of individual patients, but of bureaucratic approval.

Our current leadership and advocacy roles are seen as throwbacks to days of elitism by the HACS who believe that they, and they alone amongst a rabble of warring vested interests can provide sufficiently objective leadership to the system.

The situation is particularly acute in the UK, where one such bureaucracy, the hilariously named National Institute of Clinical Excellence, or NICE (Orwell anyone), has denied many life-saving, prolonging and enhancing therapies to patients, disproportionately to women with cancer, on the grounds of cost.

The Irish HACS have introduced a new equally hilariously named Irish NICE equivalent (‘NOICE’ anyone?) called the Interim Health Information and Quality Authority, which has delayed the introduction of the best drug we have ever seen for kidney cancer, pending cost analysis.

Another product, a long-awaited vaccine which holds the promise of preventing cervical cancer, has fallen foul of Minister Harney’s new cost-containment regulations.

Consultants have lost the battle over the new appointments. When Fianna Fail, Fine Gael, Labour, the Progressive Democrats, the Greens, Sinn Fein, the HSE and the Department want them implemented, they will be. Our failure to police the compliance of the minority of our colleagues who have taken advantage of our current contract is partly to blame for our predicament. Our options are capitulation, or the path of the kamikaze.

It is, however, more important than ever that we continue to fight the right fight which is the good fight. No free speech – no contract.

John Crown is a medical oncology consultant in Dublin.

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The New Wave of Cancer Drugs

KONG KHOO, ROSEMARY COLUCCI, WILLIAM HRYNIUK, JOSEPH RAGAZ, SANDEEP SEHDEV and COLLEEN SAVAGE

In the first Cancer Drug Access report,\(^1\) we documented the marked inter-provincial variability in access to 24 new cancer drugs. It was clear, that as a cancer patient in Canada, where you live significantly impacts your ability to access new cancer drugs.

In Cancer Drug Access Part Two\(^2\) we identified where improvements and deficiencies in cancer drug access were occurring in different parts of the country. We noted that an increasing number of treatments required self pay or private coverage. We documented the introduction of private chemotherapy infusion clinics, along with the advent and implementation of programs for charging patients for drugs not publicly funded but delivered within the public system.

In this report, Cancer Drug Access Part Three, we expand our study to include 18 additional new drugs (making a total of 42) representing a new wave of evolving treatment options for patients facing a variety of different cancers. We report on changes in access to the 24 drugs previously studied and the emergence of any trends in how patients are obtaining the 18 new drugs. We again note the increasing role of private payers and third-party insurance and we document once more that where you live in Canada makes a difference in your ability to access new cancer drugs.

**Methodology**

As previously reported, we surveyed medical oncology specialists and oncology pharmacy experts in each province as to the current funding status and availability of novel oncology drugs as of December 25, 2007. Data were compiled as previously described.\(^1,2\)

In addition to prior categories describing drug access (see legend for Table 1), we also added an “O” category to highlight where a drug was being accessed out of country but paid for by a provincial health ministry.

We also added another category in pharmaceutical company sponsored assistance programs, P1, referring to expanded access programs which enabled patients to access drugs that may not yet have received Health Canada approval or provincial funding. This category is increasingly one of the limited ways to access new cancer drugs in this situation.

Key studies that reported the effectiveness of the selected cancer drugs and their dates of publication are listed including reports presented at major cancer meetings. Preliminary reports leading to regulatory approval, especially FDA approval, are increasingly being presented to the scientific community, and subsequently via various media to an increasingly informed public sector and cancer patients. The dates are included to illustrate the complex timelines of evolving new information.

The cost in Canadian dollars of a standard course of cancer drug therapy was calculated as previously described. US retail prices were used where drugs had not yet received approval by Health Canada, and/or were not yet commercially available in Canada.

**Definition of Limited Access**

Barriers and limitations to access were defined as follows:

L1 Only for specific disease indications (usually in the form of special authorization or case-by-case request and application)

L2 Only for specific patient groups (e.g., age over 65, or receiving social assistance)

L3 Only in some institutions within the same province

L4 Only available through private payment (e.g., self-pay, third party insurer) or manufacturer’s compassionate access or assistance program but administered in a public institution
<table>
<thead>
<tr>
<th>Cancer Drug (Trade Name)</th>
<th>Cancer Indication</th>
<th>Level of Evidence</th>
<th>Date of Approval in US (FDA)</th>
<th>Date of Approval in Canada (Health Canada)</th>
<th>Approval Timing Difference in Canada vs US</th>
<th>Drug Cost for Standard Course total duration (SCDN unless otherwise stated)</th>
<th>References for Key Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pemetrexed (Alimta)</td>
<td>Non-small cell lung cancer</td>
<td>1</td>
<td>Aug 19, 2004</td>
<td>Jan 11, 2007</td>
<td>28.7 mo</td>
<td>$23,000 (6 cycles)</td>
<td>(4)</td>
</tr>
<tr>
<td>Rituximab (Rituxan)</td>
<td>First line therapy of low grade NHL</td>
<td>1</td>
<td>Sept 29, 2006</td>
<td>Dec 20, 2005</td>
<td>-9.3 mo</td>
<td>$27,000 (8 cycles)</td>
<td>(5,6,7)</td>
</tr>
<tr>
<td>Rituximab (Rituxan)</td>
<td>Maintenance therapy of follicular NHL</td>
<td>1</td>
<td>Sept 29, 2006</td>
<td>July 28, 2006</td>
<td>-2 mo</td>
<td>$27,000 (8 doses over 2 years)</td>
<td>(8,9)(10,11)(12,13,14)</td>
</tr>
<tr>
<td>Cetuximab (Erbitux)</td>
<td>Locally advanced H&amp;N cancer</td>
<td>1</td>
<td>Mar 1, 2006</td>
<td>Not approved; not commercially available in Canada</td>
<td>22+ mo</td>
<td>$16,000–$20,000 (7-8 weekly cycles)</td>
<td>(15)</td>
</tr>
<tr>
<td>Lenalidomide (Revlimid)</td>
<td>Relapsed multiple myeloma</td>
<td>1</td>
<td>June 29, 2006</td>
<td>Not approved; may be accessed through SAP</td>
<td>18+ mo</td>
<td>$74,000 US (1 year)</td>
<td>(16), (17)</td>
</tr>
<tr>
<td>Lenalidomide (Revlimid)</td>
<td>Myelodysplastic syndrome; 5q-</td>
<td>3</td>
<td>Dec 27, 2005</td>
<td>Not approved; May be accessed through SAP</td>
<td>24+ mo</td>
<td>$63,000 US (12 cycles; 1 year)</td>
<td>(18), (19)</td>
</tr>
<tr>
<td>Imatinib (Gleevec)</td>
<td>Adjuvant therapy for gastro-intestinal stromal tumour</td>
<td>1, 3</td>
<td>Not approved; priority review pending</td>
<td>Not approved; Off label indication</td>
<td>N/A</td>
<td>$38,000 (1 year)</td>
<td>(20), (21), (22), (23)</td>
</tr>
<tr>
<td>Sunitinib (Sutent)</td>
<td>Advanced renal cell carcinoma</td>
<td>1</td>
<td>Jan 26, 2006</td>
<td>Aug 17, 2006</td>
<td>6.7 mo</td>
<td>$66,000–$75,000 (1 year)</td>
<td>(24,25,26)</td>
</tr>
<tr>
<td>Sunitinib (Sutent)</td>
<td>Relapsed GIST refractory or intolerant of imatinib</td>
<td>1</td>
<td>Jan 26, 2006</td>
<td>May 26, 2006</td>
<td>4 mo</td>
<td>$66,000–$75,000 (1 year)</td>
<td>(27,28)</td>
</tr>
<tr>
<td>Sorafenib (Nexavar)</td>
<td>Advanced renal cell carcinoma</td>
<td>1, 3</td>
<td>Oct 20, 2005</td>
<td>July 28, 2006</td>
<td>8.3 mo</td>
<td>$70,000 (1 year)</td>
<td>(29), (30,31)</td>
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<tr>
<td>Sorafenib (Nexavar)</td>
<td>Advanced hepatocellular carcinoma</td>
<td>1</td>
<td>Nov 16, 2007</td>
<td>Not approved; off label use</td>
<td>1.3+ mo</td>
<td>$35,000 (6 months)</td>
<td>(32)</td>
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<tr>
<td>Pegylated liposomal doxorubicin (Caelyx)</td>
<td>Ovarian cancer</td>
<td>1</td>
<td>June 28, 1999</td>
<td>Jan 20, 2001</td>
<td>5.8 mo</td>
<td>$15,000–$16,000 (6 cycles)</td>
<td>(33), (34)</td>
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<tr>
<td>Azacytidine (Vidaza)</td>
<td>Myelodysplastic syndromes</td>
<td>1</td>
<td>May 19, 2004</td>
<td>Not approved; may be accessed through SAP</td>
<td>30+ mo</td>
<td>$56,000–$61,000 US (1 year; 12–13 cycles)</td>
<td>(35,36)</td>
</tr>
<tr>
<td>Dasatinib (Sprycel)</td>
<td>Ph+ ALL</td>
<td>3</td>
<td>June 28, 2006</td>
<td>July 7, 2007</td>
<td>12.3 mo</td>
<td>$55,000 (1 year)</td>
<td>(37,39, 38)</td>
</tr>
<tr>
<td>Dasatinib (Sprycel)</td>
<td>Refractory CML</td>
<td>3</td>
<td>June 28, 2006</td>
<td>Mar 26, 2007</td>
<td>9 mo</td>
<td>$55,000 (1 year)</td>
<td>(37,40), 38, (41,42), (43,44)</td>
</tr>
<tr>
<td>Temsirolimus (Torisel)</td>
<td>Renal cell carcinoma</td>
<td>1</td>
<td>May 30, 2007</td>
<td>Dec 21, 2007</td>
<td>6.7 mo</td>
<td>$68,000 US (1 year)</td>
<td>(45)</td>
</tr>
<tr>
<td>Bexarotene (Targettin)</td>
<td>Cutaneous T-cell lymphoma</td>
<td>3</td>
<td>Dec 29, 1999</td>
<td>Not approved; may be accessed through SAP</td>
<td>96+ mo</td>
<td>$40,000–$45,000 US (8 months)</td>
<td>(46,47)</td>
</tr>
<tr>
<td>Lapatinib (Tykerb)</td>
<td>HER2/neu positive metastatic breast cancer</td>
<td>1</td>
<td>Mar 13, 2007</td>
<td>Not approved</td>
<td>9+ mo</td>
<td>$14,000–$18,000 US (6-8 cycles)</td>
<td>(48)</td>
</tr>
</tbody>
</table>
RESULTS

Access to Cancer Drugs

Of the 18 new drugs and indications studied, only two were for curative intent, while 16 were for palliative treatment. The two new drug indications for curative/adjuvant treatment were Erbitux combined with radiation for head and neck cancer, and Gleevec as adjuvant therapy for surgically resected GIST. The latter indication is undergoing phase III clinical trial testing with preliminary results showing disease free survival (DFS) benefit but not yet overall survival benefit. The trial was powered for DFS rather than overall survival - an increasingly popular trend in adjuvant treatment, enabling earlier detection of events.

