

REPORT CARD

2004

In areas from wait times to prevention, 2004 was a year when Canadians began to hear more about cancer. A good thing, too, since this year the Canadian lifetime risk of getting cancer has risen to the estimated level of 43% for males, and 38% for females.

On the good news front, system problems are coming into sharper focus than ever before. For example, thanks to co-operation from many cancer agencies, the CACC is starting to get more comprehensive, detailed data on waiting times, a subject we have doggedly pursued over the past three years. More provinces are keeping records and divulging them publicly. We applaud their transparency, understanding the risk they run by drawing attention to the severity of waiting time problems, however we feel that transparent accounting of even the worst scenarios can be used as constructive levers to invoke change in cancer's "have-not" provinces. And we have made limited progress on getting the provinces closer to a standard measure of waiting times, which will allow future reports to make "apples-to-apples" comparisons. However, the numbers we do see indicate that in many places across the country waiting times are unacceptably long, but without a detailed breakdown of where delays are happening, it will be very difficult to address these bottlenecks.

In the tradition of earlier report cards, we continue to pursue the question of system funding. Last year's *Report Card* speculated that provincial agency funding was linked to cancer mortality: the higher the spending, the lower the mortality rate. Many challenged this finding because it didn't take into account the effect of other factors, so we decided to delve deeper into this question in 2004. A more detailed analysis

WAITING TIMES Tracking System Delays	4
PREVENTION Cancer Research Funding	10
GUIDELINES Clinical Practice Guidelines	16
CANCER COSTS Your Money or Your Life	22
The Hidden Cost of Cancer	26
POSITION PAPERS Who's in Charge?	30
Access to Systemic Therapy	32
NEWS	35

CANCER ADVOCACY COALITION OF CANADA
REPORT CARD

VOLUME 7, WINTER 2004-05

EDITOR Beth Kapusta
**CACC EDITORIAL
ADVISORY COMMITTEE** William Hryniuk, Colleen Savage,
Geoff Eaton, Sandy Yurichuk
ART DIRECTOR Bob Wilcox

BOARD OF DIRECTORS

Renaë Addis is a cancer advocate, has worked previously with a national childhood cancer foundation and is currently the Manager, Community Investment for RBC Royal Bank.

Jack Chritchley BA, MD, MSc, FRCPC is former Vice President of the BC Cancer Agency and leader of its Communities Oncology Network.

Geoff Eaton is a cancer survivor and founder of RealTime Cancer in St. John's, NL.

Jim Gowing BA, MB, BS, FRCPC is a medical oncologist and hematologist at the Cambridge Memorial Hospital in Ontario and a consultant for the Hamilton Regional Cancer Centre.

Elaine Gunter LLB, QC, is a cancer survivor and retired Director of Legislative Services for the New Brunswick Department of Justice.

William Hryniuk (chair) MD, FRCPC, is a medical oncologist and former CEO of the Hamilton Regional Cancer Centre.

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

Jaro F. Kotalik MD, DMRT, MA, was CEO of the Thunder Bay Regional Cancer Centre for North-West Ontario.

Anthony Miller MB, BChir (Cambridge) is a world-renowned investigator with research interests in cancer control, screening, diet, environment, and the prevention of chronic diseases.

Robert Pearcey, MA, MBBS, FRCR, FRCPC is Professor, Department of Oncology, Faculty of Medicine and Dentistry, University of Alberta and former Head of Radiation Oncology, WW Cross Cancer Institute, Edmonton, Alberta.

Barry Stein BCom, BCL, LLB (McGill) is a Montreal-based attorney, President of the Colorectal Cancer Association of Canada, and Vice-President of Gilda's Club in Montreal.

Sandi Yurichuk BS, MBA, is a cancer advocate and management consultant in the field of oncology.

Copyright 2005
Cancer Advocacy Coalition of Canada
Suite 204—60 St. Clair Avenue East
Toronto Ontario M4T 1N5
E-mail canceradvocacy@on.aibn.com
Phone toll free 1-877-472-3436

Disclaimer: Cancer Advocacy Coalition of Canada does not assume responsibility or liability for the contents or opinions expressed herein. Although every precaution is taken to ensure that information contained in articles is accurate as of the date of publication, differences of opinion exist and the views expressed do not necessarily reflect those of the CACC. Cancer Care in Canada should not be used for purposes of self-diagnosis or as an alternative to medical care. If you suspect you have cancer, see a physician immediately.

shows that the correlation holds up even after the effect of other factors—such as cancer incidence, the relative wealth of the provinces, and number of doctors per capita—is taken into account. Yet, in the face of the formidable challenges facing cancer agencies, the two provinces that have had the greatest success, British Columbia and Alberta, had their 2003–04 budgets limited by their respective provincial governments, with the rate of increase substantially lower than in previous years. On the other hand, several other provinces have sustained much-needed increases in level of support. And also on the positive side, New Brunswick has established the New Brunswick Cancer Network: A Cancer Control Accountability Framework, which we hope will result in that province's ability to make progress in cancer control, and that waiting times data may be made available for the first time ever.

Also on the positive side, treatment advances are coming in a cascade, with nearly 400 new potentially effective drug therapies in development. However, these agents are something of a double-edged sword in the context of the Canadian medical system. We know already that some of these new agents are effective and very costly, and most individuals would not be able to afford them. The public purse will also find it difficult to support the ever-increasing costs of cancer treatments, a fact that may delay or prevent any access by Canadians. Several of these new therapies have already been found effective in trials and approved by the American FDA for clinical use. However, it takes longer for Canada to approve new drugs, whether due to administrative inertia, or renewed fears created by the adverse events associated with some arthritis drugs, or concerns about cost-effectiveness in the Canadian taxpayer-financed system. What changes will be needed to balance the sometimes opposing requirements of the public good and the personal good that promises leading-edge treatment to all Canadians? Without weighing into this heavily loaded debate, we predict that this question will loom large in ongoing discussions about health care in our country.

The Canadian Strategy for Cancer Control (CSCC) still remains under the radar, but political murmurings indicate that behind-the-scenes support and awareness are building. The National Cancer Leadership Forum and the Canadian Cancer Society recently presented briefs to the House of Commons Finance Committee pointing to the need for increased funding for cancer control. The CACC remains a strong supporter of the Strategy. The CSCC has asked for \$50-million (plus an additional \$50 million for research) in funding to oversee improvements in target areas that include human resources; primary prevention; rebalancing the focus to increase emphasis on supportive and palliative care; research; standards; and surveillance.

Finally, this year's report card puts a spotlight on prevention—one of the most important aspects of cancer control. The challenge of putting out treatment "fires" always seems to take precedence over management of the prevention forest, yet we lose sight of this goal at our peril. After analyzing funding for research grants across the country, we have found that not enough emphasis is placed on primary prevention—especially for the kind of studies into behavioral modification that could facilitate the World Health Organization goal that we should be able to prevent one-third of all cancers.

In calling for greater emphasis on applying the knowledge we have to the mountainous problems we face, the CACC echoes a now familiar refrain that action guided by knowledge will bring about changes to reduce the substantial and devastating impact that cancer has on our lives. ●

CANADIAN STRATEGY FOR CANCER CONTROL UPDATE

Over 700 participants have spent several years crafting a Canadian Strategy for Cancer Control (CSCC) to deal with the increasing burden of cancer. Funding for the strategy remains a major challenge: last year it received only \$500,000 (as compared to the \$75 to \$100 million in annual funding assigned to the AIDS strategy). Following a Stakeholders' Conference in January 2005, the Steering Committee will formally submit a budget request for \$50 million annually to implement the strategy's recommendations, plus an additional \$50 million for research.

Political understanding of the cancer problem at both the federal and provincial level has improved. Many more politicians are also aware of the existence of the Strategy, including Prime Minister Paul Martin. The new Federal Minister of Health, Ujjal Dosanjh, has said it is a good idea. Late last fall, Senator Sharon Carstairs formally asked him what action has been taken to move it forward. At least one of our re-elected representatives, Dr. Carolyn Bennett, re-appointed in the Liberal minority government as the Secretary of State for Public Health, has an in-depth understanding of the problem (she was instrumental in the formation of Canada's new Public Health Agency and both she and agency Director, Dr. David Butler-Jones, have acknowledged that cancer is a public health problem).

Advocacy aimed at politicians at all levels has made a difference, and we have been explicitly encouraged to keep up the pressure. The efforts of many individuals and organizations, as well as strong public support for the Strategy by the Canadian Cancer Society, have been instrumental in bringing the cancer problem to the attention of politicians. In addition, efforts channeled through the National Cancer Leadership Forum (NCLF), of which the CACC is a founding member, have had an impact. The NCLF held five advocacy-training sessions in major cities across the country last fall to educate advocates about the cancer problem, and to give them the tools to engage their elected representatives and to influence media. The NCLF is also looking to galvanize public support with a social marketing campaign.

Incomplete information and different measures make it difficult to pinpoint the problems behind waiting times—and even harder to solve them

Tracking System Delays

LONG WAITS AND NO SHORT ANSWERS

BY COLLEEN SAVAGE

Waiting times are the symptom of a more sinister problem: patients don't receive treatment when it would be most effective. It defies reason to suggest that waiting has no adverse impact on outcomes; treatment choices evaporate as time passes. The point of early detection and screening programs is to ensure early diagnosis; the point of early diagnosis is to improve the odds with rapid, effective intervention; and the point of the intervention is to minimize the damage and keep people alive.

In every *Report Card* since 2000, the CACC has attempted to report on the waiting times experienced by Canadians after a diagnosis of cancer. Every year, the cancer agencies produce a list of exceptions to justify the missing data and rationalize their reluctance to be compared, claiming:

- They are not responsible for some types of waiting;
- They don't have the information;
- They define waiting times in different ways;
- The data are not comparable; and
- The subject is complex.

This year's report explores these issues to find out whether they are camouflage or a truth that needs attention. We found, of course, that statisticians can only report what they measure, and they cannot tabulate what they have been told not to count. These may be explanations for the incomplete and variable quality of data, however they are not acceptable excuses for the continued lack of transparency on waiting times. The real questions are, who determines what should be measured or not measured, and why do the cancer agencies resist common definitions that would make comparisons more meaningful?

Commenting on the quality of data, two factors are most often cited by cancer agencies claiming they are not responsible for some types of waiting: patient preference and delays in the system prior to referral.

Sometimes patients defer tests and treatments because of illness, family demands, holidays, or difficulties in traveling to the designated facility. These factors can affect the timeliness of treatment, and the health system is not responsible for the resulting added time between diagnosis and treatment. No one reports those events to separate them from other reasons for waiting, which makes it impossible to determine whether patient preference is a significant cause of long

AGGREGATE WAITING TIMES

(NUMBER OF DAYS)

	Systemic Therapy			Radiation			Agency Notes 2003	
	BREAST	PROSTATE	LUNG	BREAST	PROSTATE	LUNG		
BC	2001	28	28	28	28	28	In 2003, 90.6% of patients received treatment within 28 days Data not readily available by individual tumour sites.	
	2002	N/A*	N/A	N/A	31	31		19
	2003	25–32			25–32			
ALB	2001	28 MAX	28 MAX	28 MAX	28 MAX	28+	28 MAX	
	2002	N/A	N/A	N/A	N/A	N/A	N/A	
	2003	Incomplete			64	61	49	
SASK	2001	N/A	N/A	N/A	N/A	N/A	N/A	
	2002	N/A	N/A	N/A	N/A	N/A	N/A	
	2003	44	62	26	53	93	28	
MAN	2001	"No wait except for more common cancers."			28–35			It is important to remember that patients are prioritized according to need. As a result, patients are seen in a manner that is both timely, and reflective of their disease. More urgent cases are seen sooner, sometimes experiencing virtually no wait. Wait times start from "ready to treat" date.
	2002							
	2003							
ONT	2001	35	48	22	55**	69**	N/A	Four-point Action Plan on waiting times released in the Spring of 2004: reduce demand by lowering risk, increase resources, coordinate access, increase efficiency. CCO integrating business processes/technologies for wait times. Extra 1,700 cancer surgeries to be completed by March 2005. **Excludes University Health Network, other than radiation wait times for 2002 and 2003.
	2002	38	36	21	58	70	N/A	
	2003	40	64	25	54	63	N/A	
QUE	2001	N/A	N/A	N/A	N/A	N/A	N/A	
	2002	N/A	N/A	N/A	N/A	N/A	N/A	
	2003	N/A	N/A	N/A	N/A	N/A	N/A	
NB	2001	N/A	N/A	N/A	N/A	N/A	N/A	
	2002	N/A	N/A	N/A	N/A	N/A	N/A	
	2003	N/A	N/A	N/A	N/A	N/A	N/A	
NS	2001	N/A	N/A	N/A	N/A	N/A	N/A	Although such figures broadly reflect access to specialty services, individual patients are seen and treated according to their acuity and need. Measures to increase efficiency, resources and satisfaction are in place. Additional linear accelerator acquired in 2004 to address demand.
	2002	22	15	9	63	130	34	
	2003	N/A	N/A	N/A	N/A	N/A	N/A	
PEI	2001	N/A	N/A	N/A	N/A	N/A	N/A	Recently we have seen a decrease in our wait times for breast and prostate as the backlog is being addressed through various measures in our province.
	2002	14	6	5	73	N/A	21	
	2003	N/A	N/A	N/A	82	125	19	
NL	2001	35 to 42			70 to 84			
	2002	30	17	21	53–60	51–58	34–41	
	2003	N/A	N/A	N/A	N/A	N/A	N/A	

Note: due to the nature of our data requests, and the varying responses over the years, some fields in this chart seem empty, but more details can be found for 2003 in the chart on page 7.

* N/A= not available

waiting times. CACC suspects that these factors have a minor impact.