There was Level 1 evidence (based on phase III clinical trials results) indicating a modest survival advantage in 11 of the 16 new drugs used for palliative treatment. The evidence for efficacy for the remaining five drugs was based on objective response rates and/or quality of life measures with lower level of evidence (Level 3 evidence from phase II clinical trials).

The cost of these 16 new drugs for palliative cancer indications ranged from $15,000–$75,000 for a full course of treatment. However it should be emphasized that when a new palliative treatment is not having the desired benefit, it is given for only a small fraction of the full course, typically two to three cycles or one to two months of treatment.

Of the 42 cancer drug indications studied, nine do not have approval in Canada including one from the initial 24 drugs studied (Thalomid for myeloma) and eight drugs from the 18 new drugs studied as of Dec 25, 2007 (Erbitux for head and neck cancer, Revlimid for relapsed myeloma, Revlimid for myelodysplastic syndromes, adjuvant Gleevec for resected GIST, Nexavar for liver cancer, Vidaza for myelodysplastic syndromes, Targetin for cutaneous T-cell lymphoma, and Tykerb for relapsed HER2 positive breast cancer). Eight of these nine non-approved drugs in Canada have been approved in the US by the FDA. Only Gleevec for adjuvant GIST is yet unapproved in both Canada and the US. Two of these nine drugs have Health Canada approval for other indications, confirming safety and efficacy in the form of Notice of Compliance (NOC) or NOC with conditions (NOC/c). In such instances the drug is commercially available in Canada for off label use: Gleevec approved for CML can be used off label for adjuvant GIST; Nexavar for advanced liver cancer.

Oxaliplatin finally received NOC for metastatic and adjuvant colon cancer in 2007. One drug, Erbitux, has been approved by Health Canada for metastatic colorectal cancer but the manufacturer and the Patented Medicine PriceS Review Board (PMPRB) could not agree upon a price and the drug has not yet been marketed in Canada despite its NOC. Access to this drug is only obtained on a case-by-case basis through Health Canada Special Access Program (SAP), and then purchased through US or European Union distributors.

Eleven of the 18 new drugs are given orally and seven intravenously. This distinction may influence whether or not they are funded within the public system for all patients with cancer, as many provinces only provide oral home drugs through their separate provincial pharmacare plans for restricted populations (i.e., seniors or patients on social assistance).

✓ Approved and fully funded in that province
X Not approved or funded in that province
L1 Limited access on a case to case basis (disease specific factors)
L2 Limited access based on coverage for only specific patient groups (patients factors such as over 65, or receiving social assistance)
L3 Limited access based on variable access in that province (institutional factors; only available in some centres but not others)
L4 Limited access based on private payment of the drug (self-pay, third party insurer or manufacturer’s compassionate program) but administration of the drug provided by public cancer centre or hospital
R Recommended for funding but not yet funded; approval still in process for decision
S Self pay or third-party insurer, drug readily available through retail pharmacies
P Pharmaceutical company sponsored reimbursement /assistance program
P1 Pharmaceutical company sponsored expanded access program
C Compassionate release from pharmaceutical company
W Funded through WCB (Workers’ Compensation Board) or WSIB (Workplace Safety and Insurance Board in Ont.)
D Funded partly by donated monies from charitable sources or foundations
T Available by multi-centre Canadian clinical trial currently open
O Out of country access through prior approval by the provincial ministry of health
<table>
<thead>
<tr>
<th>DRUG AND INDICATION</th>
<th>ACCESS</th>
<th>BC</th>
<th>AB</th>
<th>SK</th>
<th>MB</th>
<th>ON</th>
<th>QC</th>
<th>NB</th>
<th>PEI</th>
<th>NS</th>
<th>NL</th>
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<tbody>
<tr>
<td>Capcitabine (Xeloda) Adjuvant treatment of Duke C colon cancer</td>
<td>P S</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>L2</td>
<td>L4</td>
<td>✓</td>
<td>L2</td>
<td>L4</td>
<td>C</td>
</tr>
<tr>
<td>Oxaliplatin (Eloxatin) FOLFOX adjuvant treatment of colon cancer</td>
<td>✓ L1</td>
<td>✓</td>
<td>✓</td>
<td>L1</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Oxaliplatin (Eloxatin) Metastatic colorectal cancer</td>
<td>✓ L1</td>
<td>✓</td>
<td>✓</td>
<td>L1</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Pemetrexed (Alimta) With Cisplatin for mesothelioma</td>
<td>PW</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>L3</td>
<td>L1</td>
<td>X</td>
</tr>
<tr>
<td>Temozolomide (Temodal) With XRT and 6 months maintenance for GBM</td>
<td>PS</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>L1</td>
<td>L2</td>
<td>L4</td>
<td>✓</td>
<td>L2</td>
<td>L4</td>
</tr>
<tr>
<td>Trastuzumab (Herceptin) Adjuvant treatment of HER/neu positive breast cancer</td>
<td>P</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>Rituximab (Rituxan) CHOP-Rituxan for DLC, B-cell non-Hodgkin’s lymphoma</td>
<td>P</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Bevacizumab (Avastin) With chemotherapy for metastatic colorectal cancer</td>
<td>P</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>R</td>
<td>X</td>
<td>R</td>
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<tr>
<td>Cetuximab (Erbitux) With chemotherapy for metastatic colorectal cancer</td>
<td>X</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>L4</td>
<td>O</td>
<td>X</td>
<td>L3</td>
<td>X</td>
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<tr>
<td>Alemtuzumab (MabCampath) Relapsed chronic lymphocytic leukemia</td>
<td>✓ L1</td>
<td>X</td>
<td>L4</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>T</td>
<td>L3</td>
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<tr>
<td>I-131 tositumomab (Bexxar) Relapsed NHL</td>
<td>✓ L3</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<td>R</td>
<td>X</td>
<td>L3</td>
<td>X</td>
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<td>Yttrium-90 ibritumomab (Zevalin) Relapsed NHL</td>
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<td>X</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>R</td>
<td>L3</td>
<td>L1</td>
<td>L3</td>
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<tr>
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<td>PCS</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>R</td>
<td>L4</td>
<td>✓</td>
<td>L2</td>
<td>L4</td>
<td>✓</td>
<td>L2</td>
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<tr>
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<td>✓</td>
<td>✓</td>
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<td>R</td>
<td>L4</td>
<td>✓</td>
<td>L2</td>
<td>L4</td>
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<td>L2</td>
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<thead>
<tr>
<th>DRUG AND INDICATION</th>
<th>ACCESS</th>
<th>BC</th>
<th>AB</th>
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<tr>
<td><strong>Al – Exemestane</strong> (Aromasin) Adjuvant treatment of ER positive breast cancer</td>
<td>PCS ✔</td>
<td>✔</td>
<td>✔</td>
<td>R</td>
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<tr>
<td><strong>Bisphosphonate – Clodronate</strong> (Various/generic) Reduce bone complications from metastatic breast cancer</td>
<td>S ✔ L2</td>
<td>L4</td>
<td>✔</td>
<td>✔</td>
<td>L2</td>
<td>L4</td>
<td>✔</td>
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<td>L2</td>
<td>L4</td>
<td>L1</td>
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<td><strong>Bisphosphonate – Pamidronate</strong> (Various/generic) Reduce bone complications from metastatic breast cancer</td>
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<td>P X</td>
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<td>L4</td>
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<td>L3</td>
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<td>C X</td>
<td>L4</td>
<td>✔</td>
<td>L2</td>
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<td>✔</td>
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<td>L2</td>
<td>L4</td>
<td>✔</td>
<td>L1</td>
<td>L2</td>
<td>C</td>
</tr>
<tr>
<td><strong>Imatinib</strong> (Gleevec) Gastrointestinal stromal tumour</td>
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<td>✔</td>
<td>✔</td>
<td>✔</td>
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<th>ACCESS</th>
<th>BC</th>
<th>AB</th>
<th>SK</th>
<th>MB</th>
<th>ON</th>
<th>QC</th>
<th>NB</th>
<th>PEI</th>
<th>NS</th>
<th>NL</th>
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<tbody>
<tr>
<td>Pemetrexed (Alimta) Non-small cell lung cancer</td>
<td>P</td>
<td>✓</td>
<td>X</td>
<td>R</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>L1</td>
<td>X</td>
</tr>
<tr>
<td>Rituximab (Rituxan) With CVP for advanced stage, low grade follicular NHL</td>
<td>P</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>L1</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rituximab (Rituxan) Maintenance Rituxan for follicular lymphoma after induction therapy</td>
<td>P</td>
<td>✓</td>
<td>L1</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>L1</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Cetuximab (Erbitux) With radiation for locally advanced H&amp;N cancer</td>
<td>X</td>
<td>L1</td>
<td>R</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Lenalidomide (Revlimid) Relapsed multiple myeloma</td>
<td>T</td>
<td>X</td>
<td>R</td>
<td>T</td>
<td>X</td>
<td>T</td>
<td>X</td>
<td>T</td>
<td>X</td>
<td>T</td>
<td>X</td>
</tr>
<tr>
<td>Lenalidomide (Revlimid) Myelodysplasia (5q- syndrome)</td>
<td>X</td>
<td>R</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Imatinib (Gleevec) Adjuvant GIST</td>
<td>PCS</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>L1</td>
<td>L4</td>
</tr>
<tr>
<td>Sunitinib (Sutent) Advanced renal cell carcinoma</td>
<td>PS</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>R</td>
<td>X</td>
<td>X</td>
<td>L1</td>
<td>L2</td>
<td>L4</td>
</tr>
<tr>
<td>Sunitinib (Sutent) 2nd line GIST</td>
<td>PS</td>
<td>✓</td>
<td>L1</td>
<td>✓</td>
<td>L1</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L1</td>
<td>L2</td>
<td>L4</td>
</tr>
<tr>
<td>Sorafenib (Nexavar) Advanced renal cell carcinoma</td>
<td>PS</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>L4</td>
</tr>
<tr>
<td>Sorafenib (Nexavar) Advanced hepatocellular carcinoma</td>
<td>PS</td>
<td>X</td>
<td>L4</td>
<td>R</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>L4</td>
<td>X</td>
</tr>
<tr>
<td>Pegylated liposomal doxorubicin (Caelyx) Ovarian cancer refractory to Platinum</td>
<td>P</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<tr>
<td>Azacytidine (Vidaza) Myelodysplastic syndrome</td>
<td>X</td>
<td>R</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>L1</td>
<td>X</td>
<td>X</td>
<td>L3</td>
<td>L1</td>
<td>X</td>
</tr>
<tr>
<td>Dasatinib (Sprycel) Refractory Ph+ ALL</td>
<td>PS</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>L1</td>
<td>L2</td>
<td>L4</td>
<td>✓</td>
</tr>
<tr>
<td>Dasatinib (Sprycel) Refractory CML</td>
<td>PS</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>R</td>
<td>X</td>
<td>X</td>
<td>L1</td>
<td>L2</td>
<td>L4</td>
</tr>
<tr>
<td>Temsirolimus (Torisel) Advanced renal cell carcinoma</td>
<td>C</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>X</td>
<td>C</td>
<td>X</td>
<td>X</td>
<td>C</td>
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<td>C</td>
</tr>
<tr>
<td>Bexarotene (Targetin) Cutaneous T-cell lymphoma</td>
<td>✓</td>
<td>L1</td>
<td>X</td>
<td>L4</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lapatinib (Tykerb) HER2/neu positive metastatic breast cancer</td>
<td>P1</td>
<td>X</td>
<td>T</td>
<td>X</td>
<td>X</td>
<td>P1</td>
<td>X</td>
<td>X</td>
<td>P1</td>
<td>T</td>
<td>X</td>
</tr>
</tbody>
</table>
### TABLE 3
**SUMMARY OF CANCER DRUG ACCESS AND PUBLIC FUNDING STATUS COMPARING PAST 24 DRUGS STUDIED AND 18 NEW DRUG INDICATIONS**
(STATUS AS OF DEC. 25, 2007)