There are other reasons why wait times are prolonged, even after referral. Sometimes, the wait is determined by the availability of laboratory or diagnostic imaging test results that may not be relevant to the patients' proceeding efficiently to the specialist consultation or treatment intervention. Surgery for the primary and curable breast cancer is often delayed for multiple investigations. So, some delay is induced by the new, very expensive cancer care pattern that may be having an adverse impact upon cure rates, while dramatically increasing costs.

We recognize that cancer centres cannot control time delays caused by a referring physician who does not act quickly to refer a newly diagnosed patient for specialized treatment. No one knows how much time is lost in that part of the process, provincial cancer agencies can only influence the process after they receive the referral and consequently, waiting officially starts then. So we have to ask, who controls the waiting time outside the cancer system? Does anyone have a plan to improve that? Clearly, if we are going to streamline the system, improve patient access and reduce avoidable delays there must be better communication and coordination between the services and the professional groups, especially with primary care physicians.

Cancer patients know all too well about the block of time spent after their first interview with their primary care physician—the wait for lab test results and for an appointment with a surgeon, a respirologist, a urologist, the delay in booking a colonoscopy, a bronchoscopy. This stage can add weeks or even months to the delay. Worrisome symptoms can lead to a diagnosis other than

cancer, but for those who do need cancer diagnosis and treatment, the waits can be long. The wait time for a colonoscopy in a Toronto hospital is anywhere from eight to 12 months. In the same city, the same procedure can be done within two weeks at a private clinic, sometimes with a fee attached for non-insured services. Since no one tracks waiting times leading up to a referral to cancer care, the CACC has never been able to add this element to annual reports on waiting times.

Provincial cancer agencies have different explanations for their lack of comparable data for waiting times. Some state that they don't collect that information, others that their definitions are different from other provinces, and it is often commented that the data can not be compared province to province because of all the different elements used to collect and tabulate it.

British Columbia and Manitoba, for example, report the period from "ready to treat" to the onset of treatment: after the patient's oncology consultation and investigation are complete and they are ready to initiate treatment. This means the investigation period for tests, further consultations, waiting for a CT or MRI, waiting for lab reports, is not reported. Once the patient is deemed ready for treatment, BC and Manitoba turn their computers on again. This comes back to the comfortable theory that the patient is receiving medical attention and is therefore not "waiting." BC has a waiting time of up to three weeks for a CT scan and two weeks for an MRI, unless the oncologist and radiologist regard the case as an emergency. Alberta, Nova Scotia and Newfoundland report average wait times, not median; and the Ontario information system does not report any waiting time longer than 20 weeks on the assumption it must be a mistake. CACC has been trying for four years to report wait times for cancer treatment but still, Quebec and New Brunswick are unable to provide any information at all.

THE CACC REQUEST

In the interest of simplicity and clarity we adopted definitions outlined by the Canadian Cancer Surveillance Alliance. In each case, CACC requested median data for only the top four cancers: breast, prostate, lung and colorectal; only for new cases; only for the calendar year 2003, and in days not weeks.

1. Number of days a patient waits from the date of referral to the date of first oncologist consultation—from the date oncology services were requested for a primary cancer to the date of radiation or systemic oncology consultation for the first course of treatment for a primary cancer site.
2. Number of days a patient waits from the date of first oncologist consultation to the date of either systemic or radiation therapy—corresponding to the first course of treatment to a primary cancer site.

DARE TO KNOW!

Despite recent current political hype about improving waiting times, the provinces have still not agreed on common definitions, still do not collect the same data elements, and still report on waiting times in different styles. Until there are appropriate data, it is not possible to identify the problems or initiate a solution. Is there a shortage of CT, MRI or PET scanners? A shortage of oncologists or technicians? The system is complex and easily fragmented to the detriment of the patient. Everyone knows that delays usually mean the cancer is growing and may be spreading, that cure might be compromised, that

Chemotherapy								Radiation Therapy								
	Referral to oncology consultant				Oncology consultant to start of treatment				Referral to oncology consultant				Oncology consultant to start of treatment			
	BREAST	PROSTATE	G.I.	LUNG	BREAST	PROSTATE	G.I.	LUNG	BREAST	PROSTATE	G.I.	LUNG	BREAST	PROSTATE	G.I.	LUNG
BC	12				13–20				12				13–20			
ALB	34	18	29	21	Not Available				39	35	18	17	25	26	34	32
SASK	25	26	28	12	19	36	17	14	19	26	12	14	34	67	30	14
MAN	Not Available				Incomplete				Not Available				Incomplete			
ONT	21	20	20	13	15	34	11	7	19	14	N/A	N/A	32	47	N/A	N/A
QUE	Not Available				Not Available				Not Available				Not available			
NB	Not Available				Not Available				Not Available				Not available			
NS	20	13	18	7	24–48 hours				20	13	18	7	46	120	62	25
PEI	7	7	0	1	Not Available				7	7	0	1	75	118	13	18
NL	21-28	N/A	28	21	Not available				35	56	35	14	Not Available			

2003 WAITING TIMES

Calendar Year 2003 except where otherwise noted.

1. Number of days a patient waits from the date of referral to the date of first oncologist consultation.
2. Number of days a patient waits from the date of first oncologist consultation to the date of first treatment of either systemic or radiation therapy.

BRITISH COLUMBIA For fiscal year 2003/04. From “ready to treat” date, the wait times for treatment were: Systemic therapy: 6 days. Radiation therapy: 6 days.

ALBERTA Average length of time, not median.

SASKATCHEWAN Data for the Allan Blair Cancer Clinic only, representing both clinics and the province as a whole.

MANITOBA From “ready to treat” date, the wait times for radiation therapy were: Breast: 28 days. Colorectal: 11 days. Prostate: 30 days. Lung: 13 days. A CCMB pilot project, not yet completed, is finalizing definitions of variables that may be used to calculate wait times.

ONTARIO For fiscal year 2003/04. Excludes wait times greater than 20 weeks. Wait times do not account for referring doctor or patient initiated delays. For systemic therapy, patients receiving radiation therapy first were excluded from the calculations. Similarly, for radiation therapy, patients receiving systemic therapy first were excluded. Excludes non-Ontarians. Includes all Integrated Cancer Programs except University Health Network (UHN) and excludes all other Ontario hospitals (approximately 55% of systemic delivery).

QUEBEC Radiotherapy centres start furnishing the centralized organization with standardized data beginning October/04. Data will be accessible in 2005.

NOVA SCOTIA Median times for patients newly diagnosed in 2002 and seen in cancer centres as part of primary treatment. Long waits for radiation treatment in breast and prostate cancer may include appropriate delays to administer hormonal or chemotherapy in sequence schedule.

PRINCE EDWARD ISLAND Prior to the linear accelerator becoming operational in Oct/03, patients requiring treatment on a linear accelerator had to travel off Island. Patients with an excessive wait are offered treatment in Halifax. Patients rarely choose to complete their radiation treatment in NS.

NEWFOUNDLAND AND LABRADOR Average length of time, not median.

patients awaiting diagnosis and treatment are in psychological suffering and often in physical pain. A good cancer-control system should navigate the patient promptly from symptom to the best evidence-based treatment intervention. Patient transit through the system must be properly tracked and reported, and the variables accounted for, or our cancer system will never know where the problems are or what to do about them.

Waiting times captured centre stage in Canada's recent federal election, and have been part of successive Health Accords between the Federal and Provincial gov-

ernments. Provinces have agreed to the following steps: Each jurisdiction agrees to establish comparable indicators of access to health care professionals, diagnostic and treatment procedures with a report to their citizens to be developed by all jurisdictions by December 31, 2005.

Evidence-based benchmarks for medically acceptable wait times starting with cancer, heart, diagnostic imaging procedures, joint replacements, and sight restoration will be established by December 31, 2005 through a process to be developed by Federal, Provincial and Territorial Ministers of Health.

Multi-year targets to achieve priority benchmarks will be established by each jurisdiction by December 31, 2007.

Provinces and territories will report annually to their citizens on their progress in meeting their multi-year wait time targets.

WAITING TIMES A National Perspective

BY BRENT SCHACTER

At the First Ministers' Meeting in September, 2004, an initiative was set out to develop a plan to more effectively manage waiting times for cancer diagnosis and treatment. The First Ministers requested data that would provide comparable indicators of access, acceptable benchmarks and an effective reporting framework.

Valid and comprehensive wait time data would help in more effectively managing the wait process for individual patients and thus ensure prompt and timely treatment while reducing worry, anxiety, stress, pain and discomfort for cancer patients and their families. In addition, collection of wait time data would enable accurate surveillance and monitoring of trends over time to evaluate and report on progress or pinpoint areas that require more effort. Wait time data would also assist in identifying factors that affect waiting time at a facility or regional level, so that corrective efforts might be applied at choke points. Experience with wait time data for cancer patients and correlating them with outcomes would also assist in setting benchmarks for best practice for wait times for diagnosis and treatment.

There is much that needs to be done in this area to have agreed upon standardized definitions for data definitions, to develop and set evidence-based benchmarks for appropriate waiting times, and to develop effective and efficient processes for data collection, evaluation, feedback and reporting to involved institutions, government and the public.

The development of effective mechanisms for collecting and reporting wait times for cancer diagnosis and treatment will enable cancer agencies and programs, hospitals and care providers to devise, fund and implement processes that will ensure timely cancer care and cancer control and improve the quality of cancer care for patients.

Brent Schacter, MD, FRCPC is Chief Executive Officer of the Canadian Association of Provincial Cancer Agencies (CAPCA)

CONCLUSIONS

In spite of First Ministers and Health Ministers promising urgent action on waiting times, promising benchmarks and targets and priority attention, it is clear that patients are the only people who know what a waiting time is. What good is a target if each province will report its progress in ways that defy comparability? The only reliable use of the data provided is to compare a province to itself to see whether the province or its cancer agency is making any progress on waiting times. Overall, the picture is not encouraging.

CACC RECOMMENDS

The CACC recommends that all provinces move to adopt the definitions of the Canadian Cancer Surveillance Alliance for waiting times data and work on agreement of the variables that need to be captured for more complete reporting. For example, data should be compiled so that:

- Sequential treatments, such as systemic therapy followed by radiation therapy, do not artificially inflate waiting times for the second modality;
- Factors that are not indications of system responsiveness are separated from the data (patients with other health problems that need resolution before treatment can begin, patients who choose to delay their appointments or treatments);
- Surgeries, which are often performed outside the cancer system, are reported separately.

All provinces should adopt a common, transparent and consistent approach to ranking the priority for urgent/routine cancer care, i.e., who waits, who does not,

and what standards should apply to those decisions. CACC believes that most cancer treatment is urgent.

Provinces should report on:

- Benchmarks and targets currently in place for their jurisdiction with respect to acceptable waiting times, by tumour site and stage of disease (the BC Cancer Agency does this already and can be used as a model);
- The percentage of patients who are seen within target time frames;
- The time required for the investigation process – i.e.

waiting times for CT, MRI and PET scans, along with other laboratory tests;

- The percentage of patients with adverse outcomes whose waiting time exceeded the median for each step: waiting for the first appointment, waiting during the investigation, and waiting for systemic or radiation therapy;
- Wait times for cancer surgery as well as systemic and radiation treatment. ●

Colleen Savage is a Toronto-based public affairs and communications consultant, and the CACC president.

WAITING TIMES: A MOVING TARGET

“Facts are stubborn but statistics are more pliable.” –Mark Twain

The goal in collecting and reporting waiting times is to identify bottlenecks that need resolution. CACC asked each province to provide data capturing two intervals: waiting for consultation, which is the period between first referral and first appointment with an oncologist, and waiting for systemic or radiation therapy, which is the period between the first appointment and the initiation of systemic or radiation therapy.

The first interval is a measure of the availability of oncologists and the ability of the cancer system to manage a growing caseload. The second interval is a measure of cancer system efficiency in assessing the tumour, organizing a treatment plan and delivering services. It is this second interval where dozens of complicating factors can affect waiting times and where arguments erupt about what is waiting and what is not. For the patient living with the knowledge that cancer continues to grow until treatment is started, all waits count.

The time between referral and the beginning of systemic or radiation therapy is not a complete measure of “waiting for treatment.” The wait times for specific types of cancer, such as breast and prostate, may reflect the method and sequence of treatment rather than the length of time a patient is waiting for treatment.

For example, in Nova Scotia, a breast cancer patient may meet with both a medical and radiation oncologist on the same day. The treatment may begin with several months of systemic therapy followed by radiation therapy. The waiting time for radiotherapy will therefore seem longer than for other cancers where multimodality therapy is not the routine and longer than in other provinces that organize their appointments another way. For these reasons, some of the variation in waiting times may be

due to treatment and referral practices, rather than representing real variation in access to resources.

To use another example, treatment for prostate cancer usually begins with hormone therapy; radiation therapy therefore begins several weeks after the first consult.

The struggle in these circumstances is to collect data with common definitions and enough detail that obvious exceptions like these can be separated from the aggregate, giving a true picture of real wait times. In the interim, two provinces already use “ready to treat” as the start point for measuring wait times and other provinces seem likely to move in that direction. It leaves a hole in the data – one that fails to identify the impact of equipment shortages and human resource shortages on patient waiting times.

All provinces note that cancers are not equally urgent. The most urgent cases are said to receive priority at every stop – for the first appointment, for investigative tests and for systemic or radiation therapy. However, the data collected by provinces does not allow any practical way to identify when that priority ranking has kicked in, or how many of the patients who waited longer for their treatment had adverse outcomes. The lack of transparency about how that ranking is determined can only lead to fears that it might not be completely fair.

These explanations from cancer agencies describe the inability of provinces to take the first steps toward an improvement in waiting times:

- Clear and consistent definitions;
- Information systems that support transparency and accountability;
- Common reporting measures.

Benchmarks and targets will be meaningless if the provinces continue to capture and report on waiting times in ways that defy comparison. By avoiding the first steps, provinces are able to report selectively to their citizens and conceal the unpalatable.

A shift in emphasis from basic science research to prevention research is our best chance to control the rising cancer tide

Cancer Research Funding

WHERE DO THE DOLLARS GO?

BY DRS. ANTHONY MILLER, FRED ASHBURY, AND WILLIAM HRYNIUK

After years of emphasizing basic science research to conquer cancer, we must rethink our approach. We have seen a limited impact in cancer prevention—some success with tobacco control, dietary change, screening and better treatment for some cancers—but we have been unable to prevent the rise in number of people diagnosed with cancer as the population ages. The result is that those who have escaped death from other causes are now reaching the age when cancer becomes common, to the point where more than 40% of Canadians will develop cancer in their lifetime. This should be of increasing concern to each of us personally and as a society because the cost of effective cancer treatment is rising rapidly, threatening to become an unbearable burden to our health-care system. Yet the World Health Organization (WHO) has concluded that over a third of cancers worldwide could be prevented. The Council of the Canadian Strategy for Cancer Control has endorsed the WHO's evaluation and set up a Primary Prevention Action Group to help facilitate cancer prevention. What can we do to prevent more people from developing cancer?

Federal government and voluntary contributions for cancer research amount to more than \$146 million a year, with two-thirds coming from federal tax dollars directed to the Canadian Institute for Health Research (CIHR), and one-third from public donations to the Canadian Cancer Society channeled to the National Cancer Institute of Canada (NCIC).¹ The CACC examined how this money is spent. Most goes toward basic research, and much less toward research that will prevent cancer.

We began our analysis of research grants in 2004 using an electronic, word-based search of the Canadian Research Information System (CRIS) Database for CIHR and NCIC projects whose titles or abstracts indicated they were directed at cancer prevention. This search turned up mostly basic research projects that had little relation to cancer prevention in humans, but whose titles or abstracts contained the word "prevention." For example, both CIHR and NCIC funded projects to study proteins or DNA related to the growth of mouse skin cells, with the ostensible goal of preventing skin cancer in humans. Now non-melanoma skin cancer in humans can be readily recognized, cured in almost all cases, is rarely fatal, and can easily be prevented by avoiding excessive sun exposure. Yet these two projects received more than half a million dollars over three years. The real problem is not how to prevent skin cancer in mice, but how to get more adults to avoid excess sun exposure, and make sure their children do the same.

We realized that if we wanted to properly analyze research allocation, we would have to individually review the title or abstract of each of the 1,600 research projects funded by CIHR and NCIC to find out the funding level for cancer prevention research in humans. For this purpose we classified projects into six categories of research: Basic, Diagnosis, Treatment, Supportive Care, Palliative Care, and Prevention (see page 13 for definitions).

Our definitions were guided by an international classification of cancer research called the Common Scientific Outline. Using our definitions, we performed a full audit of the research portfolios of both the CIHR and the NCIC.

Over 70% of total funding (approximately \$100 million) is allocated for basic research, 13% for diagnosis and treatment, 2% each for supportive and palliative care, and the remaining 13% for prevention (see Figure 2).

The application of existing knowledge on prevention is potentially one of the most economical and effective tools we have for combating the rising human and financial toll of cancer. Unfortunately, we still need to learn how to use this knowledge most effectively. For example, we need behavioral science research both at the societal and the individual level to tell us how to curb the smoking epidemic in women, and how to encourage people to lose weight and exercise more (primary prevention). Furthermore, next to nothing is being spent on tertiary prevention research—that is, trying to reduce the chance of recurrence in cancer survivors after they have completed initial treatment. Survivors are at the highest risk, since 13% of them will develop a second type of cancer and over the course of their lives a substantial proportion will also develop a recurrence of their original tumor. Of the \$19 million spent on prevention research, no more than \$3 million was allocated for studies on behavioral modification research to reduce the risk of cancer developing or recurring. We feel this allocation, a mere 2% of the entire cancer research total, is far too low. That's less than nine cents for each Canadian.

Sadly, this situation is not unique to Canada. The US spends four times as much as we do on cancer research on a

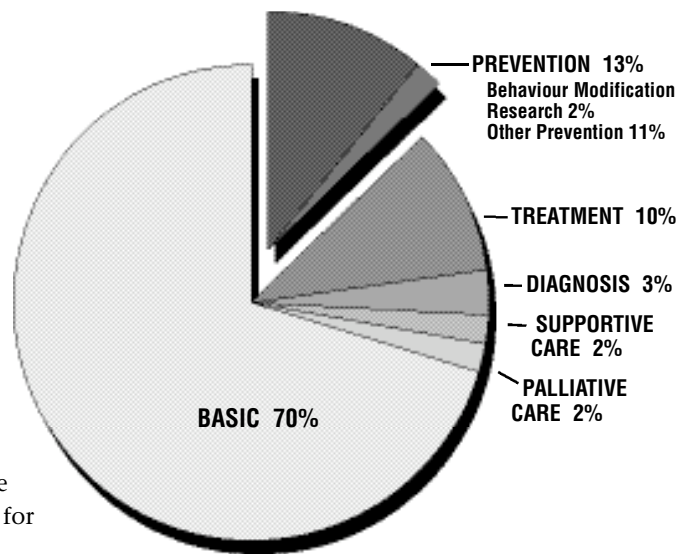


FIGURE 1: **NCIC + CIHR RESEARCH FUNDING ALLOCATION**

FIGURE 2: **RESEARCH FUNDING ALLOCATION**

TYPE OF RESEARCH	NCIC	CIHR	NCIC + CIHR
Basic	65%	73%	70%
Diagnosis	3%	3%	3%
Treatment	16%	7%	10%
Supportive care	3%	2%	2%
Palliative care	2%	1%	2%
Prevention	10%	14%	13%

per capita basis and, in total, forty-fold more. Yet, Americans are not much better off than we are as regards the cancer epidemic. Even though the amount coming through Cancer Society donations and allocated to research by the NCIC is three times higher in Canada than the US on a per capita basis, the shortfall comes both in the per cent allocated to prevention by both NCIC and CIHR, and to a greater degree, in the low level of federal funding to CIHR. Federal funding for cancer research should be closer to \$400 million annually (an additional \$300 million) and a much greater proportion should be directed at prevention in humans. Simply throwing more money at research overall isn't the answer; the fundamental flaw appears to be in how the dollars are allocated to the different streams of research.

AN OUNCE OF PREVENTION

A look at the numbers shows some evidence that actions designed to prevent cancer are working. If we consider the incidence in terms of the number of cases at each age group (age-standardized incidence rate or "ASIR"), the incidence of lung cancer in males has been falling for some years. Credit must go to investigators working on smoking cessation programs. We laud and encourage the NCIC's establishment of units across the country for this purpose, under the aegis of the Centre for Behavioural Research and Program Evaluation. Colorectal cancer is falling in both sexes. For other common cancers, the number of new cases has remained about the same. For example, after a rise attributable to early detection and screening, the ASIR for breast cancer is now stable, while death rates from breast cancer are falling, although largely due to better treatment. Prostate cancer seems to have stopped increasing in incidence, an increase that was due to the widespread use of the PSA test, even though we have no confirmation such usage saves lives. However, the ASIR's for lymphoma, thyroid cancer, and melanoma are increasing, and especially in the case of lymphoma, we need to find out why.

The CIHR and the NCIC claim that a great deal of the research support they provide can be regarded as related to cancer control either now or in the future, maintaining that much basic research eventually leads to advances in diagnosis, treatment and prevention. However, this has not often happened in the past and it may be a rather distant hope that much basic research will eventually have such application.

It is also often stated that many Canadian basic cancer researchers are "world class," and that is true. Measured by the standards researchers tend to apply to themselves (peer-review): publications in prestigious journals, international recognition, and success in grant applications, our Canadian researchers are indeed outstanding. But much of this is self-fulfilling. Peer review is just that, review of what a researcher has done or is proposing to do by his or her peers, who think similarly and apply the same standards. To most scientists, managed research is anathema. "We do not know where the next advance will come from," they say, so that scientists must be free to pursue their own aims, with the example in Canada of Dr. Bob Noble before them, who set out to discover drugs to help diabetics, and ended with a drug that helped cure cancer. There is nothing wrong with serendipity, but should it drive how such a large proportion of cancer research money should be spent?

What tends to happen is that scientists follow leads. The current lead is that the solution to cancer lies in our genes, so billions of dollars the world over were and continue to be spent to determine the exact constitution of the human genome, in the hope of determining individual susceptibility to cancer-causing substances, developing new drugs specific for the cancer-causing process and new means of detecting cancer. Instead, we have multiple reports claiming major advances only to find out they were established in model systems (tissue culture or animals), and that it would be decades before they might be proven useful in humans. We don't have decades; the epidemic of cancer is already here. There is an emerging recognition that determining gene-based individual cancer susceptibility is extremely difficult, and the highly effective new drugs now coming to the clinic have been extremely expensive to develop, making the potential for the

widespread implementation of more individualized therapies even more difficult to imagine.

This is not the first time the basic science establishment has promised us the moon and failed to deliver. One has to admire their incorrigible optimism, while fearing the consequences of their enthusiasm. Not surprisingly, they have tended to resent funds being “siphoned away” from basic science to cancer control research and, understandably, some have done everything in their power to ensure that as little as possible went that way.

When we look at what we now know about preventing cancer, little of that knowledge came from basic science research. It was epidemiologists who identified the associations between lung cancer (and other cancers) and tobacco use, epidemiologists who identified the links between obesity and lack of physical exercise and cancer, occupational health specialists who noted the links between carcinogens in the workplace and occupational cancer (and epidemiologists who confirmed them) and clinicians who recognized the links between exposure to sunlight and skin cancer. It is now up to the behavioral and social scientists to explore ways of putting this knowledge to work. To be fair, basic science has set the scene for our knowledge on diet and cancer, but the extent to which it is true, and what can be done about it, still needs evaluation by epidemiologists, nutritionists, and behavioral scientists.

As a result of basic research, potentially valuable new drugs are being discovered (almost 400 in the pipeline at the latest count), but clinicians working with statisticians in the discipline of clinical trials still have to determine whether and how they should be applied in humans. Only one drug out of 13 ever makes it to routine clinical use. Even if the genetic revolution produces a potential breakthrough, its utility will have to be established by epidemiologists and, for drugs, by clinical researchers. And how all this is applied, and delivered more effectively and efficiently will have to be evaluated by behavioral scientists and health policy researchers.

We know that 30% of cancers are due to tobacco use, another 20% to 30% attributable to diet and alcohol, 10% from obesity and lack of physical exercise, smaller proportions from past occupational exposures and some due to factors

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 tumor-directed therapies, or their combinations. Complementary therapy is included if it is tumor 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 “normal” people 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 tumor i.e. tertiary prevention.

in our external environment. The fact that preventable cancers continue to occur is in part because not everyone who is exposed to cancer causing substances does anything about it (How many continuing smokers do you know? Are you watching your diet?), and in part because we cannot get rid of the risk incurred from past exposures. This is why the majority of lung cancers in males in Canada now occur in former smokers, and why occupationally induced cancers continue to occur, even though the carcinogen may have been recognized and removed from the workplace. It takes about 40 years for the full effects of prevention to be seen.

In spite of this delay in reaping the full benefits of prevention, there is no excuse for failing to apply the knowledge we have. Everyone who smokes can reduce their future risk if they stop now. Therefore, we must re-double our efforts to prevent young men and women from starting smoking, and if they have started already, help them to stop. We should eat a healthy diet, avoid obesity, ensure regular exercise is part of our daily life, and if we know there are hazardous chemicals in our work environment, we must ensure they are removed. We should protect ourselves against sunlight, and work to prevent the contamination of our environment with carcinogens. Moreover, these changes in lifestyle to prevent cancer also reduce people's risk of developing other chronic diseases, such as cardiovascular disease and adult-onset diabetes. Adolescents should understand that cervical cancer is caused by a sexually transmitted virus, and can be prevented by using condoms—the same measures taken to prevent AIDS.

To bring about these changes, we need far more clinical research studies in behavioral modification at the individual level, especially among those who continue to smoke and Canada's almost one million cancer survivors. This clearly creates the need for much more expenditure on such research, and for training clinical investigators in this arena. Again, this emphasizes the need for an organized and concerted national effort focused on cancer prevention, rather than the fragmented and inadequate approach we have currently. The reward will be a major step forward: control of the cancer epidemic.

We do not advocate abolition of support for basic science. We owe much to the investigators working in their diverse fields and to those who have gone before. But we do ask for re-evaluation of what has been achieved in the immediate past and where research is now focused. This has already been recognized as necessary by the cancer research community through the CIHR², by the Canadian Cancer Research Alliance arm of the Canadian Strategy for Cancer Control, and by the NCIC preparing a position paper on research priorities. However, the resulting long-term funding commitments tend to be in self-perceived priority areas. In the case of the CIHR, an additional \$2.4 million has been allocated over six years for research in risk behavior and prevention. This is a yearly increase of a little more than one cent per Canadian.

We believe that re-evaluation of priorities cannot be performed in an unbiased way by science researchers themselves, or left to the Scientific Advisory Boards of CIHR and NCIC. The latter two groups are made up of esteemed and dedicated individuals from a wide variety of disciplines, and without exception all have made significant contributions, but they are predominantly scientific investigators, and the fixes they have been approving from their collective perspective haven't yet controlled cancer. Something has to change in a big way.

CACC RECOMMENDS

In the UK, an all-parliamentary committee oversees cancer control and its link with cancer research. They have the power to take evidence and make recommendations. Canada needs a similar body to ensure alignment of research priorities with societal priorities, perhaps the same body providing oversight to the Cancer Agency (see page 30).

A standard classification of research should be adopted. The International Cancer Research Portfolio would be a place to start, although it does not adequately distinguish basic from human research, and needs to be modified to specify the subcategories of primary, secondary, and tertiary prevention research

New monies are needed from the federal level and should be assigned more according to public health priorities, and less according to individual investigators' priorities. To us, that means much more prevention research. More emphasis should be placed on identifying individuals at high risk and studying ways to modify their behavior. Special attention should be given to cancer survivors.