<table>
<thead>
<tr>
<th>Province</th>
<th>Past 24 Drug Indications</th>
<th>18 New Drug Indications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Approved and Funded</td>
<td>Limited Access</td>
</tr>
<tr>
<td>BC</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>AB</td>
<td>14</td>
<td>7</td>
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<tr>
<td>SK</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>MB</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>ON</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>QC</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>NB</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>PEI</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>NS</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>NL</td>
<td>8</td>
<td>11</td>
</tr>
</tbody>
</table>

**FIGURE 1**
**ACCESS TO 42 CANCER DRUGS, BY PROVINCE, 2007**

In Table 3 and Figure 1 the column heading “Approved and Funded” refers to a ✓ or a ✓ plus L1. In both instances, a decision has been taken that any patient who needs the drug for a specific indication will receive it.
TABLE 4  SUMMARY OF LIMITED ACCESS VARIABLES FOR 42 CANCER DRUGS
(STATUS AS OF DEC 25, 2007)

<table>
<thead>
<tr>
<th>PROVINCE</th>
<th>CASE BY CASE REVIEW</th>
<th>SPECIFIC GROUPS ONLY</th>
<th>VARIABLE ACROSS THE PROVINCE</th>
<th>PRIVATE PAY</th>
<th>TOTAL NUMBER OF LIMITATIONS</th>
<th>NUMBER OF DRUGS WITH LIMITATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>BC</td>
<td>16</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td>AB</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>17</td>
<td>20</td>
<td>14</td>
</tr>
<tr>
<td>SK</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>10</td>
<td>2</td>
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<tr>
<td>MB</td>
<td>11</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>6</td>
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<tr>
<td>ON</td>
<td>7</td>
<td>13</td>
<td>1</td>
<td>20</td>
<td>41</td>
<td>15</td>
</tr>
<tr>
<td>QC</td>
<td>11</td>
<td>0</td>
<td>7</td>
<td>3</td>
<td>21</td>
<td>8</td>
</tr>
<tr>
<td>NB</td>
<td>6</td>
<td>9</td>
<td>7</td>
<td>18</td>
<td>40</td>
<td>15</td>
</tr>
<tr>
<td>PEI</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>NS</td>
<td>0</td>
<td>11</td>
<td>1</td>
<td>17</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td>NL</td>
<td>10</td>
<td>11</td>
<td>1</td>
<td>7</td>
<td>29</td>
<td>13</td>
</tr>
</tbody>
</table>

Table 4 is a summary of all the limitations in play, derived from Table 2. There are 224 limitations on 42 drugs. For example, Nova Scotia has 29 limitations but there are only 11 drugs involved. The final column on the far right is the number used to summarize these limitations, per drug, on the opposite page (Table 3 and Figure 1).

CANCER DRUG ACCESS BY PROVINCE

British Columbia
BC provides and funds 13 of the 18 new drugs studied but with increasing limitations through the BC Cancer Agency (BCCA) Compassionate Access Program (CAP). Each request for use of each drug is processed electronically through the Provincial Systemic Therapy Program to ensure the request fits the increasingly tight eligibility criteria defined by Provincial Tumour Groups. Each new drug submission undergoes evaluation by the BCCA Priorities and Evaluation Committee (PEC) that defines its provincial treatment policies and treatments. These treatment protocols with accompanying pre-printed orders, and patient information handouts are continually refined in real time for cancer care teams throughout the province, and disseminated on-line throughout the province through the BCCA website.

The BCAA through its provincial oncology drug budget is the payer and provider for all oral, take home cancer drugs and intravenous cancer drugs for every resident of the province. The provincial pharmacare plan is responsible for most supportive care drugs for cancer but does not cover cancer drugs. Through its central management of all cancer drugs, BC is able to negotiate volume drug pricing, standardize treatments, obtain timely evidence based and consensus driven guidelines, provide common resources for patients and care providers, and evaluate utilization and outcomes for cancer drugs.

Alberta
Alberta fully funds four of the 18 new drugs and provides an additional seven through “Directors Privileges” where patients can access these drugs through private payer options. A medication incident in Alberta (and another in Manitoba) stimulated a detailed review of cancer drug safety. The resulting recommendations were implemented in Alberta and many other provinces. The incidents also led to the creation of the Systemic Therapy Working Group at the Canadian Association of Provincial Cancer Agencies which has helped increase cancer drug safety and standards nation wide.

British Columbia and Alberta reached an agreement to look at common sourcing of drugs for the two provinces, but cancer drugs are not included.

Saskatchewan
Saskatchewan approved four of the new drugs/indications. The Self Pay Drug Program (SPDP) contains only
two parenteral (intravenous) drugs: Avastin and Zometa. Maintenance Rituxan for follicular lymphoma, formerly available only through the SPDP, is now on formulary and fully funded. Most of the expensive new oral drugs studied are included in the SPDP for private pay. The recently elected Saskatchewan (Conservative) Party fulfilled a campaign pledge to fund Avastin for metastatic colorectal cancer. Billing for Avastin for the first line treatment of colorectal cancer patients was stopped January 30, 2008 and patients who paid for Avastin are being reimbursed retroactive to November 7, 2007.

Saskatchewan has incorporated the Variant Medical Oncology (VMO) electronic cancer system making it the third province after Manitoba and Alberta to use this platform. The system will be an important tool for evaluating utilization and outcomes analysis of cancer treatments.

**Manitoba**

Manitoba provided access to seven of the 18 new drugs/indications. The provincial intravenous cancer drug budget has been consolidated under Cancer Care Manitoba (CCM). An inter-provincial purchasing agreement with Saskatchewan will allow for volume pricing and purchasing for the two provinces.

The VMO electronic cancer system (designed in Manitoba initially as the OpTx system) has been implemented province-wide across all 23 locations providing chemotherapy in Manitoba including the 14 Community Oncology Network sites and four community hospitals. Chemotherapy dispensing services in Winnipeg have been consolidated to the main CCM clinic sites. Oral cancer drugs now provided through Manitoba Pharmacare will eventually be included in the CCM budget.

**Ontario**

Ontario has approved seven of the 18 new drugs/indications.

Newer oral cancer drugs are increasingly funded on an exceptional access basis only. Exceptional access is not available for drugs administered in a hospital/clinical setting. Streamlining of the exceptional access process (formerly known as Section 8) will mean creating a list of specific drugs that would be available via this mechanism, as opposed to the previous practice of physicians applying for any drug that their patients might need.

The Trillium Drug Plan, for citizens under age 65, is an income-based, formulary-based plan, in place since 1995 to assist with high cost prescription drugs.

The Ministry of Health has yet to make any public comment on the Cancer Care Ontario (CCO) proposal for providing self pay parenteral cancer drug treatments within the 14 CCO regional cancer centres, but the practice has quietly taken root across the province.

Ontario is the home jurisdiction for Joint Oncology Drug Review (JODR), evaluating new drug submissions on behalf of eight other provinces (all but Quebec) and replacing the Common Drug Review in that role. JODR will soon complete its one year trial period and is due for evaluation. A multi-province Advisory Committee has been created to provide oversight to JODR. Many provinces continue their own pre-existing processes for evaluating new cancer drugs and deciding their funding priorities.

**Quebec**

Quebec has approved nine of the 18 new drugs studied, in whole or in part. Avastin is now funded for both first line and second line treatment of metastatic colorectal cancer. Thus Quebec is the third province to fund this indication, after BC and Newfoundland.

As noted in previous Report Cards, approval of new drugs in Quebec, unlike other provinces, does not automatically result in funding in each hospital or centre. On the other hand, individual hospitals in Quebec have the mandate and ability to approve individual cancer drugs more flexibly in their individual institutions than in many other provinces. For example, Zevalin is provided within the McGill system but not in the rest of Quebec and prior to its provincial funding approval, Avastin was provided for individual cases in some academic institutions provided a third party payer covered the cost.

Quebec remains independent of JODR. In 2005 a provincial cancer committee was established to coordinate approaches in oncology within Quebec attempting to emulate centralized oncology initiatives in other provinces. At the same time, a pharmacy body has been advising on oncology treatment guidelines. However, the Registry system, the data collection capability, and therapy consensus and approval mechanisms, are not yet uniform.

**New Brunswick**

New Brunswick funded six of the new drugs studied, in whole or in part. The New Brunswick Cancer Network initiated in October 2005 continues to develop a provincial systemic therapy review process. New Brunswick follows JODR recommendations for funding new cancer drugs. The prior process remains in place for self pay or case-by-case provision of expensive cancer drugs through individual hospitals within regional health authorities.

**Prince Edward Island**

PEI funded three of the 18 new drugs/indications. Moreover, PEI now approximates the inter-provincial average, having increased the number of fully funded drugs from five (second lowest in Canada in 2006) to 14
in 2007. This was made possible by a one time allocation of an additional $1 million for cancer drugs in 2007. This is a huge sum for a province of 140,000 people and one hopes ongoing funding will be provided for future patients requiring these treatments. A provincial process for evaluating cancer drugs remains to be developed.

**Nova Scotia**

Nova Scotia funded six of the new drugs/indications. Sutent for renal cell carcinoma and refractory GIST was added the Pharmcare formulary. The Provincial Systemic Therapy Program continues to evolve, incorporating an ethical framework for vetting new drug treatments in addition to clinical and pharmacoeconomic review.

A universal drug plan for the province as second payer after private insurance will come into effect March 1, 2008, covering drugs that are listed as formulary family income determines the deductible and annual caps for deductible and copayment. A separate program, Drug Assistance for Cancer Patients, helps pay the cost of approved cancer-related drugs where the family income is $15,720 or less. Standard benefits include chemotherapeutic agents, pain medications, antiemetic agents and laxatives for use with chronic opioid therapy.

**Newfoundland and Labrador**

Newfoundland has funded five of the new drugs studied. Xeloda and Temodol are the only two oral drugs funded through the Oncology Drug Budget, which usually includes only IV chemotherapy drugs). Other oral take home cancer drugs are provided mainly through the provincial pharmacare plan (i.e., Provincial Drug Program).