A concerted attempt should be made to estimate the dollar figures required to achieve specific cancer control goals. The corporate sector is already engaged in this process. It is not an impossible feat.

We must not wait any longer to ensure that the taxes and donations expended in our name are put to better use. Given the rate at which the cancer epidemic is galloping through the population, answers are needed now, not in 20 or 40 years. ●

NOTES

1 Numerous cancer charities receive donations for research and allocate them to the extent their funds allow. The National Cancer Institute of Canada (NCIC) is the largest charitable funder of cancer research in Canada, but the largest overall source of cancer research funding is the Canadian Institutes of Health Research (CIHR). The NCIC administers research for the Canadian Breast Cancer Research Alliance, which includes funding from the Canadian Breast Cancer Foundation, the Avon Flame Foundation and Health Canada. Other funding partnerships include the Canadian Prostate Cancer Research Initiative and the Canadian Tobacco Control Research Initiative, both with funding from a variety of partners other than the NCIC.

2 "Cancer Research on the Agenda", *Oncology Exchange*, Feb 2004

Dr. Anthony B. Miller is Professor Emeritus in the Department of Public Health Sciences, University of Toronto, Director of the Canadian National Breast Screening Study, a consultant to the World Health Organization and a consultant to the US National Cancer Institute. He directed the National Cancer Institute of Canada Epidemiology Unit 1971 to 1986.

Dr. William Hryniuk recently returned to Canada from the US, where he practiced as a medical oncologist, taught at medical schools, and developed and directed major cancer centers and regional cancer control programs. He has also been an active researcher, having received continuous peer-reviewed funding for 30 years for both basic and cancer control research from both the NCI and the NCIC. He is currently the voluntary Chair of CACC, and Medical Director of CAREpath Inc.

Fred Ashbury, PhD, is President, PICEPS Consultants, Inc. He holds university appointments at McGill, Toronto, and Guelph. His research interests include cancer clinical trials, physician behaviour change, and health promotion.

Canada's clinical guidelines vary widely from province to province, showing the need for a new approach

Clinical Practice Guidelines

HERE A GUIDELINE, THERE A GUIDELINE

BY COLLEEN SAVAGE

CACC has long been concerned about the variations in access to new cancer treatments across the country, a confusing situation that does not seem to reflect the most up-to-date knowledge. We have wondered whether the differences are due to the provincial layer in Canada's sluggish approval process, or whether it's mostly about money. We know it isn't only about evidence of effectiveness. Oncologists go to the same conferences and read the same peer-reviewed journals regardless of where they live, so why do they write different guidelines? Ultimately, the problem lands on the shoulders of the cancer patient, who may or may not be offered the benefit of current knowledge in cancer treatment, or who might have to pay in one province for a treatment that is covered in another province.

The Institute of Health Economics in Edmonton has a report in progress on *Variations in Access to Cancer Drugs Across Canada*, (Devidas Menon, Philip Jacobs, Tania Stafinski, Leigh-Ann Topfer, and Gavin Stuart). Their interim findings were reported by the *Edmonton Journal* in June 2004. "Of 115 established cancer drugs, only seven are provided free to cancer patients in all 10 provinces. Although nearly half of the drugs are available free in at least nine provinces, the rest are a mixed bag—available in some provinces, not in others." One of the authors, Devidas Menon, told the *Journal* he has heard of people moving to another province in order to get their cancer treatment covered.

The next question is, why do these variations occur? CACC research found that the guidelines written by cancer agencies—not the same as the formulary drug listings of provincial drug plans—are at the root of the problem. Guidelines are developed for many purposes, covering all facets of cancer care, describing the best approaches to screening, diagnosis, the sequence of treatment, and the most effective use of many possible interventions. Treatment guidelines are meant to be written after a thorough review of the evidence found in professional journals and presented at scientific conferences. Good guidelines are dated and are regularly updated.

The CACC looked at recent and significant developments in the knowledge of cancer treatments—in some cases a new drug, in other cases a new way to use a drug. Only four provinces display information about treatment protocols on their web sites: British Columbia, Ontario, Nova Scotia and Newfoundland. To balance this

information against an international standard, we searched the guidelines of the National Comprehensive Cancer Network (NCCN), a not-for-profit US-based alliance of 19 leading cancer centers. The NCCN web site (www.nccn.org) holds a complete library of clinical practice guidelines, including a set written in plain language for patients.

As the charts on page 20 and 21 show, Canadian provincial cancer agencies do not offer the same cancer treatments promoted by the NCCN and we believe that some provincial cancer agencies recommend outdated practices for cancer control. Why? How could this happen in a publicly funded health system where the treatment centres have no commercial interest in the choice of therapy?

The first problem seems to be that Canada does not have one central agency for the development of cancer guidelines. Provincial cancer agencies have developed their guidelines independently, using different processes, or adopted guidelines from other provinces because the effort is time-consuming and costly. Vast amounts of medical time and expertise are spent writing clinical practice guidelines in Canada, adding to the voluminous sets of guidelines developed around the world. Everyone has a point of view; everyone wants his or her own guideline. Is there a point where this massive duplication of effort has no value to the cancer patient?

Aside from the exercise focused within our cancer agencies, each province has been independently reviewing oral cancer drugs covered by their publicly funded drug plan. Last year, the provinces began uploading reviews of new oral drugs to the Common Drug Review (CDR) to streamline the process and avoid duplication of effort. Nothing similar is in place for reviewing infusion drugs delivered within a cancer clinic.

PHARMACOECONOMICS

Pharmacoeconomic analysis is key to understanding why some cancer drugs are not readily accessible to cancer patients in different provinces. Cost does matter.

WHO SHOULD WRITE GUIDELINES THAT INCORPORATE COST-EFFECTIVENESS?

In oncology, as in other areas of clinical practice, carefully constructed clinical practice guidelines are valuable in ensuring cancer patients receive appropriate, evidence-based care. However, proper application of therapeutic interventions requires a thorough understanding of the principles underlying those interventions and not simply a superficial knowledge of the clinical practice guidelines itself.

Co-morbid medical conditions, patient preferences, social and domestic circumstances are just some of the additional factors that need to be taken into account. There will always be special circumstances not covered by clinical practice guidelines. Patients whose care is managed in a multi-disciplinary setting adequately staffed with trained specialist medical staff intelligently using clinical practice guidelines do have better outcomes.

In all areas of health-care delivery, fiscal constraints inevitably restrict interventions. Physicians and other health-care providers need to be vigilant to ensure that clinical practice guidelines they write or use are based on evidence of effectiveness. Any clinical practice guideline that is based on cost effectiveness should be explicit and transparent ensuring that any more effective, if more costly, interventions are being made known to the patient.

This is not to suggest that physicians should not have a role in advising third party providers (eg. cancer agencies) on what constitutes a cost-effective intervention with the limits of their budget. However, physicians who provide that advice should not be the same physicians who are delivering patients clinical care that is paid for by that particular third party. This would be especially important if those physicians had entered into an employer/employee relationship with the third party provider. Such a relationship for physicians providing direct care to patients represents a clear conflict of interest potentially inhibiting their primary responsibility, which is to advise individual patients of all evidence-based treatment options.

Economic health of the province does matter. This is no longer just about clinical evidence of effectiveness; this is also about funding for cancer treatments competing with other health-care priorities.

Pharmacoeconomics is the measurement of costs and outcomes in an attempt to determine whether

the usefulness of the drug is greater than the cost of the drug. Readers may wish to visit a number of good web sites for more information about pharmacoeconomics, including the Canadian Council for Health Technology Assessment (www.ccohta.ca), which is home to the CDR.

The purpose of pharmacoeconomic evaluations conducted by CDR and by cancer agencies is to:

- Estimate the potential lives extended or saved, or quality of life improvement if cure is not possible;
- Predict the future expenditures from using these drugs for the approved indication;
- Compare these numbers to the existing options, such as the current standard treatment and other alternatives such as surgery/radiation alone if that is a legitimate option for the type of cancer.

There is no simple rule that makes it easy to determine the benefit of one drug over another. All pharmacoeconomic evaluations include a mechanism to account for the importance of saving lives, improving the quality of life and extending life. But keep in mind how the process works at CDR: the evaluations are sent to a reviewer, who writes a conclusion and forwards it to CDR staff where all the reviews are edited and assessed for quality. Then an expert committee looks at the pharmacoeconomics and the systematic review together and makes a recommendation to the provinces about whether or not this particular drug is worth the money.

Similarly, reviews done by cancer agencies will certainly start with the systematic review of clinical evidence, but always end with, “Can we afford it?” At Cancer Care Ontario, for example, which is renowned for its Program in Evidence-Based Care and the rigor of its reviews in creating clinical practice guidelines, the decision to offer a new treatment is not made by either of those groups. In fact, these groups can only make recommendations that go to a Policy Advisory Group (PAG), where the pharmacoeconomic analysis is presented.

The PAG has a problem: they have a responsibility

to live within the budget. Any new clinical practice guideline they accept will incur new costs. When there is not enough money, the guidelines seem to remain in draft form for many months and treatment choices remain locked in the past. Across the country this is the norm, not the exception: evidence exists that a new treatment can save or extend life, but the cancer centre cannot afford to offer it to patients. They don’t have the budget and their health ministry is not able to respond in a positive fashion to their pleas. Health ministers cannot extract another dollar from their colleagues, the finance ministers. The latest solution from Ontario is to transfer the PAG’s responsibility out of Cancer Care Ontario and into the expert committee that recommends listings for the public drug benefit plan—i.e., more directly under the control of the health minister.

The element that is missing from Canadian pharmacoeconomic analysis at every level is called Cost of Illness (COI) evaluation. To the best of our knowledge, this type of study is not a factor in any of the evaluations done by CDR, provincial cancer agencies or public drug plans. COI calculates the direct and indirect costs attributable to the disease. Instead of comparing the costs of alternative treatments, it provides a picture of existing costs from the disease, which is already being treated with some standard of care. Looking at those costs would be a practical way to form an opinion on the importance of any new expenditure, but nobody is doing it.

We could go further. According to Health Canada, the loss to the Canadian economy—not the cost of care, but the lost productivity from premature cancer deaths—was \$10.6 billion in 1998. We are losing talented people who die before they should, before their potential contribution to this country, to their communities and families can be realized. Dr. Albert Schumacher, President of the Canadian Medical Association, urges politicians to recognize the intrinsic link between economic policy and health policy. “We must recognize that investment in health pays dividends on the other side of the ledger through enhanced competitiveness.”

TURNING EVIDENCE-BASED GUIDELINES INTO CLINICAL PRACTICE

The Canadian Cochrane Network and Centre offers this definition of evidence-based clinical practice¹, “Decision making and problem solving using a hierarchy of scientific evidence derived from clinical research; determining whether to apply interventions and which interventions to apply based on weighing benefits and risks, inconvenience and costs within the context of patient values.”

Again, it is clear that cost is a factor, but for the first time we see a reference to patient values. New cancer patients enter a steep learning curve to understand the language of oncology, not always able to articulate what they want in precise terms. “Keep me alive” is actually a vague instruction because there might be several ways to do it and some are more unpleasant than others. Nonetheless, patients know what they don’t want: unmanageable side effects, long-term disability, intractable pain, long-distance travel to treatment, excessive or under-treatment, added risk. Waiting times are covered elsewhere in this publication; Canadians don’t want long waiting times either.

Every patient will bring personal values into the treatment decision and ultimately only the patient will decide whether to proceed or switch or stop. The addition of patient preference to the discussion can mean that a guideline is apparently not being followed—the patient does not want surgery, cannot afford to pay for the recommended drug or simply does not want any more. This is anecdotal information, not researched, not available to us as evidence that patients are the ones driving the treatment decision.

However, there is evidence that all the carefully researched clinical practice guidelines are not being followed. The best example was recently published by Cancer Care Ontario, noting that provincially, up to 50% of patients with stage III colon cancer were not receiving the recommended adjuvant chemotherapy after surgery, and screening programs for breast and colorectal cancer reach only a small percentage of the target population (*Ontario Cancer Plan 2005-2008*).

The impasse comes from trying to maintain a system of clinical practice guidelines that are completely up to date and are not skewed by cost. Canadian courts have ruled^{2, 3} that physicians must inform patients of the most effective treatments and the Canadian Medical Association agrees this is the physician’s ethical obligation. “Patient preference” becomes a cynical description of the choice to be made if the recommended treatment is not available quickly or not covered by the province. The “preference” to pay directly for the MRI, PET scan,

WHAT IS EVIDENCE?

If provincial cancer agencies can come to such different conclusions about what is best and what is unproven, perhaps the problem lies in the evidence being reviewed. Perhaps the problem lies in the time it takes for evidence to accumulate, and the difficult balancing act of caution versus urgency. How much evidence is enough? How urgently do cancer patients need something new to improve survival rates?

The widely accepted foundation for evidence-based medicine comes from Dr. David Sackett.⁵

“Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients.”

Levels of evidence

Some types of evidence are better than others: the most credible are randomized controlled clinical trials (RCTs), and systematic reviews. The least credible evidence includes anything that cannot be tested by a third party, such as case studies, opinions and research conducted without comparison groups.

Level 1: Large randomized trials with clear-cut results (low risk of error) and systematic overview or meta-analysis of high-quality randomized, controlled trials.

Produces evidence of an intervention that is usually reliable, always acceptable and considered useful and effective.

Level 2: Small, randomized trials with uncertain results (moderate to high risk of error).

Produces evidence of an intervention that is acceptable, of uncertain efficacy and may be controversial. The weight of evidence is in favor of usefulness/efficacy.

Level 3: Nonrandomized clinical trials, cohort studies, cross sectional studies.

Produces evidence that may not be acceptable because of uncontrolled biases; efficacy may be uncertain and reliance on this type of evidence may be harmful.

Level 4: Nonrandomized, historical controls.

Non-analytical studies, of interest but not evidence.

Level 5: Uncontrolled studies, case series.

Do not qualify as evidence.

or other diagnostic procedure, or for the new treatment, depends entirely on the personal finances of the patient. Lacking the funds, patients tend to complain. Oncologists can feel pressured by their cancer centre to guide the patient toward something that is readily available, avoiding the messy confrontation of patients calling the boss, the minister and the media.

RESPONSIBILITY TO THE PATIENT

Ideally there should be no conflict in the obligations of physicians and cancer centres to offer the best possible care to all patients. Everyone agrees that is the goal. The inherent conflict arises from the word “possible.” Like every other part of the health system, cancer centres have a limited amount of cash, staff and time. Priorities are established, often using a

process that is not as transparent as it should be.

The challenge for patients and physicians is to find a path to the most effective care, even if the local cancer centre does not provide it, even if provincial guidelines do not acknowledge it. The simple fact that pharmacoeconomics and budgets play such an important role in the funding of cancer treatments means that oncologists are forced to consider cost of treatment instead of effectiveness of treatment. The CACC believes oncologists do their best to advocate for their patients and often take organizational duress because of it. Indeed, pressure on physicians to follow cost-containment policies creates a conflict of interest. An article in the *Canadian Medical Association Journal* describes the conflict as due to the very nature of government interests “because it is a remuneration plan,

COMPARISON SUMMARY

TUMOUR SITE	THERAPY	NCCN GUIDELINES	BC	ON	NS	NL
BREAST CANCER	Aromatase inhibitor anastrozole, (Arimidex), as adjuvant therapy for post-menopausal women	Anastrozole is an alternative to tamoxifen	Anastrozole can be considered for post-menopausal women who have contra indications to tamoxifen	Tamoxifen Website indicates a draft guideline for aromatase inhibitors as adjuvant therapy (Oct. 2003)	Tamoxifen Note: guidelines derived from Canadian consensus document (Jan. 2001)	Tamoxifen No mention of anastrozole as adjuvant therapy (undated)
	Aromatase inhibitor letrozol (Femara) extended adjuvant therapy in post-menopausal women after 5 years of tamoxifen	Consider 5 years of letrozole after tamoxifen	Consider 3 years of letrozole after tamoxifen (updated Nov. 2004)	Website indicates a draft guideline for aromatase inhibitors as adjuvant therapy (Oct. 2003)	No mention of this product	No mention of this product
COLON CANCER	Antibody therapy bevacizumab (Avastin) and cetuximab (Erbix) for advanced (metastatic) colon cancer	Bevacizumab, used in combination with IV 5-FU-based chemotherapy is approved for first-line therapy. Cetuximab is indicated in combination with irinotecan-based therapy for patients refractory to irinotecan-based chemotherapy or as single-agent therapy for patients intolerant to irinotecan.	No mention of these products	Guideline in various stages of development but not available at this time	No mention of these products	No mention of these products
	Oxaliplatin for advanced (metastatic) colon cancer	First line therapy (combined) with leucovorin and 5-FU for advanced (metastatic) cancer in patients who can tolerate intensive therapy 5-FU/leucovorin/oxaliplatin (is) superior to bolus 5-FU/leucovorin/irinotecan as first-line therapy	With capecitabine for metastatic colorectal cancer, not curable with surgery or radiation (June 2004)	Guidelines in various stages of development but not available at this time	No mention of this product.	No mention of this product

conducted through physicians, that places the interest of third parties (i.e., the cost to the overall system) over the interests of the patient.”⁴

CACC RECOMMENDS

A pan-Canadian agency should be established to create, update and disseminate clinical practice guidelines for cancer (see page 30).

This cancer agency should have the resources and mandate to conduct timely expert reviews based solely on clinical evidence of effectiveness, leaving the questions of cost and coverage to the provinces that pay for the treatments. It would act as a central clearinghouse for information about cancer treatments, making this information fully available to the public as well as health professionals.

The cancer agency would also be responsible for developing effective methods to promote and evaluate the use of best-practices guidelines, reporting annually to the Canadian public. ●

NOTES

- 1 The Canadian Cochrane Network/Centre. A primer on evidence-based clinical practice, July 2003. www.cochrane.mcmaster.ca
- 2 *Reibl v. Hughes* Supreme Court of Canada (1980) 114 D.L.R. (3rd) 1 (S.C.C.) Material information for informed consent includes anything a reasonable person in the patient’s position would want to know.
- 3 *Seney vs Crooks*, Alberta Court of Appeal (1998) AJ No. 1060 (QL): “a patient should be advised of a known treatment which others in the same specialty consider superior, even if the doctor does not agree.”
- 4 Caulfield T, Siminosky K. Physicians responsibility and drug formulary restrictions. *CMAJ* 2002; 166(4): 458-460.
- 5 Sackett DL et al, *BMJ* 1996;312:71-72.

COMPARISON SUMMARY

TUMOUR SITE	THERAPY	NCCN GUIDELINES	BC	ON	NS	NL
PROSTATE CANCER	Docetaxel (Taxotere) for hormone-refractory incurable prostate cancer	Numerous systemic chemotherapeutic regimens offer significant palliative benefit in androgen-independent (hormone refractory) prostate cancer including estramustine/paclitaxel, docetaxel/estramustine, mitoxantrone/prednisone	Docetaxel as first or second line therapy when disease not amenable to radiation therapy (Jan. 2005)	Guidelines in various stages of development but not available at this time	No guideline for treatment of prostate cancer	No guideline for treatment of prostate cancer
NON-SMALL CELL LUNG CANCER	Adjuvant chemotherapy	For patients with stage I or II disease, a category 1 designation (best level of evidence) as adjuvant chemotherapy for margin-negative disease after surgical resection. Carboplatin/paclitaxel included as an alternate regimen.	Adjuvant cisplatin and etoposide for fully resected stage I, II or IIIA disease in individuals age 18-75 to start within 60 days of surgery (Nov. 2004)	A draft guideline exists but is not available at this time	No guideline for NSCLC	At present there is no role for adjuvant chemotherapy in resected NSCLC, but this remains an area of active research (undated)

© National Comprehensive Cancer Network, Inc. 2001, 2002, 2003, 2004. NCCN and NATIONAL COMPREHENSIVE CANCER NETWORK are registered trademarks of National Comprehensive Cancer Network, Inc.

British Columbia Cancer Agency website www.bccancer.bc.ca

Cancer Care Ontario website www.cancercare.on.ca

Cancer Care Nova Scotia website www.cancercare.ns.ca

Newfoundland Cancer Treatment and Research Foundation website www.nctrf.nl.ca

An exclusive CACC analysis compares the effect of budget, incidence, doctor shortages and GDP to find out why mortality rates differ from province to province

Your Money or Your Life II

BIGGER BUDGETS MEAN BETTER OUTCOMES

BY DR. WILLIAM HRYNIUK AND DR. ANTHONY MILLER

This year's report points to a compelling relationship between expenditures and lower cancer mortality rates—a correlation the CACC first introduced in *Report Card 2003*. A new analysis undertaken by the CACC suggests that the amount spent by a cancer agency on cancer control is the single most important factor correlating with lower mortality rates—more significant than smoking, cancer incidence, gross domestic product (GDP) per capita and number of doctors.

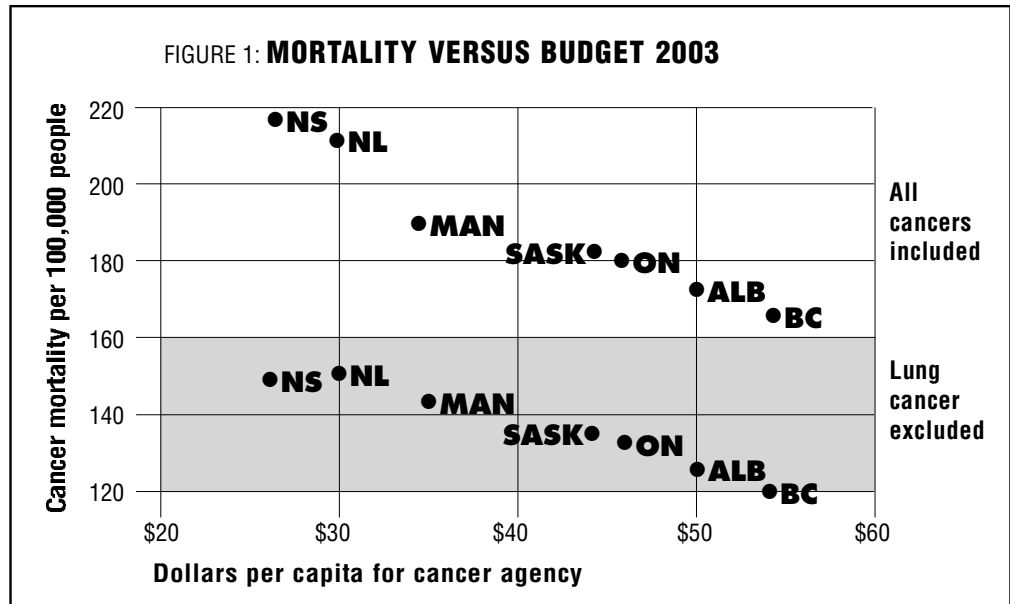
Last year's report suggested that the more a provincial government allocated to its cancer agency, the lower the cancer mortality. The association held up whether or not lung cancer was included in the seven-year analysis, suggesting that differences in provincial smoking patterns were not a factor. Based on this finding, we speculated that a further decline in cancer mortality could be achieved if the amount of effort expended in cancer control was great enough. We speculated that such an effort could be measured in dollar terms. For example, in British Columbia, which provides the highest per capita support of its cancer agency (at \$55 per year), mortality from cancer was decreasing compared to the rest of the provinces. Last year, we graphed the relationship between expenditures and mortality for the year 2002. This year, with the inclusion of Ontario data, the relationship is even more pronounced for the year 2003. (Figure 1).

However, last year's analysis did not take into account other factors which could have contributed to cancer mortality in each province. To determine whether higher expenditures are the predominant factor responsible for lowering cancer mortality rates, we performed a comparison that isolates the effect of several additional factors that might play a role, including GDP per capita, Cancer Incidence and access to health professionals.

RESULTS

Incidence, GDP and Budgets all correlated with mortality rates to a variable extent. However, the relationship between lower mortality rates and Budget became stronger and more significant as the years progressed, while the effect of the other factors weakened (Figure 2). When analyzed as single variables, Budgets were more significantly correlated with cancer mortality rates than GDP for every year. The number of doctors in each province (analyzed as all doctors and oncology specialists alone) did not correlate with mortality rates in any year.

In a statistical comparison of combinations of these factors, Budget was more significantly correlated with mortality rates than GDP in each year. This was particularly evident for the province of BC, which, despite having a GDP in the middle of the range, had the highest



Budget and the lowest mortality rate. Cancer Incidence was better correlated with mortality than other factors in earlier years, but became decreasingly so. Cancer Incidence has historically been the major determinant of cancer mortality. However, by the year 2003, Budget became significantly more important than Incidence as a correlate of mortality rate. Again, although BC had higher Incidence than some of the other provinces, it still had the lowest mortality rate.

DOLLARS MATTER

Last year's analysis met with skepticism when we pointed out that mortality from cancer depends on where you live, due to varying emphasis put on cancer control in different provinces. It has often been argued that health-care expenditure does not correlate with overall population mortality¹. However, several recent studies have shown that health-care expenditure does correlate with overall adult mortality^{2,3}. Indeed, organized efforts to reduce smoking and thus reduce lung cancer mortality in males, and better cancer treatment have been credited with contributing to recent increases in overall population longevity^{4, 5, 6}. Thus, cancer control not only works in the individual, but when properly applied, its effects can be measured in society as a whole.

Our new analysis supports last year's conclusion that the greater the expenditure by organized agencies on cancer control, the lower the mortality rate, even after taking account of other factors. Since the correlation between higher expenditures and lower mortality was stronger than for the other factors of smoking, Cancer Incidence, GDP, and number of doctors, we would argue that it is the most important one. In a nutshell, the number of dollars spent on cancer *does* matter.

The number of doctors in each province did not correlate with mortality rates. However, this should not be taken as evidence that there is no shortage of doctors or oncologists. There is, in fact, a

FIGURE 2: **MORTALITY CORRELATION COEFFICIENTS**

(r-values shown only if significant)

Year	ASIR	GDP	Budget
1997	.93	-.79	-.86
1998	.98	-.80	-.94
1999	.97	-.79	-.92
2000	.99	NS	-.88
2001	NS	NS	-.95
2002	.91	NS	-.97
2003	.90	NS	-.98

NS = r-value not significant

Relationship between cancer mortality and Incidence, GDP and cancer agency Budgets. Correlation coefficients indicate the extent to which two variables are related to one another in a linear (straightforward) way. A correlation coefficient of 1.0 (positive or negative) indicates perfect correlation. A positive r-value in the table above indicates, for example, that as incidence increases so does mortality; a negative r-value means that as the GDP or Budget increases, mortality decreases. Many of the significant correlation coefficients in the table are very close to 1.0.

critical shortage of both in some provinces. However, the aggregate of all the other factors is so much larger a component of overall budget that the impact of doctor shortages is obscured.

IMPLICATIONS

Since we could not quantify the relationship between dollars spent on cancer control and cancer mortality among provinces with cancer agencies, we considered it useful to estimate what it would cost to align budgets with British Columbia, the province where cancer mortality has been dropping most. The incremental cost to the Canadian health-care system would be about \$650 million, or \$20 per person (2003 dollars).