The Cancer Care Program became the insurer of last resort after third party insurers for a select few expensive oral cancer drugs. The provincial cancer program will cover the costs of these drugs when patients do not have private insurance, and will financially assist those patients not able to cover their co-pays for these cancer drugs. Lack of human resources, particularly oncology pharmacists, prevents tracking of utilization and appropriate use of certain drugs. Special authority access in NL is based on a list of drugs that are available through this mechanism.

After expanding the prescription drug plan in January 2007 to cover lower-income families, NL further expanded drug coverage in October 2007 for all citizens facing high prescription drug costs. The sliding scale of financial support is available to families with a total family income of $150,000 or less. Drugs covered are those listed on the provincial formulary and those approved by special authorization.

**DISCUSSION**

**Inter-provincial Drug Approval Timelines**

The variable and delayed access to effective cancer drugs has been compounded in 2007 by the appearance of still more new drugs and new treatment indications for existing drugs, a trend that will undoubtedly continue. This has been aggravated by the ongoing variability in provincial treatment guidelines and provincial drug funding processes.

Many provinces, particularly the western provinces and some of the Atlantic provinces, are moving toward integrated single plans for cancer drugs encompassing oral, take home and intravenous cancer drugs. Moreover, the western provinces have province-wide electronic systems to improve access to electronic patient cancer records and chemotherapy ordering systems. Alberta, Saskatchewan, and Manitoba have deployed the comprehensive Varian Medical Oncology (VMO) cancer system and electronic cancer chart, with an electronic drug order entry component. British Columbia provides an electronic cancer chart available at the four regional cancer centres and five of the satellite clinics staffed by BCCA physicians.

Overall, across the provinces, there remain variable timelines for approval, funding, and listing on provincial formularies despite the new JODR process. There is increasing use of special authority access within provincial cancer organizations and Special Access Programs and expanded access programs to gain access to drugs not yet approved or marketed in Canada. The complexity of the process for doctors and patients accessing new drugs, although better in some areas, has not improved substantially.

**Approval Timelines in Canada and the US**

The time difference between Canada and the US to approve new cancer drugs is now a median of seven months, for the 10 (of 18) new drugs that received NOC from Health Canada. This compares favourably with the median delay of 15 months noted for the 24 previous drugs studied in the 2005 Report Card.

It should be noted that application for NOC for a new cancer drug or indication through Health Canada’s Therapeutic Products Directorate is an entirely voluntary process for manufacturers. Most new drugs are submitted for approval to the US FDA first, as the United States is the world’s largest market. A decision to submit for approval in Canada (representing only two per cent of the world market for drugs) is influenced mostly by fiscal parameters, based on a business model.

Many patients with rare or less common cancers may face difficulty accessing drugs for which there is only a small market and no incentive for approval in Canada (in addition to variable access within the publicly funded system). Consequently, the differences in approval times
between Canada and the US reflect several factors including Health Canada timeliness of review, and whether or not the drug manufacturer has submitted an application.

A manufacturer’s decision about whether (or when) to market a drug in Canada is influenced by the relative ease of entry, or difficulty, compared to other countries. The multiple regulatory steps in Canada are more cumbersome than in the US, where FDA approval opens a vast market immediately. In Canada, federal approval to market the drug is followed by: federal drug pricing approval at PMPRB, (which is now expressing an interest in conducting cost-effectiveness reviews); JODR reviews of clinical evidence and cost-effectiveness (with a subset of clinical and pharmacoeconomic reviews by others); province by province funding approvals with related reviews and price negotiations (often duplicating work already done by other Canadian agencies and jurisdictions); and guideline writing by each province to ensure different notions of appropriate use fit the payment model.

Unlike the FDA system, Health Canada does not disclose ongoing reviews of new drugs nor whether they are undergoing priority reviews. The Health Canada website could be redesigned for better organization, clarity and transparency along the lines of the FDA website to more accurately relay the current status, submitted documentation and evidence (including negative studies), and updates of its drug reviews.

The JODR process will require better coordination and integration with approval processes at Health Canada, as well as more efficient utilization of provincial cancer agency expertise and input. JODR is in discussions with the Canadian Partnership Against Cancer (CPAC) about what roles CPAC may play in cancer drug evaluation and access, especially through its Cancer Control Guidelines Action Group.

**The Rising Prices and Costs of Cancer Drugs**

The emerging new cancer drugs offer modest incremental benefits at very high cost that are challenging for most public and private payers to bear. Emerging efforts to control these costs include volume purchasing as developed between Manitoba and Saskatchewan. The western provinces with more developed provincial cancer information systems and infrastructure are able to better gate expensive new drugs through special authority type access. These systems permit utilization monitoring and outcomes analysis when new drugs are delivered to the general population.

New tools are emerging that incorporate and prioritize the complex issues, values and competing interests or principles inherent in making difficult decisions around expensive cancer drugs. In fact, we suspect many of the cancer agencies in Canada that are successful at vetting and providing new cancer drugs are to some extent incorporating the components of these tools. Further research to correlate the success rate and timeliness of approving new drugs inter-provincially with the degree of comprehensiveness and sophistication of analytical tools might validate them.

As other countries and their national public health systems struggle to evaluate new expensive cancer drugs, novel access and payment processes have emerged. In Britain, the National Institute for Clinical Excellence (NICE), which is responsible for evaluating cost effectiveness of new drugs, recommended against Velcade as a benefit under the National Health Service. Rather than drop the price, the manufacturer offered to pay for the drug for those patients who do not respond to it. A situation like this happened in Canada many years ago with Taxotere for metastatic breast cancer for a brief period of time where the manufacturer, Rhone-Poulenc Rorer at that time, offered to pay for two cycles and if patients were responding, the public system would pay the subsequent cost. This “pay for results” could be applied to the more expensive new drugs for public funding, as a mechanism to help identify patients who benefit. Governments should fund post-market research to corroborate the results of new cancer drugs and find more cost effective ways to use them. Increased research needs to be done to identify the subsets of patients who benefit the most from new cancer drugs, so that patients who do not benefit are not subjected to ineffective treatments.

**Patient Needs and Challenges**

Evidence of effectiveness and median survival rates (i.e., who benefits for how long) do not always adequately address the realistic possibility of long-term survival for some patients, who are disadvantaged when caught in aggregates, medians and averages. Such generalized analysis is driven by the absence of precise information about the type of patient who will benefit from an expensive new drug. Without biomarkers to identify the patient, or phase 4 trials to report on real-world effectiveness of new drugs, funders retreat, to the detriment of current and future cancer patients. Exceptional access is increasingly limited to narrow indications, further decreasing the likelihood of great successes for some patients. Exceptional access could be more readily available if designed on a two-month trial basis, followed by the routine restaging tests that accompany any new treatment, to quickly demonstrate whether a new drug is effective for a patient. This concept could be applied in cases where previous treatments have failed, adding much-needed data about real-world effectiveness of new drugs. Trial prescriptions are commonly used in other diseases to determine patient response before continuing with a new treatment and have helped to optimize the appropriate use of drugs. The same structure could be developed for cancer patients.
In the meantime, physicians involved with treating cancer increasingly struggle with access to new cancer drugs for their patients and have to make bedside rationing decisions to balance the competing needs of individuals, public payers and society when prescribing expensive new cancer drugs.52

As further discussed in The Cost of Cancer Drugs, page 51, private payers, employers and individuals will either bear more of the brunt of the cost of cancer drugs not paid by the public system, or not be able to access them at all. It may be time to explore a national comprehensive public or public-private insurance program such as the one recently implemented in the Netherlands.53

Recommendations
The complex issues around access to cancer drugs remain unresolved and require:

1. Establishment of a national catastrophic drug strategy and drug plan;
2. Development and implementation of Canada-wide guidelines in a timely and consistent manner to speed access and provide national consistency;
3. Introduction of an ongoing evaluation process for new drugs which includes a robust pharmacoeconomic model;
4. Establishment of a single oncology drug budget and formulary in each province integrating parenteral and take-home cancer drugs;
5. Increased translational research to identify the subsets of patients who benefit from the new drugs;
6. Phase 4 (post-approval) trials to confirm treatment results in the cancer population at large;
7. Incorporation of substantial patient involvement into decision-making;
8. Transparency about decision-making;
9. A repository of accurate information regarding applicable funding sources for each drug whether government ministries, third party insurers, research agencies, or compassionate assistance programs of pharmaceutical companies;
10. Redesign the Health Canada website for better organization and clarity along the lines of the FDA website to more transparently and accurately relay the current status and submitted documentation of its drug reviews.

Dr. Kong Khoo, Dr William Hryniuk, Dr. Joseph Ragaz and Dr. Sandeep Sehdev are Directors of the CACC, Colleen Savage is CEO. Rosemary Colucci is a graduate of Ryerson University and consultant to the health sector in strategic planning and stakeholder relations.

References
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The Cost of Cancer Drugs in Canada

KONG KHOO, ROSEMARY COLUCCI, WILLIAM HRYNIUK, ROBERT KAMINO, TANIA REDINA and COLLEEN SAVAGE

INTRODUCTION
In past CACC Report Cards, we have investigated the west-east gradient in cancer mortality in Canada and observed the high degree of correlation between mortality and governmental spending on provincial cancer control programs across the spectrum of prevention, screening, treatment, and supportive care.

In the 2005 and 2006 Report Cards, we also reported on the uneven access to newer cancer drugs across the provinces and noted an increased reciprocal reliance on alternate and less reliable sources of funding particularly in eastern Canadian provinces. However, we remained uncertain as to how the west-east gradient in cancer mortality was related to access to these new and effective cancer drugs.

This year, using a database generously made available to us by Brogan Inc., we studied in more detail the west-east gradient in cancer drug expenditures and sources of payment for them.

METHODOLOGY
Payments by the public system and private payers were determined in each province for a selected group of the 42 drugs studied in the accompanying article (Drug Access Part III) for the years 2002 to 2006 inclusive. Data were extracted from the claims database at Brogan Inc., which collates drug costs and reimbursements from public drug plans and insurance companies. Information about drug costs paid by provincial cancer agency and cancer clinic budgets is not available in the Brogan database and hence investigation into the total public contributions is limited. In Ontario, Quebec, Manitoba and the Atlantic provinces where significant public data are available, we were able to compare public and private payment for the drugs and years in question. Each drug and year was scrutinized by province to determine which cancer drugs were given in substantial amounts (by number of claims and total value of claims).

In order to provide a perspective on the relative size of expenditures we related drug cost data to the burden of cancer in each province, by expressing the results as dollars per incident cancer case in each province for each year. The numbers of incident cancer cases were derived from the 2002-2006 issues of Canadian Cancer Statistics, Table 3, “Estimated New Cancer Cases by Major Cancer Site.”

Description of the Brogan Database
The Brogan Inc. private drug plans database is comprised of pay direct drug benefit claims paid by most major private insurers in Canada. These claims represent approximately 67 per cent of the total private drug plan business. The database in total collects information on more than 10 million (anonymized) claimants with 91 million prescriptions annually. The record breakdown is as follows: 34 per cent from Ontario, 28 per cent from Quebec, 29 per cent from Western Canada and nine per cent from Eastern Canada. The Brogan database captures between one third (33 per cent for Manitoba) and four fifths (84 per cent for Ontario) of all private insurer drug claims depending on the province. The reported data were extrapolated to represent the complete private market in that province.

Patients who self pay for their cancer drugs are not included in the Brogan Inc database, or in the analysis below. It is important to note that many cancer patients pay for their own drugs, or part thereof through either self-pay, a co-payment plan with their insurance company or payment to a hospital where a drug may be administered even if it is not publicly funded.

The 42 cancer drug indications actually represented 24 separate Health Canada approved drugs. These 24 drugs were searched in the Brogan Inc. database. We analyzed the years 2002 to 2006 as data were incomplete for 2007; this represented 23 of the 24 drugs that were approved in 2006 or earlier; the exception was Sprycel which received Health Canada approval only in 2007. Six drugs (Thalomid, Revlimid, Vidaza, Torisel, Targettin, Tykerb) are not yet Health Canada approved, have no designated DIN (Drug Identification Number), and are not commercially available in Canada. The Brogan Inc. database does not include any of these six unapproved drugs.
All 24 searchable drugs were primarily cancer drugs, although a small number have non-cancer indications: mainly Rituxan for rheumatoid arthritis, and various immune cytopenias or disorders, and bisphosphonates (clodronate, pamidronate and Zometa) for osteoporosis and Paget’s disease of bone.

The Brogan Inc. public drug plan database includes for the most part, the oral take-home drugs covered by the provincial pharmacare plans including the three aromatase inhibitors (Anastrazole, Femara, Aromasin), the bisphosphonates (clodronate, pamidronate, zoledronic acid), Xeloda, Temodol, Tarceva, and Gleevec. The three aromatase inhibitors, with Xeloda, Temodol, Gleevec and Traceva represented the seven major drugs both by volume and volume captured. This represented only a minority (30 per cent) of drugs studied (seven of the 23). Public payer claims for newer oral drugs such as Sutent and Nexavar were included in the study.

Although some parenteral drugs are listed in the Brogan public database (Rituxan in three provinces, Campath in one) there were few claims; and some of the Rituxan claims could be for rheumatoid arthritis or non-cancer use. Most of the parenteral cancer drugs studied, Herceptin, Alimta, Oxaliplatin, Avastin, Erbitux, Velcade, Bexxar, Zevalin, Mabcampath (other than one province) were also not listed in the Brogan Inc database. The parenteral drugs are recorded in provincial cancer agency or cancer centre program budgets that were not included in the Brogan database. PEI had no data in the Brogan Inc. database. Saskatchewan only had IV pamidronate listed. Alberta only had the three bisphosphonates listed and no cancer drugs were listed in the public database. Hence the data below for public claims varies by province and represents a relatively small proportion of the total cancer drug budget for each province..

The Brogan Inc. private drug plan database also included for the most part the oral, take-home cancer drugs; the three aromatase inhibitors, Xeloda, Temodol, Gleevec, Tarceva were the seven drugs captured in the private database. Some of the newer oral drugs such as Sutent and Nexavar had significant number of claims in Ontario, Quebec, Alberta; a small number in New Brunswick, Newfoundland, Nova Scotia, British Columbia; and none in PEI, Saskatchewan or Manitoba. Only a handful of parenteral cancer drugs studied had claims, all of small volume and value of claims including Avastin in Alberta, Saskatchewan, and British Columbia (limited to 2006). Even in the two largest provinces, Ontario and Quebec, private claims for parenteral drugs were restricted to small numbers for Avastin, Erbitux, Campath, and Velcde. Hence most of the Brogan Inc private drug plan claims are for the oral take-home cancer drugs.

In both the Brogan public and private payer databases, parenteral drugs represented only about 10 per cent or less of the total costs of the 23 drugs captured.

In summary, in both the public and private drug plans studied for this article, seven drugs represent the majority expenditure in each province. The seven drugs are the three aromatase inhibitors (Anastrazole, Femara, Aromasin) as well as Xeloda, Temodol, Tarceva, and Gleevec. While these drugs account for the majority of the provincial cancer drug expenditure, it is important to note that the total cancer drug expenditure is but a small proportion of overall provincial drug budgets, i.e., usually less than 10 per cent.

![TABLE 1](PRIVATE PAY FOR CANCER DRUGS IN CANADIAN PROVINCES FOR 2002–2006, EXPRESSED PER ESTIMATED INCIDENT CANCER CASE IN EACH YEAR)

<table>
<thead>
<tr>
<th>Prov.</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
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<tbody>
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<td>BC</td>
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<td>$39.61</td>
<td>$66.63</td>
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<td>$81.07</td>
</tr>
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<tr>
<td>ON</td>
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<tr>
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<td>$478.58</td>
<td>$456.46</td>
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</table>

Table 1 shows the private payments for each year from 2002 to 2006 in each province for 23 individual new cancer drugs, expressed relative to the incident cancer cases in each province for each year. Major inter-provincial differences are seen. The private sector is responsible for much less payment per cancer case in the four western Canadian provinces as compared to provinces east of the Manitoba border. Seven drugs (the three aromatase inhibitors, Xeloda, Temodol, Gleevec and Traceva) account for the majority of the claims and costs shown.
Differences between the provinces in terms of private sector contributions in 2006 are depicted graphically in Figure 2. The western provinces spend much less on drugs through private pay mechanisms per incident cancer case than the rest of the country.
RESULTS
Figure 1 shows that, as an increasing number of the 23 drugs became available commercially in Canada from 2002 to 2006, private payouts for these selected cancer drugs increased steadily within each province. The costs shown represent predominantly the seven most common oral take-home drugs described above. A small number of claims for Avastin, Erbitux, Campath, Velcade, Herceptin and Rituxan were seen in specific provinces. The rising contributions from the private drug plan sector in Ontario and Quebec are especially striking. BC was the one exception: total private drug plan costs actually decreased from $2.5-million in 2005 to $1.6-million in 2006.

These drugs also were used for indications beyond the 42 specific indications studied including other Health Canada approved indications and off label indications. For example, we only looked at Xeloda on our Drug Access report cards for the Duke C colon cancer indication, but it is also approved in Canada for metastatic breast cancer and metastatic colorectal cancer, alone or in combination with other drugs or radiation, so the data gathered represents use for all these indications collectively. It was not possible to determine if the small number of privately funded parenteral drugs studied were administered in private infusion clinics, or public institutions.

Figures 3 and 4 compare the rising costs of the 23 drugs over the period 2002 to 2006 for both the public and private payers for the provinces of Ontario and Quebec. The main drugs accounting for the majority of these costs are the seven drugs mentioned above, Xeloda, Temodol, Gleevac, Tarceva and the three aromatase inhibitors. While the public systems in these provinces continue to pay a higher portion of the costs especially for these seven drugs, the proportion borne by the private payer sector in each is steadily increasing as well. In Ontario it rose from 31 per cent in 2002 to 40 per cent in 2006 (Figure 3); and in Quebec from 28 per cent in 2002 to 39 per cent in 2006 (Figure 4).
Figures 5 and 6 compare the public and private payer expenditures in two contrasting regions, three Atlantic provinces (New Brunswick, Nova Scotia and Newfoundland) and Manitoba for the 23 drugs. Results are in sharp contrast to the patterns observed in Manitoba, Ontario, Quebec and presumably in BC and Alberta as well. In the Atlantic provinces, private payer expenditures exceed the public provision for take-home oral drugs. Data for PEI are not available.

Figure 6 illustrates Manitoba where oral take-home drugs of the three aromatase inhibitors are provided mainly through the public, provincial Pharmacare plan. Xeloda, Temodal, Gleevec and Tarceva are provided publicly for all age groups under the auspices of Cancer Care Manitoba. Here one can see that there is minimal private payer outlay for the studied cancer drugs.

In BC and Alberta the cancer agency budgets fully fund oral take-home drugs, and as a result these are not captured in the Brogan Inc. database. In those cases it is reasonable to assume the costs are at least comparable to those shown for Manitoba. Data for Saskatchewan are not available in the Brogan Inc. database.
Private insurers and patients in different parts of the country bear very different burdens for the cost of cancer drugs.

DISCUSSION

Cancer Drugs: Cost versus Access
Analysis of the data in Table 1 revealed that the cost of drugs to the private sectors of Ontario and Quebec is doubling every two years and in the provinces’ public systems every two and a half to three years at least for oral take-home drugs. This trend, observed for only a small portion of the drugs studied (aromatase inhibitors, Xeloda, Temodol, Gleevec, Tarceva and to lesser extent Sutent), is disconcerting because the impact of many more new, high cost cancer drugs has yet to emerge. Aromatase inhibitors represent the most frequent claims but Gleevec represents the most costly drug for both the public and private payers (data not shown).

Gleevec is used for two relatively rare diseases, CML and GI stromal tumour, but many of the new generation of similar tyrosine kinase inhibitors have already shown activity across a number of different and more common cancers. Consequently the costs can be expected to escalate even more. Already trials are being reported or are in progress combining two or more new expensive cancer drugs or targeted therapies.

Large inter-provincial differences were detected, not only in the amount paid from the public versus the private purse as shown in Table 1 and Figure 2, but also in the total dollars spent on these drugs. The differences were not random but appeared to be restricted to provinces east of the Manitoba border, since the other western provinces are already providing them in their publicly-funded budgets. This variation in sources of payment for the drugs corroborates our impression stated in the 2006 Report Card that the eastern provinces rely more heavily on private pay for cancer drugs compared to the western provinces where access to and public coverage for cancer drugs is much more extensive. The numbers given do not include patient self-pay, which includes complete payment by the patient, co-payment with the insurance company or payment to a hospital for a drug not covered, nor the wide spread reliance on compassionate access to cancer drugs in the Atlantic provinces, previously documented, so the inter-provincial differences might be expected to be even larger.

Conclusions
Data restrictions imposed by the nature of the database place some limits on generalizations which can be made. Also, the data did not allow us to compare the rate of increase for all cancer drugs versus all other drugs. However, as new life-saving cancer treatments rapidly enter the marketplace, the overall cost of cancer drugs will continue to increase at a rapid rate. Currently, however, while cancer drug costs are increasing, they generally comprise a small portion of the overall provincial drug budgets, usually less than 10 per cent. Further research is needed on this aspect but the early trends are unmistakable.

For the newer generation of oral, take-home cancer drugs already in the marketplace in Canada, the costs to both the public system and private insurers are increasing rapidly, despite multiple barriers to access and variable access within different parts of the country. Private insurers and patients in different parts of the country bear very different burdens for the cost of cancer drugs. Cancer patients themselves bear an inordinate financial burden vis-à-vis other patients with life-threatening disease, particularly east of the Manitoba border and even more so in the Atlantic provinces. Cancer patients, in large numbers, must rely on their private insurance plans, or in many cases on their own means to fund their life-saving treatment.

Notwithstanding the needed improvements for a more timely and efficient drug approval process, it is becoming abundantly clear that the public system cannot provide complete coverage for new cancer drugs entering the marketplace at the prices being charged for them.