PROVINCIAL TRENDS

Unfortunately, the provincial governments of Newfoundland, Ontario, Alberta, and British Columbia have recently taken steps, which, in our opinion, could degrade cancer control effort in those provinces. For example Newfoundland, Ontario and British Columbia have disbanded or weakened their cancer control agencies, or relegated them to more remote reporting relationships to their ministries of health. Longer lines of communication will almost certainly make it more difficult to reach the final decision makers and to convince these governments of the funding necessary to prevent, treat and control cancer.

While funding to the BC Cancer Agency for drugs has kept pace with demand, funding for all other cancer control efforts has been frozen for the last four years, in spite of a steady 3% increase in the total number of cancer cases during that interval. Freezing the budget for these other services amounts to a cut of 12% over the four-year period. In order to preserve direct treatment services, other aspects such as organized screening, surveillance, outreach, and education will have to be reduced. This will undoubtedly jeopardize the outstanding results posted by BC. In Alberta, the increase in funding level required to meet rising demand was not provided in 2003/2004, but seems likely to be somewhat restored in 2004/2005. Alberta has maintained second-best status for cancer control in the country, and will need to sustain appropriate funding to hold that rank.

ADDITIONAL CONSIDERATIONS

There are several caveats attached to any conclusions drawn from this analysis.

- First, some of the cancer agencies include oral anti-cancer drugs in their budgets and some do not. To the extent that this introduces differences, our estimates of the effects of budgets on cancer control will be inaccurate. However, while we intend to do a follow up of this factor, we suspect it will result in small differences that will not substantially alter the overall results.
- Second, we have not considered the factors of obesity and lack of activity, which have been shown to affect cancer incidence and possibly cancer mortality rates. In the absence of available provincial data for the years analyzed, we cannot surmise what effect these factors might have on the present analysis.
- Third, in order to keep the numbers comparable across all provinces, we used the ASIR and ASMR data from *Canadian Cancer Statistics*. In some cases individual provincial registries will have slightly different numbers, or more up-to-date information.
- Fourth, the Ontario data includes only that from Cancer Care Ontario, which provided direct cancer care to approximately half the population and we adjusted the figures accordingly. In future analysis, Ontario's data will need correction to account for the fact that CCO's budget covers the entire province for some programs (screening, epidemiology, and education), but radiation and chemotherapy for approximately half; Ontario's per capita budget figures will be lower as a result.
- Fifth, the Budget in each year cannot affect the cancer mortality in that year. However, the fact that for seven consecutive years a higher expenditure was consistently associated with a lower cancer mortality rate and the fact that each province retained its position relative to the others, argues strongly that this relationship is a causal one, not just statistical happenstance.
- Finally, it has been suggested that migratory patterns from province to province may be an important factor but we don't think it is material. For example, BC is the destination of many retirees, which, if anything, would increase provincial mortality rates, and while it has a greater Asian population, their incidence and mortality rate from cancer will approximate those of the rest of the population with the passage of time.

METHODOLOGY

To determine the extent to which higher expenditures are responsible for lowering the cancer mortality rate, we performed a comparison that isolates the effect of several additional factors, including gross domestic product per capita of a province, incidence and doctor shortages.

Specifically, we looked at the number of doctors in each province, the wealth of the province, measured as gross domestic product (GDP) per capita, and the incidence of cancer in its population, measured as Age Standardized Incidence Rate (ASIR). Generally speaking, the higher the socio-economic status, the lower the cancer mortality. GDP functions as a surrogate for socio-economic status⁷. We studied the correlation between these factors and cancer mortality rates as measured in the usual form of age-standardized mortality per 100,000 population, or ASMR. To keep the numbers comparable across all provinces, we used the ASIR and ASMR data from the annual report on cancer statistics by the NCIC and Health Canada, which include actual numbers for 1997–2000 and modeled estimates for 2001–2003.

We compared the relationship of each of these other factors to cancer mortality rates with that of the dollars per capita provided to each provincial

cancer agency for cancer control (“Budget”). Figures used to calculate Budgets were provided by the cancer agencies, usually from their audited year-end budget statements. The costs include supplies, personnel, administration, and other costs directly involved in monitoring, preventing, screening, and treating cancer on an outpatient basis. Costs excluded in-patient care, capital equipment, and research, which either vary greatly from year to year, or do not immediately affect cancer control.

Our findings are based on seven years of data for the seven provinces with organized cancer agencies, namely Alberta, British Columbia, Manitoba, Newfoundland, Nova Scotia, Saskatchewan, and Ontario. For each of these provinces, data are available for 1997 through 2003, except for Nova Scotia for which expenditure data from 1997–2001 are missing. For the first time the annual analysis of mortality and spending includes Ontario data. The data supplied for Cancer Care Ontario was adjusted to take into account the fact that it served half the province’s population. Relevant data were not available from New Brunswick, Prince Edward Island or Quebec because they do not have organized cancer agencies.

CONCLUSION

Despite all of these caveats, the strength and consistency of the relationship between expenditure and mortality supports the conclusion that the relationship is a causal one.

Since the correlation between expenditures and mortality was stronger than for smoking, Cancer Incidence, GDP and number of doctors, we would argue that it is the most important. This year’s more detailed analysis continues to support the suggestion in last year’s Report Card: the number of dollars spent on cancer *does* matter. We dare not continue to ignore this.

CACC RECOMMENDS

Governments have to do their part: only governments can improve cancer budgets, reduce waiting times and the shortage of health-care professionals. Better use of cancer dollars, more investment in the areas that make the most sense: research into effective cancer control, prevention, early diagnosis, rapid effective treatment supported by evidence and clinical practice guidelines.

Federal and provincial investment in cancer control must ensure equitable access to consistently high standards of care across the country. ●

NOTES

- 1 Nair C. and Karim R. An overview of health care systems: Canada and selected OECD countries. *Health Rep.* 1993; 5:259-79
- 2 Cremieux PY, Ouellete P, and Pilon C. Health care spending as determinants of health outcomes. *Health Econ.* 1999; 8:627-39
- 3 Miller Jr RD, and Frech HE. Is there a link between pharmaceutical consumption and improved health in OECD countries? *Pharmacoeconomics* 2000; 18 Suppl 1:33-45
- 4 Crispo A, Brennan P, Jockel KH, et al. The cumulative risk of lung cancer among current, ex- and never smokers in European men. *Br J Cancer* 2004; 91:1280-6
- 5 Jatoi I, Miller AB. Why is breast cancer mortality declining? *Lancet Oncol.* 2003; 4:251-4
- 6 Lichtenberg FR. The economic and human impact of new drugs. *J Clin Psychiatry* 2003; Suppl 17:15-18
- 7 Several studies have shown that the lower the socioeconomic status, the higher the overall cancer incidence (MacKillop WJ, Zhang-Salomons J, Boyd C, et al. Associations between community income and cancer incidence in Canada and the United States. *Cancer* 2000, 89:901-12). Since higher incidence is generally associated with a higher death rate, the lower the socioeconomic status, the higher the cancer death rate (MacKillop WJ, Zhang-Salomons J, Groome PA, et al. Socioeconomic status and cancer survival in Ontario. *J Clin Oncol* 1997, 15:1680-1689). A higher expenditure on cancer control by a province could simply reflect that province having more resources for health care. Thus, a lower cancer death rate might not be due to higher expenditure, but rather due to the better financial condition of the province and a healthier citizenry.

A first-person account of the financial, physical and emotional costs of a cancer diagnosis

The Hidden Cost of Cancer

CANCER COSTS MORE THAN DRUGS AND DOCTORS

BY GEOFF EATON

Cancer costs Canadian taxpayers millions of dollars a year in the “visible” costs of drugs, equipment, and professionals. However, the financial, physical and emotional costs of a cancer diagnosis are largely invisible to those who aren’t intimately connected to a cancer patient, but from my experience, they are substantial. Recent studies¹ suggest that families lose up to one-third of their after-tax income, and that is probably a serious underestimate since the figure doesn’t include out-of-pocket expenses in the immediate post-diagnosis period.

My name is Geoff Eaton, I live in St. John’s, NL and I am a 29-year-old cancer survivor.

Since my original diagnosis six years ago, my cancer experience has opened my eyes to the significant challenges patients face: great expense for drugs and travel, lost income and insurability, and the reality of a healthcare system that provides little to no emotional support or assistance in physical rehabilitation.

In 1998, I was diagnosed with Acute Myeloid Leukemia at the age of 22. I had three rounds of chemotherapy, spent three months in Toronto undergoing “point-of-no-return” chemotherapy to wipe out my bone marrow, a lifetime dose of full-body radiation, and a bone marrow transplant from my dad at Princess Margaret Hospital. A few weeks after returning home, I spent a month in intensive care on life-support in a drug-induced coma and lived a severely adjusted life as a patient for 18 months before beginning the return to ‘normal’ life, whatever that is.

In April 2001, I celebrated the two-year anniversary of my transplant, a point that was supposed to mark a significant reduction in my risk of relapsing. Three months later, I was diagnosed with a relapse. I had more chemotherapy and spent a month at the Ottawa Hospital for a stem cell transplant, and 10 months as a full-time patient.

THE FINANCIAL BURDEN OF CANCER

Cancer has changed the lives of me and my family forever, with drug, medical, and travel expenses and lost income exacting a huge financial toll. During the first nine months of

my first diagnosis, my parents paid \$12,000 for my drugs, required travel and related medical expenses, such as materials to maintain my Hickman catheter at home, etc. (this figure excludes their travel for treatment assessments and their three-month stay in Toronto during my transplant and recovery, and their loss of income at various times during my treatment over four years).

DRUG COSTS

Treatment costs for drugs and travel were the most onerous financial burden to me and my family throughout my treatment. In January 1999, I left the hospital after my second round of chemotherapy. I was prescribed di-flucan to help manage the symptoms of a tough fungal infection while I transitioned back to out-patient life. I can imagine the surprise on my father's face when the pharmacist explained that the 20% co-pay for this drug, for one week, was \$220. My insurance company paid the remaining 80%. Without health insurance my week of di-flucan would have cost \$1100. In Newfoundland and Labrador, as in many provinces, my drugs were covered while I was an in-patient, but upon leaving the hospital these drugs became my responsibility.

In total, I paid \$9,400 in 2002 for drug and travel costs associated with my relapse. Some portion of drug expenses is deductible from federal income tax, however of the \$9,400 in allowable medical expenses I incurred, I was entitled to a tax credit of just over \$2,200. In other words, about \$7,200 in unforeseen expenses in a year when my ability to earn income was significantly reduced by my cancer treatment.

INSURANCE COMPLICATIONS

During my first cancer challenge I was covered under my parents' health insurance as I was still a student and considered a "dependent." However, when I turned 25, my health insurance company promptly

MAJOR PROBLEMS AND EXPENSES INCLUDE:

- Catastrophic drug costs borne by patients, especially those without private insurance.
 - A complex system of reimbursement based on previous year's earnings.
 - Bone marrow growth factor hormones (GCSF) required by many patients to boost white blood cell counts is not covered when out of hospital (costs can reach over \$2000/month).
 - Medical equipment costs.
 - Private nursing and rehabilitation expenses.
 - Lost income and retirement savings for patient.
 - Foregone promotions and lost opportunities.
 - Workplace discrimination.
 - Difficulty obtaining life insurance (or at a very high cost).
 - Incidental costs: parking (daily parking rate at Princess Margaret Hospital, for instance, is \$16.00, multiplied over several weeks of daily visits).
 - Private counseling costs incurred because of inadequate psycho-social support.
 - Lost work/income for caregivers.
- As of January 4, 2004, a new federal Compassionate Care Program will pay compassionate care benefits up to a maximum of six weeks to a person who has to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks. Unemployed persons on EI can also ask for this type of benefits. This does not help most cancer patients who will survive the disease and still depend heavily on family members during their treatment.
- Travel costs for family.

closed my file, as I was no longer a student nor considered a “dependent.” I have had no medical insurance since—most former cancer survivors are considered to be too high risk by insurers, or cannot afford the high premiums. Having no medical insurance corrupted my financial planning and created serious stress regarding how I might pay for additional treatment if I were to relapse a second time. Not to mention how I plan my financial future.

Obtaining health insurance is very difficult for survivors—I have been told that it is not an option until at least five years after active treatment. My parents bought a small policy when I was very young and I’m certain that is the only life insurance I will ever have. Planning a financial future without health insurance is problematic: your focus switches from beginning to save for retirement to saving for the possibility that you may again face huge medical expenses related to treatment while trying to avoid leaving your family with a financial burden if treatment fails.

THE SOCIAL AND EMOTIONAL TOLL

As a young patient I faced significant obstacles of a social nature. Upon my diagnosis I began intensive treatment that severely limited my energy and immune system. I was isolated from my social circle, both when I was in hospital and often when I was released and recovering. Cancer left my social life broken in many places.

Throughout the transition back to a healthy lifestyle I received no psychosocial support from the healthcare system. Were it not for a very close friend who is a counselor, my challenges would have been far greater and I know my perspective and ability to support others facing challenges similar to mine would be drastically hampered.

As a cancer survivor I am still the same fun-loving,

off-the-wall guy. But I also have this whole new part of me built in as a result of facing my own mortality. That new part comes with some incredible gifts, my perspective on life and all things in it is perhaps the most valued. However, the damage to my social life and to my friendships is substantial. Not many 29 year olds have the perspective I do, nor can they relate to my experience. Finding those to whom I can connect with and relate to on an emotional and spiritual level is a new challenge directly related to my diagnosis.

In 2000, I started a charity, RealTime Cancer, to educate and support young people dealing with cancer. In my professional capacity as founder and executive director of RealTime Cancer, one of my main roles is to speak to young people about cancer, to share my experiences and the valuable lessons I’ve learned. My challenges with cancer have taught me much. But these lessons have come at a great cost to me and my family.

SYSTEM PROBLEMS AND SOLUTIONS

My experience highlights several “system” problems that create an unfair burden on the cancer patient and their family. As Canadians we may refer to our healthcare system as universal and believe that our healthcare needs are handled by the government through taxes, however the reality is quite different. Every day patients incur massive expenses directly related to their diagnosis. If I had the ability to wave a wand and make one sweeping change, I would increase prevention efforts that would keep people from becoming patients in the first place.

The federal and provincial governments must reduce the penalties of being a patient by increasing the tax credit percentage relating to medical expenses. Governments should introduce policy that provides incentives for individuals to stay healthy and prevent

a cancer diagnosis, rather than requiring individuals to use net disposable income to pay for preventative therapy. The “catastrophic” drug costs borne currently by the cancer patient should be covered whether the patient is in or out of the hospital.

The NL drug card program is set up so that those earning lower incomes but comfortably above the poverty line (\$25-40,000) are hit hardest by the drug costs, as their disposable income is not substantial, yet it will often be significant enough to push them well above the allowable earnings limit. In addition, personal savings must be used before help is forthcoming.

RECOMMENDATIONS

Catastrophic Drug Costs. The “catastrophic” drug costs borne currently by the cancer patient should be covered whether the patient is in or out of the hospital.

Extension of Caregiver Benefits for Non-palliative Situations. I would strongly support a policy change that decreases the financial burden on the support networks of the patient. This is a win on many levels, as the support network would have more financial resources to help provide the patient with the best possible care and environment in which to recover. Supporters that are less financially challenged will have reduced stress levels and can focus more energy where it needs to be, on the patient. The Compassionate Care Program is a great step in this direction, but why exclude patients who are often totally dependent on family whether or not they are considered palliative? In 1999 I left the hospital six to eight weeks earlier than doctors expected, and was 100% dependent on family, unable feed myself or walk. I left hospital to recover in a more familiar and comfortable environment at home, and in doing so, I dramatically reduced the costs to the healthcare sys-

tem while increasing the stress and financial burden on my family. Extending the Compassionate Care Program to family members who are caring for those in very dependent states is a solid step towards improving the support systems for patients, relieving a significant burden from the health-care system and allowing patients and families more freedom in decisions involving recovery. Everyone wins when the patient has the choice to recover in comfortable surroundings in the care of family who have the support of their government to take care of their loved ones and reduce demand on precious hospital resources.

Comprehensive Psycho-social Support. Cancer patients experience massive emotional and social challenges, and require adequate psychosocial support throughout the period from diagnosis to end of treatment and especially through the transition back to “normal” life. These services should be provided by the cancer clinic as an integral part of therapy (some cancer centres “ration” the number of covered visits, or offer no services at all).

Transition Care. Many patients have major physical challenges after treatment and providing them with resources and programs to help the rebuilding process is a win for everyone. Ensuring that patients regain strength and stamina allows them to return to being a productive person who can get back to contributing to our community as opposed to relying on it. A physical rehabilitation program, ideally delivered by existing community resources, is essential for patients experiencing very involved treatments such as high-dose chemotherapy and bone marrow transplants. ●

NOTES

1 Barr et al -Int J Oncol 1996 8:933 Indirect costs were figured in this study, but such items as foregone promotions, lost opportunities and other items were not.

The sheer scale of Canada's cancer problem demands that cancer control be addressed directly by governments, not as a part of some other national program

Who's in Charge?

THE CASE FOR A NATIONAL CANCER AGENCY

Cancer is the most serious public health problem facing Canada in terms of its complexity, incidence and prevalence. Yet no one is in charge. No individual or group or organization has national responsibility for cancer care and there is no national plan for the implementation of a system for cancer control. No one is responsible to make the system work; no one is responsible for the outcome of cancer control. In fact no one is responsible to even evaluate the quality of cancer care.

Cancer now afflicts 40% of Canadians, with 70% more new cases predicted within two decades. The massive and complex issues of cancer control tend to be sidelined by provincial health systems that react to perceived higher profile health crises like SARS, West Nile virus, AIDS and Avian Flu. Across the nation, there are striking differences in cancer survival outcomes. Efforts to control the disease are fragmented and vary widely province-by-province, community-by-community and even between professional groups.

In 1995, and again in 2002, the World Health Organization (WHO) recommended that nations develop national cancer control programs to reduce the number of new cancer cases and improve quality of life for people with cancer. This has not yet been done in Canada. The range of services incorporated in the term "cancer control" and needing improvement starts with prevention, and moves through screening, diagnostics, treatment, supportive care and palliation. Related issues, such as the supply of human resources, research investment, cancer surveillance and monitoring can have a significant impact on the volume of cancer cases and the prospects for survival.

Canada is one of the few nations in the developed world that has failed to implement a national strategy for cancer control. We have one on paper: the Canadian Strategy for Cancer Control was agreed to four years ago by widespread consensus among all the leading cancer voices in the country, including doctors, patients, academics, researchers, charities and health care managers. The Strategy has been continuously refined and updated but Canada has yet to commit to its implementation.

No progress has been made because the Strategy suffers from lack of formal recognition, lack of priority attention, lack of funding, and lack of political will to get on with it. The

Canadian Strategy for Cancer Control (CSCC) must be implemented with sufficient funds and a qualified leadership to address the complex issues of cancer care and control. The cost of *not* doing this is to endure increasing losses to our economy:

- 950,000 potential years of life lost every year (based on actual figures for 2000)
- \$1.8 billion per year in hospital costs for cancer care (1998 figures)
- \$10.6 billion per year in lost production due to premature mortality (1998 figures)

If Canada is to make the necessary changes to address the burgeoning prevalence forecast for 2012 then we need to put in place right now a plan to implement cancer control that will result in a falling incidence of new cases of cancer, consistent high quality of diagnosis, screening and care across the country. The plan must be accountable to the people, national in scope and continuously measured. The organization that administers the plan will undoubtedly be a partnership between all the federal and provincial health care organizations and the volunteer sector responsible for the delivery of cancer care.

Canada needs a National Cancer Agency to take control of cancer, providing leadership, expertise and commitment to the challenge ahead.

CACC RECOMMENDS

The formation of a virtual National Cancer Agency with:

- The Governing Council of the CSCC as the advisory body to the federal government on cancer control;
- Experts drawn from across the country (including patient advocacy groups) who will remain in their respective jurisdictions but will be supported by a localized secretariat, i.e., a “virtual” agency;
- An expanded membership for population-based representation, still focused on expertise in cancer control and responsible for recommending allocation

of new cancer control funds to provinces;

- A dedicated ten-year cancer control fund. The Agency will receive funding requests from provinces for new federal funds earmarked for cancer control. The funds will be allocated to priority cancer control initiatives, as determined by each province, that are specifically related to the priorities of the Strategy.

The Agency should be responsible for:

- Overseeing implementation of the CSCC, using funds to be accessed by the provinces for purposes tied to the goals and best practices identified in the Strategy; recommending the transfer of cancer control funds between federal and provincial authorities (based upon performance);
- Implementation in a collaborative fashion with stakeholder groups including the federal, provincial and territorial governments, the provincial cancer agencies, professional associations, charities, patient advocates and the many NGOs active in cancer;
- Provinces must retain the right to determine what part of the Agency’s national cancer control priorities they will implement, however, money would flow only to provincial initiatives that are compatible with the national strategy and measured, monitored and reported;
- Financial monitoring and controls to ensure the funds are spent only on new initiatives, not for basic operating costs of the current system;
- Serving as policy advisor to the federal government on new federally funded cancer programs;
- Monitoring and surveillance of cancer control efforts, including a national cancer registry;
- Creating, updating, disseminating and evaluating Clinical Practice Guidelines, and acting as a central clearinghouse for information about cancer treatments for the public and health professionals;
- Annual public progress reports. ●

This article is the synthesis of a position paper jointly authored by the members of the CACC board of directors.

New measures for value, streamlined care and more effective government approvals are key to ensuring access to best therapies for patients

Access to Systemic Therapy

ISSUES AND ANSWERS

A host of effective new anti-cancer medications have been developed since nitrogen mustard was discovered 62 years ago. These drug therapies have reduced cancer mortality, increased longevity, and made the lives of countless cancer patients more comfortable¹. New drugs now in development and in clinical testing will undoubtedly lead to further advances. However, the costs associated with developing and marketing new drugs are escalating. An important question we must ask ourselves is, “Who will pay?”

Pharmaceutical firms and governments are struggling to provide the new drugs in timely fashion at a reasonable cost, but they need better ways of evaluating cost versus value. Professional care providers are sometimes not able to access drugs that they believe can make a difference for their patients. The complexities of the system sometimes result in patients failing to receive an effective new drug, or having their treatment so delayed that the benefit of the new drug is diminished. Health-care professionals are caught in a modern dilemma, trapped between responsibility for patient well-being and health-care system restraints. The result: patients are often powerless to influence their own care decisions. CACC recognizes that the treatment delivery system is already strained, and until there is a national plan to implement a system of cancer control, the problems will worsen.

The CACC has identified several system problems and suggests some strategies for improvement.

FEDERAL DRUG APPROVAL PROCESSES

Safety and efficacy

How it works: If a new drug is safe and effective, Health Canada issues a Notice of Compliance (NOC), and lists the approved indications for its use.

Problems and gaps: The approval process is lengthy, seriously backlogged and unable to meet its own targets for review times. Pending approval, physicians must apply to Health Canada’s Special Access Program for exceptional use of the drug in individual cases.

Pricing

How it works: Drug pricing is established by a separate review, which attempts to maintain the cost in the same range as that for similar drugs. “Clinical breakthrough”

drugs can exceed the therapeutic class price. Problems and gaps: The cost of development of new drugs may exceed the price limits deemed reasonable by the Patented Medicines Pricing Review Board, which discourages manufacturers from approaching the Canadian market.

Common Drug Review (CDR)

How it works: Once approved for safety and pricing, new drug applications must then be submitted to CDR for a recommendation as to whether or not the provinces should list the drug as a benefit. CDR was recently developed to reduce duplication of reviews by provincial drug plans.

Problems and gaps: Some provinces still maintain separate review processes and instead of decreasing the time from NOC to clinical use, CDR actually increases it.

Approval Times

How it works: Health Canada set targets for timely review of new drug submissions and priority review for breakthrough products.

Problems and gaps: The targets are not being met².

PROVINCIAL DRUG APPROVAL PROCESSES

Separate Guideline Process

Some provinces develop their own guidelines for the use of a new product. Medical experts in these provinces may decide the approved indication from Health Canada's NOC is too generous or, conversely, may recommend use of a drug even if it does not receive an NOC and has not gone through CDR.

Separate Funding Approval Process

Funding must then be approved by each provincial government. Faced with increasing demands for health care dollars, provinces are in no hurry to fund new drugs that have received medical approval. Timelines for approval vary and lobbying by interested parties may be required to expedite the process.

WHO PAYS FOR THE DRUGS

Most funding for cancer drugs comes from provincial government transfer payments to hospitals, cancer agencies and drug plans. Under the Canada Health Act, intravenous drugs are an insured service if administered in hospital, in which case only the provincial government can reimburse costs. Payment by private insurance or by individuals is prohibited.

Oral drugs are covered by provincial government drug plans, which generally cover those who are low-income, or over 65. Several provinces offer universal coverage for people under 65 who do not have private insurance. Patients ineligible for the plans or without private insurance need to qualify for special assistance that is income-tested or they may not get access to the treatment of choice.

Patients may not always be informed by their oncologists about effective drugs not covered by their provincial government. The same drugs may be covered in other provinces but as a rule, patients cannot access them by traveling elsewhere in Canada, only by moving to a province that covers the drug. They may pursue compassionate use programs, or pay for treatment outside Canada.

GUIDELINES MAY BECOME RULES

Clinical guidelines written by medical experts were intended to describe best practice. There is a risk that guidelines will be interpreted by government review agencies as rules. Guidelines cannot and are not intended to cover all situations, and oncologists recognize the exceptions. Instead of being allowed to exercise best judgment when exceptions arise, oncologists may have to submit documentation requesting special approval, requiring extra time and delaying treatment. In addition, conflicts of interest can arise if the people writing the guidelines or ruling on special requests are also responsible for budgets.

LACK OF ACCESS MAY INFLUENCE SURVIVAL

Differing provincial guidelines, timelines for availability, and patterns of practice lead to considerable inter-provincial variation in access to cancer therapies. Combined, these factors might partially explain why cancer mortality varies so much from province to province.

COST-EFFECTIVENESS versus COST CONTAINMENT

More effective drugs can reduce surgery, visits to doctors' offices and emergency rooms, reduce hospital stay and family financial burdens, delay or render unnecessary the need for palliative care, and replace the use of less effective drugs that are still costly³. They also produce healthier, more productive citizens who might contribute back to the economy and eventually "pay" for their own treatment. The advent of such drugs has produced a major shift: from the provision of medical service to consumption of medical products⁴.

The fact remains, however: the new drugs are expensive, and cost-effectiveness must factor into their deployment. Cost-effectiveness is usually expressed in terms of the incremental cost per quality-adjusted life-year gained. Better methods of expression are needed to allow value judgments in a larger context so that tensions among efficiency, equity, and opportunity costs can be resolved⁵. The *overall* cost effectiveness should be determined. Thus, a new drug might increase a cancer agency's budget, but it might reduce overall health care cost, or even produce a net gain to the economy.

Of course, if cancer prevention measures were implemented as part of health system services, drug costs and waiting times would both be reduced. Then, a meaningful comparison could be made between the overall cost-effectiveness of preventative measures applied to the general population vs. the overall costs of systemic therapy given only to those with cancer.

However, because health-care budgets are silos, cost savings realized in one area cannot readily be transferred to others. Present care delivery systems are unnecessarily complex, disconnected, and even discordant. As a result, true cost-effectiveness is rarely determined and financial decisions about provincial drug listings or comparisons between costs of prevention versus treatment are usually based on inadequate data and lack consistency⁶. Budgets simply grow, or payment is delayed or denied in the name of "cost containment."