Although we have shown that BC, in particular, and the western provinces in general, continue to have the best access to publicly funded cancer drugs, it is likely only a matter of time before private pay increases in the western provinces.

The corroboration of our impression last year that disproportionately large amounts were being spent in the private sector to pay for cancer drugs in provinces east of Manitoba encourages us to continue pursuing the relationship between drug access, cost, and cancer mortality. The cost differences documented herein may accurately reflect differences in the total cost of cancer
drugs and sources of payment in each province. If so, it would be a reasonable assumption that access to cancer drugs was and continues to be an important contributor to the inter-provincial differences in cancer mortality documented in our previous Report Cards. It is also likely that private cost sharing for drugs of the type studied here will soon increase in the western provinces. How the 3.5 million uninsured and underinsured Canadians will then continue to access expensive life-saving cancer drugs is unclear. More than likely most patients will not be able to afford them, with dire results.

The current data indicate that two-tier, or multi-tier medicine is becoming well established in the eastern half of Canada at least as far as provision of new oral take-home cancer drugs is concerned. And it is arriving in a completely unregulated and uncoordinated fashion.

**Recommendation**

1. More data must be made available on cancer drug expenditures borne by public and private payers.

2. Data is needed on self-payment by patients for cancer drugs.

3. Only a multi-pronged, collaborative approach involving all the stakeholders will solve the complex issues around cancer drug access, cost and delivery.

4. The development of a nation-wide system providing equitable access to cancer drugs will require an independently-led process to determine how the various stakeholders can contribute to a seamless plan that protects vulnerable cancer patients.

*Dr. Kong Khoo* and *Dr. William Hrynynuk* are Directors of the CACC, *Colleen Savage* is CEO. *Rosemary Colucci* is a graduate of Ryerson University and consultant to the health sector in strategic planning and stakeholder relations. Robert Kamino is Vice-President, Consulting Services, with Brogan Inc. and his colleague *Tania Redina* is an economist. Brogan Inc is a healthcare data, research, and consulting company, providing strategic advice, analysis, data and market intelligence to the pharmaceutical industry, insurers, government, and others involved in the delivery of health care.

As shown in table 2, the dollar amount paid out by the public system for the drugs in question varies considerably among the provinces of Manitoba, Ontario, Quebec, and those in the Atlantic region. In particular, the greatest level of public support is seen in Manitoba, and is 60 per cent lower in provinces comprising the Atlantic region.

**TABLE 2**

<table>
<thead>
<tr>
<th>Province</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
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</thead>
<tbody>
<tr>
<td>Manitoba</td>
<td>409</td>
<td>621</td>
<td>880</td>
<td>1012</td>
<td>1043</td>
</tr>
<tr>
<td>Ontario</td>
<td>299</td>
<td>408</td>
<td>539</td>
<td>660</td>
<td>832</td>
</tr>
<tr>
<td>Quebec</td>
<td>340</td>
<td>537</td>
<td>664</td>
<td>775</td>
<td>942</td>
</tr>
<tr>
<td>Atlantic</td>
<td>159</td>
<td>200</td>
<td>238</td>
<td>336</td>
<td>368</td>
</tr>
</tbody>
</table>

As shown in Table 3, the total dollar amount paid out (public plus private) for the drugs in question varies considerably from province to province. Since each province maintains its funding level relative to the others every year, (except for Manitoba in 2006), the inter-provincial differences become magnified with the passage of time, culminating in a difference of $665 per case in 2006, comparing the Atlantic region with Quebec.

**TABLE 3**

<table>
<thead>
<tr>
<th>Province</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
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<td>1123</td>
<td>1178</td>
</tr>
<tr>
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<td>1385</td>
</tr>
<tr>
<td>Quebec</td>
<td>471</td>
<td>779</td>
<td>1032</td>
<td>1235</td>
<td>1542</td>
</tr>
<tr>
<td>Atlantic</td>
<td>335</td>
<td>435</td>
<td>539</td>
<td>790</td>
<td>877</td>
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</tbody>
</table>
INTRODUCTION
Diagnosis and treatment of patients with cancer are fundamental imperatives, requiring a superior level of interdisciplinary knowledge and skill. However, the effects of a cancer diagnosis on the patient and family require an additional dimension of service called supportive care (Breitbart et al). Supportive care includes activities that help patients and families cope with the burden of the illness: the need to adjust to the physiological and psychosocial effects of a cancer diagnosis, and the need to prevent or withstand the side effects of treatment. The effects from the burden of illness in cancer include not just physical symptoms, but spiritual, emotional, social, and economic as well (Fitch, 2000; Klastersky, Schimpff, & Senn, 1999). Hence, the required focus of a supportive care program is on symptom management, patient/family adjustment, financial stress, community resources, spiritual needs and palliative care.

To be successful in meeting these needs, the focus must be on a supportive care program grounded in the elements of a therapeutic relationship, an evidence-based and family-centered approach, and interprofessional collaboration, (Fitch, 2000). The inclusion of well developed supportive care programs have become an essential feature denoting excellence in oncology services, centres and regional networks. Conversely, in programs without adequate supportive care, patients and their families may experience unmet needs to a serious degree (Sanson-Fisher et al, 2000; Whelan et al, 2000).

Since nurses work in all contexts of oncology care, from health promotion and screening to acute care, community programs, inpatient hospitals and regional ambulatory centres, and understand the impact of illness, they are ideally positioned to provide leadership in supportive care. Beyond the delivery of expert clinical care to the individual, nursing considers the oncology patient and their family as a unit. Comprehensive assessment and resolution of patient issues, enhancement of communication, interprofessional team management and coordination of community services are well recognized as legitimate nursing roles in providing supportive care.

In the past two decades, advanced practice roles have also emerged including that of clinical nurse specialist and nurse practitioner. Nurses in these categories provide additional nursing expertise to patients, families and all members of the health care team (CNA, 2002).

In order to deliver these services, various nursing models have evolved over time.

NURSING MODELS IN SUPPORTIVE CARE
In the inpatient and ambulatory care settings, groups of nurses work collectively to fulfill their accountabilities. While their role is defined by legal and regulatory bodies, the organization of their work, i.e. the care delivery model, is specific to the context and reflects the values of an organization, management philosophies and fiscal considerations (Tiedeman & Lookinland, 2004).

In the earliest care delivery model, total patient care, the nurse assumed responsibility for all aspects of a single patient’s care or an assigned group of patients over one complete shift. She/he would not necessarily resume care of the patient on her/his return in the functional model of care, responsibilities were assigned shift-to-shift, based on the skill of the care giver and the complexity of the patient’s problems. Continuity of care for a particular patient by any one nurse was not a feature. Team Nursing provided care to a defined group of inpatients under the responsibility of a team leader who, along with other nursing team members, completed the tasks of patient care, shift to shift. (Tiedeman & Lookinland, 2004). Continuity of care was not a fundamental aspect.

Primary Nursing
The professional role of the nurse evolved from the 1960s, owing to the burgeoning complexities in patient acuity, technology and specialized programs. Practice standards required competence in more areas of nursing. The inclusion of a greater number of allied professionals in the health care team necessitated broader coordination functions. Recognizing the importance of patients and families as partners in care gave rise to an enhanced focus on their expectation and goals and improved family-centredness. Efficiencies in fiscal management resulted in a shorter length of hospital stay and the need for learning about and contributing to
community resources for care, education and coping. The importance of providing continuous care to a patient by the same nurse was becoming recognized.

The Primary Nursing model evolved to meet the new challenges. The shortfalls in old models of care, such as fragmentation, depersonalization, and discontinuity of care were redressed. The Primary Nursing model emphasized the importance of both continuity of care and the accountability of a single nurse for management of the patient’s care plan. The Primary Care model has emerged within both the hospital and the ambulatory care setting (Jassec, 2002). Nursing models have evolved from a predominantly task orientation, delivered discontinuously and intermittently, to nursing care being delivered in all of its dimensions by the same individual, thus providing continuity.

The Primary Nursing model has one other important attribute. One of the current major issues in health care is the requirement to maintain a skilled and satisfied pool of nursing staff. To that end, efforts are being made to provide an enriched setting for nursing practice that produces not only safe but also satisfying care. The Primary Nursing care model is considered ideal for primary hospitals, because nurses report a higher degree of job satisfaction where they have the responsibility, authority and autonomy to execute their professional role. Furthermore, the two constructs, safe care and satisfying care, are positively correlated: more satisfied nurses deliver better care. Most importantly, the result is healthier, more satisfied patients.

Notwithstanding the strengths of Primary Nursing and the high degree of acceptability of the model among nurses, there is a need to refine its role (McFarlane & Bennett, 2006), and support it within the institution. Team commitment, accountability, motivation, and social support from the supervisor and colleagues all have been shown to improve nurses’ professional satisfaction (Pearson et al, 2006). Simply put, successful introduction of Primary Nursing has an important pre-requisite: a willingness on the part of other key professionals, particularly physicians, to forge the partnership links needed. Not all jurisdictions have been able or willing to achieve this end.

As a first step in evaluating the status of supportive care for cancer patients within the existing cancer care system, CACC conducted a survey across Canada to determine the extent of Primary Nursing in outpatient cancer clinics.

METHODOLOGY

Nurses were surveyed for their style of practice in large and small cancer centres, across eight provinces. Responses were received from all but Quebec and Newfoundland and Labrador.

A large centre was defined as one that delivers both radiation and chemotherapy. In provinces where such centres were lacking, the dominant site for cancer care delivery was selected. The distribution of 26 cancer centres selected for the survey captured large and small centres in each province surveyed (where both sizes exist) and broadly reflects the population: ten centres in Western Canada, 11 in Ontario and five in Eastern Canada.

One full time staff nurse working in a medical oncology clinic and one nursing supervisor from each centre were interviewed by an experienced oncology nurse with extensive experience in delivering Primary Nursing. Nurses working in medical oncology clinics were chosen because patients receiving chemotherapy are among those needing the most extensive supportive care. Respondents were assured neither they nor their centre would be identified in the final analysis. The majority of the surveys were conducted by telephone during October and November 2007. A small number of interviews were conducted in person during the 2007 Canadian Association of Nurses in Oncology conference in Vancouver. The survey questionnaire can be found on the CACC Web Site with other background documents related to this Report Card.

Forty-nine interviews were conducted, with 26 staff nurses and 23 supervisors. Thirty-two were with nurses working in large cancer centres and 17 working in smaller centres. Respondents were identified through a network of contacts including senior officials within the cancer system, within the organized nursing community, and at times by direct request to hospital officials.

Both staff nurse and supervisor surveys included questions related to Primary Nursing. Questions probed whether:

1. patients were permanently assigned to the nurse and physician
2. physicians and nurses worked as a team/partnership
3. continuity of care was provided by the same team/partnership after initial treatment had been completed
4. the content of the follow-up provided to the patient was beyond medical considerations
5. time was spent on clerical and non-nursing duties

The survey questionnaire was developed with the assistance of Dr. Dauna Crooks, Dean of Nursing at the University of Manitoba, and Dr. Margaret Fitch, Head of Oncology Nursing and Supportive Care, Odette Cancer Centre, Sunnybrook Health Science Centre and Leader of the Rebalancing the Focus Action Group of the Canadian Partnership Against Cancer.

Survey results were tabulated into a database and the aggregate data were analyzed by descriptive methods.
The data are therefore reported in an aggregate and qualitative manner.

**Data limitations**

As a snapshot of nursing practices in cancer clinics, the survey is limited by the relatively small number of individuals interviewed. To improve the reliability of results, a response rate of 80 per cent was set as the minimum for any individual question to be included in this analysis. In fact, the majority of survey questions achieved a response rate of 90 per cent or higher, reinforcing the interviewers’ impressions of forthright cooperation with the survey. Nevertheless, a larger survey would be required to confirm these results.

### COMMENTS BY NURSES INTERVIEWED

**Question:** Is there something else you want to add regarding your vision and goals in meeting the supportive care needs of your cancer patients?

**Answers:**

- “I enjoy Primary Nursing for the continuity provided and am able to see and evaluate outcomes of my efforts.”
- “I prefer the independence and collegial relationships of Primary Nursing. Patient and nurse satisfaction are higher. Clinical trials nurses can do primary nursing. Clinic nurses do not.”
- “All centres should have Primary Nursing so all patients have full directions and a nurse.”
- “Nurse the patient, not the clinic or the doctor.”

**Question:** If more than 25 per cent of your time is spent on non-nursing duties please specify the type of non-nursing work you perform.

**Answers:**

- File charts
- Serve meals
- Requisitions
- Coffee and cookies
- Escort patients to toilet
- Make beds
- Water plants
- Empty laundry bags
- Fax orders
- Enter doctors’ orders into computer system

### RESULTS

All staff nurses interviewed worked in an outpatient cancer clinic setting, providing direct care to cancer patients. Slightly more than half of the supervisors (57 per cent) spend at least some of their time providing such services.

Seventy per cent of all respondents said the Primary Nursing model was practiced in their clinic.

**Working with oncologists**

Whether responding as staff nurses or as supervisors, in large centres or smaller ones, 73 per cent of the nurses reported they worked closely with oncologists as part of a team that was meant to provide continuity of care to their own patients. Staff nurses also reported (84 per cent) that these oncologists have their own patients, as opposed to randomly receiving patients who arrive at the clinic.

**Continuity of care**

When staff nurses were asked whether they follow their assigned patients from initial contact with the clinic through to the completion of active treatment, 74 per cent said yes, and 86 per cent of their supervisors agreed that this was the case.

One of the ways organizations support the nurse-patient relationship is by providing patients with an email address, phone or pager number to contact their own nurse with questions between appointments. Eighty-five per cent of the nurses and supervisors confirmed this practice was in place at their clinics. In the remaining clinics, patient inquiries are answered by a triage system staffed by health professionals who did not necessarily know the patient.

Following active treatment, the same arrangements for direct patient contact with their own nurse were typically in place. Eighty-three per cent of the respondents said their patients could reach them by email, phone or pager after completion of active treatment for any issues that arose between routine follow-up appointments.

**Range of supportive care services**

Through a series of questions focusing on all the elements of the Primary Nursing model, the role of nurses was explored in more detail. Table 1 shows the affirmative answers offered by all staff nurses and supervisors, when asked if these elements were incorporated into the role of nurses in their outpatient cancer clinic. Highlighted areas show less than 75 per cent and less than 50 per cent of respondents have a role in delivering that service.

**Post-treatment Supportive Care**

Supportive care is not limited to the period of active treatment. After active treatment has been completed,
### Table 1: Aggregate Result – Elements of Primary Nursing

<table>
<thead>
<tr>
<th>Nursing Role</th>
<th>Symptom Management</th>
<th>Psychosocial Support</th>
<th>Patient Education</th>
<th>Clarify Treatment Plan</th>
<th>Refer to Other Services</th>
<th>Follow Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess Needs</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>96%</td>
<td>96%</td>
<td>69%</td>
</tr>
<tr>
<td>Develop Plan</td>
<td>92%</td>
<td>82%</td>
<td>86%</td>
<td>82%</td>
<td>76%</td>
<td>57%</td>
</tr>
<tr>
<td>Coordinate Care</td>
<td>90%</td>
<td>82%</td>
<td>92%</td>
<td>86%</td>
<td>80%</td>
<td>57%</td>
</tr>
<tr>
<td>Follow Up On Plan</td>
<td>94%</td>
<td>82%</td>
<td>86%</td>
<td>80%</td>
<td>76%</td>
<td>59%</td>
</tr>
<tr>
<td>Evaluate Outcome</td>
<td>76%</td>
<td>67%</td>
<td>63%</td>
<td>67%</td>
<td>57%</td>
<td>51%</td>
</tr>
</tbody>
</table>

Table 1 shows the overall responses for all centres combined. Between 51 and 69 per cent of respondents followed up with their patients to ensure interventions were enacted for almost all aspects of Primary Nursing, except for symptom management (76 per cent).

### Table 2: Large Centres – Elements of Primary Nursing

<table>
<thead>
<tr>
<th>Nursing Role</th>
<th>Symptom Management</th>
<th>Psychosocial Support</th>
<th>Patient Education</th>
<th>Clarify Treatment Plan</th>
<th>Refer to Other Services</th>
<th>Follow Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess Needs</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>94%</td>
<td>94%</td>
<td>59%</td>
</tr>
<tr>
<td>Develop Plan</td>
<td>91%</td>
<td>81%</td>
<td>81%</td>
<td>75%</td>
<td>69%</td>
<td>47%</td>
</tr>
<tr>
<td>Coordinate Care</td>
<td>88%</td>
<td>75%</td>
<td>88%</td>
<td>78%</td>
<td>72%</td>
<td>50%</td>
</tr>
<tr>
<td>Follow Up On Plan</td>
<td>91%</td>
<td>78%</td>
<td>81%</td>
<td>72%</td>
<td>66%</td>
<td>50%</td>
</tr>
<tr>
<td>Evaluate Outcome</td>
<td>69%</td>
<td>59%</td>
<td>53%</td>
<td>56%</td>
<td>41%</td>
<td>38%</td>
</tr>
</tbody>
</table>

Tables 2 and 3 portray the data from large and small centres separately. Of note is the fact that nurses in the larger centres appear to have a lower rate of follow-up and a lesser role in evaluating outcomes than nurses in the smaller centres.

### Table 3: Smaller Centres – Elements of Primary Nursing

<table>
<thead>
<tr>
<th>Nursing Role</th>
<th>Symptom Management</th>
<th>Psychosocial Support</th>
<th>Patient Education</th>
<th>Clarify Treatment Plan</th>
<th>Refer to Other Services</th>
<th>Follow Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess Needs</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>88%</td>
</tr>
<tr>
<td>Develop Plan</td>
<td>94%</td>
<td>82%</td>
<td>94%</td>
<td>94%</td>
<td>88%</td>
<td>76%</td>
</tr>
<tr>
<td>Coordinate Care</td>
<td>94%</td>
<td>94%</td>
<td>100%</td>
<td>100%</td>
<td>94%</td>
<td>71%</td>
</tr>
<tr>
<td>Follow Up On Plan</td>
<td>100%</td>
<td>88%</td>
<td>94%</td>
<td>94%</td>
<td>94%</td>
<td>76%</td>
</tr>
<tr>
<td>Evaluate Outcome</td>
<td>88%</td>
<td>82%</td>
<td>82%</td>
<td>88%</td>
<td>88%</td>
<td>76%</td>
</tr>
</tbody>
</table>

### Figure 1: Nurses Providing Supportive Care Advice After Active Treatment

Figure 1 shows the responses when the interviewers asked whether these aspects were personally covered by the nurses in their clinic.
ongoing supportive care can be described as seven major activities:

- Advice on factors increasing the risk of recurrent cancer
- Advice on how to reduce the risk of recurrent cancer
- Advice on reducing the risk of delayed side effects of therapy
- Advice on how to reduce the risk of other chronic diseases
- Sexual counseling
- Advice on unique psychosocial issues facing cancer survivors
- Advice on reducing ongoing symptoms of treatment (fatigue, pain)

Seventy-two per cent of the staff nurses and supervisors interviewed said that ongoing follow-up support for patients continued at their clinic after the completion of active treatment.

**Measuring volume and time**

Staff nurses were asked how many patients per week receive their personal supportive care services; 60 per cent of the nurses answered 21–50 patients and 32 per cent answered 51–100 patients. The latter group, with the highest number of patients, were evenly split between large cancer centres and smaller ones.

Seventy-nine per cent of staff nurses and supervisors estimated that more than half of their patients receive supportive care and 49 per cent estimated that more than 76 per cent of their patients receive supportive care.

To explore this point further, the survey asked what proportion of nursing time was spent providing supportive care services to patients. Forty-seven percent of staff nurses and supervisors reported that supportive care consumed more than 76 per cent of available nursing time and 40 per cent reported it as between 51 and 75 per cent of nursing time.

From time to time non-nursing duties take these highly trained and valuable professionals away from patient care, reducing the amount of time available for supportive care. The survey asked how much time staff nurses spend on clerical and non-nursing duties, excluding necessary tasks such as documentation of

**FIGURE 2 STAFF NURSING TIME SPENT ON NON-NURSING DUTIES**

<table>
<thead>
<tr>
<th>Percentage of staff nursing time spent on non-nursing duties</th>
<th>47 Respondents</th>
<th>0–25%</th>
<th>26–50%</th>
<th>51–75%</th>
<th>76–100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff nurses (n=25)</td>
<td></td>
<td>15</td>
<td>7</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Supervisors (n=22)</td>
<td></td>
<td>11</td>
<td>8</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Large cancer centres (n=31)</td>
<td></td>
<td>20</td>
<td>9</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Smaller cancer centres (n=16)</td>
<td></td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>
nursing processes and self-education. The results are shown in Figure 2. A significant minority, 47 per cent of all respondents, estimate more than one quarter of staff nursing time is lost to non-nursing duties. The more detailed breakdown showed 13 per cent believe more than half of available staff nursing time goes to non-nursing duties.

When staff nurses were asked what these non-nursing duties would entail, the tasks included clinic upkeep and cleaning as well as clerical work for the clinic and individual physicians.

**DISCUSSION AND CONCLUSIONS**

Although the individuals surveyed for this report largely believe their clinics have adopted Primary Nursing, the test questions inserted to explore the elements in place lead to a somewhat different conclusion. The responses shown in Tables 1, 2, and 3 indicate a widespread lack of follow-up to ensure that nursing plans were carried out and the results evaluated. It appears that Primary Nursing may be an operational title rather than a descriptor of roles and responsibilities. In addition, the diminutive involvement of nurses in follow-up and evaluating outcomes of the services they have designed and delivered – notably in large cancer centres – may be viewed as a sign of organizational confusion.

The amount of time lost to clerical and non-nursing duties is similarly disturbing, as it underlines a lack of professional control over the nurses’ responsibilities to patients. It can be estimated from a perusal of the data in Figure 2 that, in the aggregate, almost one third of oncology nurses’ time is spent on non-nursing tasks – a high rate of time squandered to the detriment of cancer patients.

Health system managers would do well to recall the old adage “nurses should nurse and clerks should clerk.” If nurses were able to practice to the full scope of their profession, patient care would improve and no doubt money would be saved by avoiding any further deterioration of the patients’ health. The barriers to full adoption of Primary Nursing in cancer clinics could be a combination of organizational and attitudinal factors. Given the increasing strains on the cancer system, the appropriate use of professional resources is overdue.

**RECOMMENDATIONS**

Follow-up is an integral part of supportive care, along with assessment of patient outcomes and evaluation of care processes. Primary Nursing is impeded without these elements. Cancer centres should identify and remove the barriers to a fully implemented Primary Nursing model of care.

Nurses have a legitimate role in referring patients to supportive care services, in effect navigating patients through the bewildering silos they have to traverse. Failure to maximize this role undermines the goal of seamless, timely and efficient cancer care.

Nurses must be relieved of the many extraneous tasks that abound in a clinic so their professional time is applied to nursing patients. This fundamental principle needs active support from cancer agencies, clinic managers and physicians. In lieu of the time lost to non-nursing duties, cancer clinics should be organized so that one day of nurses’ time per week (in-shift time) is dedicated to patient navigation.

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**Dr. Margaret Fitch**, Head of Oncology Nursing and Supportive Care, Odette Cancer Centre, Sunnybrook Health Science Centre and Leader of the Rebalancing the Focus Action Group of the Canadian Partnership Against Cancer.

**Janet Rush** is a nursing and health care consultant whose specialty is research and program evaluation. She holds academic appointments at McMaster University, Trent University and the University of Manitoba.

**Colleen Savage** is a public affairs and communications consultant who serves as President and CEO of the CACC.

**References**


A more detailed review of clinical cancer news may be found in the January 2008 issue of the Journal of Clinical Oncology, or by Googling “Clinical Cancer Advances, 2007”

CANCER STATISTICS

Turning the Tide

The latest report from the US shows the cancer death rate dropped more rapidly in the period from 2002 to 2004 compared to the period from 1993 to 2002, (2.1 per cent per year compared to 1.1 per cent per year). The acceleration in decline is attributed to a combination of more effective prevention, new screening methods, and better treatments. In Canada, over the period 1997 to 2003 (the last year for which data are available), the cancer death rate decreased at an annual rate of approximately 0.7 per cent.

PREVENTION OF CANCER OCCURRENCE

(PRIMARY PREVENTION)

Dietary Modification

The Women’s Health Initiative (WHI) is an eight year randomized study of almost 49,000 subjects. To date, the results of the dietary interventions are:

(a) Breast Cancer

Risk was significantly reduced in women who had the highest intake of fat at the beginning of the study and who actually reduced their fat intake.

(b) Ovarian Cancer

Risk was reduced in women who decreased the fat content of their diet. Positive results did not begin to appear until four years had elapsed.

(c) Colon Cancer and other Cancers

Dietary fat reduction did not decrease risk.

SCREENING

(SECONDARY PREVENTION)

MRI More Sensitive for Breast Cancer Screening

MRI screening is more sensitive and more specific than mammography for detecting breast cancer. According to the American Cancer Society, MRI screening should be conducted for women who have a lifetime risk of breast cancer scored at 20–25 per cent or greater. This includes women who have:

- a BRCA1 or BRCA2 mutation
- a first-degree relative (parent, sibling, child) with a BRCA1 or BRCA2 mutation,
- had radiation to the chest at age 10–30
- Li-Fraumeni syndrome, Cowden syndrome, or Bannayan-Riley-Ruvalcaba syndrome, or one of these syndromes in a first-degree relative.

There still isn’t enough evidence to recommend MRI screening in women who have:

- Up to a 15–20 per cent lifetime risk of breast cancer,
- lobular carcinoma in situ,
- atypical lobular hyperplasia,
- atypical ductal hyperplasia.

very dense breasts or unevenly dense breasts when viewed on a mammogram

already had breast cancer, including ductal carcinoma in situ.

MRI Also Useful in Contralateral Diagnosis

A newly published study shows MRI scans can be useful for finding tumours in the opposite breast of women newly diagnosed with the disease in one breast, and should be considered before surgical treatment. Not all investigators agree, however.


PREVENTION OF CANCER RECURRENTNESS

(TERNARY PREVENTION)

BREAST CANCER

Adjuvant Taxol not for everyone

Recent re-analysis of a large randomized adjuvant chemotherapy study conducted over ten years ago in women with node positive disease showed that patients whose tumours were either estrogen receptor negative or HER2/neu positive benefited from the addition of paclitaxel. However, women whose tumours were both hormone receptor positive and HER2/neu negative did not benefit. The new insight from this more mature analysis could change the adjuvant treatment of approximately 50 per cent of women with node positive breast cancer. If so, this would avoid the toxicity of unnecessary chemotherapy and substantially reduce the cost of treatment.

PROSTATE CANCER

Flaxseed may slow prostate cancer growth

Flaxseed appeared to slow the growth of the prostate cancer by 30–40 per cent when added to the diet 30 days before surgery. These results need to be repeated and expanded before definitive dietary recommendations can be made.

Treatment depends on who sees the patient

Researchers analyzed the records of 85,088 men with localized prostate cancer who were age 65 or older and diagnosed between 1994 and 2002. They found a strong association between a doctor’s specialty and the treatment the patients ultimately received. More than 67 per cent of
the men opted for surgery when they saw only a urologist, compared to only 15-33 per cent (depending on age) who saw both a urologist and a radiation oncologist. A separate study showed a higher level of dissatisfaction one year after treatment in men who chose surgery rather than radiation. Men with newly diagnosed prostate cancer should discuss treatment options with a radiation oncologist as well as a urologist, because of the differences in complications of the two methods.

**LUNG CANCER**

Shark cartilage doesn’t work
Shark cartilage extract AE-941 (Neovastat) was evaluated in 384 patients with inoperable stage III non-small cell lung cancer. Half received shark cartilage extract plus standard treatment and half received a placebo plus standard treatment. Patients receiving shark cartilage lived an average of 14 months, compared with nearly 16 months for patients receiving placebo.

**HEAD AND NECK CANCER**

Erbitux effective in advanced disease
Patients with widespread cancer of the head and neck region were randomized to receive cetuximab (Erbitux) combined with chemotherapy or chemotherapy alone. Those on Erbitux lived an average of 10 months, compared to seven months for those who did not. The most common side effect was a temporary skin rash.

**ADVANCED LIVER CANCER**

Nexavar, the first effective systemic treatment
Until recently, there has been practically no effective systemic therapy for advanced liver cancer. A randomized clinical trial compared sorafenib (Nexavar) with placebo. Nexavar targets both the tumour cell and the tumour blood supply. Patients who received the drug lived an average of nearly 11 months, compared with only ten per cent of patients taking either lower doses or placebo. Because dietary supplements are not regulated, the quality, consistency, and safety of store-bought ginseng supplements are not reliable, according to the researcher.

**ADVANCED THYROID CANCER**

Axitinib the first effective biologic therapy
Effective treatments are not available for patients who cannot be treated with surgery or radio-iodine. In a phase II clinical trial (no control group) 60 patients with thyroid cancer resistant to other treatments were given axitinib, an orally administered inhibitor of tumour blood vessel growth. Significant tumour shrinkage occurred in 22 per cent of patients. Tumour growth was arrested in another 50 per cent of patients. According to the lead researcher, these response rates have never been seen with chemotherapy. Fatigue occurred in 43 per cent of patients, with more serious effects including high blood pressure and protein in the urine occurring in five to seven per cent.

**Myeloma**

Two randomized studies have firmly established the efficacy of lenalidomide (Revlimid®) in prolonging survival in patients with myeloma who have failed other treatments including its predecessor, thalidomide (Thalomid). Lenalidomide does not cause the nerve damage seen with thalidomide, but does suppress the bone marrow and causes blood cloting.

**SURVIVOR ISSUES**

Childhood cancer survivors need better follow-up
Two thirds of childhood cancer survivors develop at least one chronic health condition because of their cancer or cancer treatment. Including secondary cancers, heart problems, lung disease, stroke, and premature menopause. Over 8000 childhood cancer survivors were surveyed. Eighty-eight per cent had received medical care of any kind in the previous two years, but only 14 per cent received cancer related care, and 18 per cent received risk-based care. Only 49 per cent received a mammogram, and 28 per cent received an echocardiogram, compared to current guidelines. The Children’s Oncology Group has published long-term follow-up guidelines for childhood, adolescent, and young adults who are cancer survivors at www.survivorshipguidelines.org.

**BREAST CANCER**

Herceptin toxicity to the heart does not increase over time
Trastuzumab (Herceptin) added to chemotherapy for women with early stage HER2/neu positive breast cancer lowers the risk of recurrence by 52 per cent after three years compared with chemotherapy alone. However, at 3 years Herceptin caused congestive heart failure (CHF) in four per cent of the women compared with 0.8 per cent in women not receiving Herceptin. After five years, the occurrence of CHF remained at four per cent and among those who experienced an initial decline in heart function, there was improvement over time.
Last year, I reported on the failure of provinces to support best treatment of chronic lymphocytic leukemia (CLL) with rituximab, a drug which produces durable remissions. I asked “how many times will this have to happen?” Well, it is still happening, and here in Ontario it is getting worse.

I regularly see patients with CLL who might benefit from rituximab. The latest case involved a 55 year old woman whose disease I was able to control for 12 years with conventional treatment but recently her disease accelerated. Her lymph nodes became enlarged, obstructing urine flow from her kidneys, threatening her life. She was weak from anemia and seriously predisposed to infections (neutropenia). Chemotherapy that had previously controlled her disease was only partially effective, failed to relieve the urinary obstruction, and caused intolerable side effects. We couldn’t get rituximab for her by simply stating her diagnosis, but after frustrating delay we obtained it via another route. The first two doses normalized her blood counts, resolved her nodes, and restored urine flow, without any side effects. She should be well on her way to complete recovery with the last two doses.

I fear that in many provinces, with the exception of BC, oncologists frustrated with the inability to treat their patients will move to other jurisdictions where treating their patients is supported by expedient access to effective treatment. Patients in Ontario may suffer grave consequences waiting for the government to make rituximab available.

Caregivers are also constantly frustrated by lack of access to diagnostic tools. A 60 year old patient, in remission for five years after bone marrow transplant for lymphoma, coughed up a small amount of blood. A chest CT scan was normal. He did not fit any of the Ontario “trials” for PET scanning. However, a PET scan obtained through other means showed slight activity in a bronchial tube. A bronchoscopic exam directed to this difficult-to-reach location revealed cancer cells but no tumour. Successful surgery for invasive lung cancer was then performed giving him an excellent chance for a prolonged and useful life. Had we not pursued the clinical suspicion that his symptoms were not due to lymphoma, we probably would have had a negative routine bronchoscopy. We would then have waited until the lung cancer grew to be visible on a CT scan, but perhaps by then it would have become inoperable.