CACC RECOMMENDATIONS

1. Develop a *streamlined* cancer care delivery system.

To produce optimum outcomes and control costs without sacrificing quality, disease-specific management pathways should be constructed by consensus of all caregivers. The caregivers should then collectively, and at one sitting, apply these pathways to each patient *immediately after diagnosis* to devise a menu of treatment options. This approach, already practiced in the best centres, is feasible when coupled with modern information systems, and results in:

- Continuity of care
- Reduced waiting times
- Monitoring of each component contributing to outcome
- Recognition of opportunities for cost savings
- Participation of patients in treatment selection

2. Assess the *overall* cost-effectiveness of new drugs within the context of *streamlined* care described above.

3. Based on the results of the *overall* cost-effectiveness analysis, and subject to each locale establishing *streamlined* care, provide government support for the cost of new drugs according to an agreed-upon threshold of cost-effectiveness.

4. Expedite approval processes by federal and provincial governments.

5. Develop national clinical practice guidelines, while providing oncologists latitude to use discretionary professional judgment to deal with exceptions.

6. Reinforce ethical practices:

- Disclose all treatment options and share decision-making with patients;
- Refer patients to other centres delivering best practice;
- Separate financial issues from treatment recommendations;
- Encourage and protect the advocacy role of health care providers. ●

This article is the synthesis of a position paper jointly authored by the members of the CACC board of directors.

NOTES

- 1 Lichtenberg F. *The Economic Value of Medical Research*. University of Chicago Press 2002
- 2 Rawson NS. Timeliness of review and approval of new drugs in Canada from 1999 through 2001: is progress being made? *Clin. Ther.* 2003, 25:1230-47
- 3 Thomas M, Mann J. Increased thrombotic events after change in statins. *Lancet* 1998, 352:1830; Maroun J, Asche C, Romeyer F, et al. A cost comparison of oral tegafur plus uracil/folinic acid and parenteral fluorouracil for colorectal cancer in Canada. *Pharmacoeconomics* 2003, 21:1039-51; Jansman FG, Postma MJ, van Hartkamp D, et al. Cost-benefit analysis of capecitabine versus 5-FU/Leucovorin in the treatment of colorectal cancer in the Netherlands. *Clin. Ther.* 2004, 26:579-89
- 4 Rawson NS, Kaitin KI. Canadian and US drug approval times and safety considerations. *Annals of Pharmacotherapy* 2003, 37: 1403
- 5 Rawlins, MD. NICE Work—Providing guidance to the British National Health Service. *New Engl. J. Med.* 2004, 351:1383-4
- 6 West R, Borden EK, Collet JP, et al. "Cost-effectiveness" estimates result in flawed decision-making listing drugs for reimbursement. *Can. J. Public Health* 2002, 93:421-5

NEWS

PREVENTION

LIVER CANCER

Stopping liver cancer before it starts

Liver cancers (hepatoma and hepatocellular carcinoma) are among the most common cancers world wide because of their association with hepatitis B and C viral infections, which are common in the eastern hemisphere. Much liver cancer is preventable through hepatitis immunization. In North America, alcohol-induced cirrhosis is a common precursor of liver cancer. Individuals infected with the virus who then develop chronic active hepatitis and advanced fibrosis or cirrhosis are at greatest risk of developing this cancer. The antiviral drug lamivudine not only reduces progression of cirrhosis for those with viral hepatitis, but it also decreases development of hepatoma by 50%.

COLON CANCER

Promising side effects?

Individuals taking statin drugs to reduce blood cholesterol levels may have less risk of developing colon cancer. This intriguing observation has not yet been subject to a controlled trial, therefore, statins are not yet indicated for the prevention of colon cancer.

TREATMENT

PROSTATE CANCER

Chemo promising for prostate patients

For the first time, chemotherapy (in the form of added docetaxel) has been shown to significantly prolong

survival in men with hormone-refractory incurable prostate cancer. Though this drug is in common usage in Canadian cancer treatment centres, most provinces have not yet endorsed it for incurable prostate cancer.

BREAST CANCER

Aromatase inhibitors beneficial for post-menopausal women

A series of important international controlled trials show that aromatase inhibitors improve disease-free survival when used as an adjuvant therapy for post-menopausal women with localized disease, and, in the intermediate term, appear safer and with fewer toxicities for post-menopausal women with hormone-sensitive breast cancer. Aromatase inhibitors, which reduce the body's ability to produce the estrogens necessary for breast cancer cell growth, had previously been shown to be more potent than tamoxifen for the treatment of women with metastatic (incurable) breast cancer.

Three large international controlled randomized studies compared adjuvant therapies under various conditions. The first trial comparing anastrozole (Arimidex) and tamoxifen showed anastrozole improved disease-free survival by at least 10%, and reduced second cancers in the opposite breast by half. Another study testing the aromatase inhibitor letrozole (Femara) found that recurrence could be further reduced by continuing treatment with this new drug in patients who had received five years of tamoxifen. A third study

concluded that switching to exemestane (Aromasin) instead of continuing tamoxifen significantly improved disease-free survival.

Optimum use of aromatase inhibitors in conjunction with tamoxifen has yet to be established, and long-term effects on survival and toxicities remain to be determined. CACC recommends that women contemplating or completing adjuvant tamoxifen should return to their oncologist to see if they might benefit from an aromatase inhibitor.

LUNG CANCER

New options for lung cancer patients

Lung cancer has been notoriously hard to treat, but finally there is some better news. Large trials continue to show that chemotherapy after surgery for localized lung cancer can delay recurrence of disease and prolong survival.

In addition, Pemetrexed (Alimta) has been developed for mesothelioma, a variety of lung tumor caused by exposure to asbestos. Encouraging early trial results with liposome vaccine (L-BLP25) for Stage IIIb lung cancer are leading to broader trials internationally and in Canada.

COLON CANCER

New therapy still awaits approval

Oxaliplatin is being used in some provinces for the treatment of advanced colon cancer, and there is evidence that it can also reduce recurrences when given after surgery for localized disease (adjuvant therapy). Last year the CACC *Report*

NEWS

Card noted that this drug had not yet been approved for advanced colon cancer, despite the fact that this is a standard of care in Western Europe and the U.S. A year later, Health Canada has still not approved its use for any indication.

Antibody therapy extends life

Two antibodies have been developed which are effective in prolonging survival in patients with advanced colon cancer: Avastin, which destroys blood vessels feeding the tumor (antiangiogenesis), and Erbitux, which directly inhibits cancer cell growth. Avastin has serious but infrequent side effects while Erbitux has more frequent but less serious side effects.

Brain Cancer

New hope for brain cancer

Glioblastoma multiforme, one of the most malignant and common brain tumors was, until recently, unresponsive to all known systemic therapies. Temozolomide has now been shown to substantially improve survival when used in conjunction with radiation.

HEMATOLOGIC MALIGNANCIES

Advances for advanced hematologic cancers

Velcade, a biologic agent with a unique mode of action (it works by inhibiting cells' ability to degrade unnecessary proteins), has been shown in a recent study to be effective against a variety of advanced hematologic malignancies including myeloma, follicular lymphoma, and

mantle cell lymphoma. To date, side effects have been common but rarely life-threatening. It has been approved for use in myeloma by the FDA in the U.S. and patients with the other forms of malignancies (e.g. mantle cell lymphoma) are being invited to participate in studies of Velcade to further define its scope of activity.

Progress in non-Hodgkins lymphoma

Researchers reported on two small trials of tositumomab bound to radioactive iodine (Bexxar) at the American Society of Clinical Oncology (ASCO). Sequential therapy with tositumomab and radioactive iodine following either fludarabine or a combination of cyclophosphamide, vincristine and prednisone produced complete responses in the majority of previously untreated advanced-stage non-Hodgkins lymphoma patients.

SUPPORTIVE CARE

Mapping treatment side effects

Genetic mapping analysis appears capable of predicting who will experience the most improvement in quality of life during chemotherapy for colon cancer. This opens the door to exploring entirely new pathways for improving patient care.

A more effective anti-nausea cocktail

Aprepitant, a drug with a unique mode of action, is very effective in preventing nausea and vomiting

caused by chemotherapy. It adds significant relief to patients receiving combinations of other antiemetics.

Exercise reduces fatigue during treatment

Fatigue is common in patients receiving chemotherapy and radiation, and can be debilitating. Studies confirm that this fatigue can be substantially diminished by moderate exercise during treatment.

The haze will pass...

Fatigue, menopausal symptoms, and cognitive dysfunction are significant side effects of chemotherapy. In breast cancer patients, they improve after one to two years, but are still present. Recent longer-term studies indicate that cognitive dysfunction is temporary in most patients.

Preventing bone loss during adjuvant therapy

Zoledronic acid, administered once every six months, can prevent bone loss in young women with early breast cancer receiving adjuvant anastrozole (an aromatase inhibitor) after they have been rendered postmenopausal. Side effects were negligible.

Prevention of Mucositis

Palifermin, a hormone that stimulates growth of surface cells, substantially reduces the severity of chemotherapy- and radiation-induced damage to the lining of the mouth in patients receiving high-dose chemotherapy for hematologic malignancy. This reduces the need for intravenous feeding, use of pain

medications, and risk of serious infection. Side effects were mild to moderate in severity, and transient.

THE PROFESSIONALS

The Perfect Storm

The Canadian Medical Association calls the doctor shortage a “perfect storm,” the convergence of three overwhelming forces. The CMA 2003 National Physician Survey released last summer reported:

- 60% of family doctors either limit the number of new patients they see or have closed practices;
- As many as 3,800 doctors may be retiring in the next two years;
- 26%, or 15,000 doctors nationwide, plan to reduce the number of hours they work. Only 4% plan to increase their hours.

Ontario Association of Radiologists

The OAR's Waiting List Crisis Update, 2004, has found that radiology wait lists are getting worse, that waiting times for the same diagnostic test varies widely from community to community, and wait lists exceed acceptable medical standards of care by months and in some cases by over a year.

- 94% of MRI patients are on waiting lists longer than is medically appropriate, 89% for CT, and 72% for ultrasound.
- 90% of radiologists said in the last year there has been little or no progress in reducing waiting lists.
- CT procedures experienced the greatest wait list increase, a direct reflection of the unavailability of MRI as well as the expanded role of CT.

Registration of Randomized Controlled Trials

On July 26, 2004, the Canadian Institutes of Health Research (CIHR), the largest publicly funded granting agency in Canada, announced that all new CIHR-funded randomized controlled trials (RCTs) must be registered with an International Standard Randomized Controlled Trial Number (ISRCTN). CIHR's decision to adopt an open trial-registry approach was based on public interest, sound ethical principles, excellence, public transparency, accountability and collaboration. CIHR hopes that, among other benefits, trial registration will encourage and increase collaboration among researchers, the private sector and the community, reduce the risk of publication bias, wasteful duplication of research efforts, and contribute to global efforts to reduce or eliminate disease. Basic information about each registered trial will be posted on the public web site of the ISRCTN register (www.controlled-trials.com).

PROVINCIAL NEWS

Newfoundland and Labrador

The Newfoundland Cancer Treatment and Research Foundation (NCTRF) launched the Seamless Care Outcomes Assessment Project, the first in Canada to measure clinical and economic outcomes in oncology pharmacy practice.

The Newfoundland Cancer Treatment and Research Foundation, NL's cancer agency, has been in effect disbanded, raising

questions about a potentially negative impact on cancer control in the province. NL has the second highest cancer mortality in Canada.

New Brunswick

After years of being without an organized cancer agency, New Brunswick has established and funded New Brunswick Cancer Network: A Cancer Control Accountability Framework—a “managed network model” that falls short of being a full fledged cancer agency, but which was designed to meet many of the same objectives. As well, the *Smoke-free Places Act* came into force on October 2, 2004, prohibiting smoking in enclosed public places and indoor workplaces.

Ontario

As a result of an intensive lobbying effort by interested groups and catalyzed by CACC, the Ontario Ministry of Health and Long-Term Care increased funding for new cancer drugs by 25%.

Dr. Terry Sullivan, a renowned scientist in cancer prevention, has been appointed CEO of Cancer Care Ontario, signaling a commitment to new directions in cancer control. Departing CEO Alan Hudson has gone on to lead the Ontario wait times strategy.

Proposed legislation for a smoke-free Ontario will make all workplaces and enclosed public spaces in Ontario 100% smoke-free, protecting workers from second-hand smoke and prohibiting smoking in private homes while a home-care worker is there or when children are

NEWS

present in a licensed in-home day-care program. The legislation is expected to come into force May 31, 2006.

Alberta

After extensive lobby efforts by a patient and the press, the Alberta provincial government increased funding to the Alberta Cancer Board to extend the scope of use of rituximab, an antibody highly effective against lymphoma.

The Alberta Cancer Board has opened its state-of-the-art Radiosurgery Centre, becoming the first site in Canada to offer Novalis Shaped Beam Surgery to cancer patients. Located at the Tom Baker Cancer Centre, this new non-invasive technology will help treat Albertans with cancerous and noncancerous tumors in the brain, spine, prostate, liver and lung.

British Columbia

The BC Cancer Agency has received approval for purchase and use of a PET/CT scanner for routine clinical use, and for the facilities to produce the short-lived radioactive chemicals necessary for PET scanning. It is the first provincial agency to receive such approval, although the Juravinski Cancer Center in Hamilton, Ontario has had some access to the PET scanner at McMaster University, and Quebec has also approved PET scanning for routine use. Elsewhere in Canada PET scanning is regarded as experimental, despite the fact it has been proven to be useful and has been routinely employed in the U.S. since 1997.

From its inception in the 1930s until 2003, the BC Cancer Agency was responsible to the public through a Board of Trustees. The current provincial government has removed that direct reporting relationship, eliminated the public Board of Trustees and dismantled the administration and management of the Agency. The Agency now reports to the Provincial Health Services Authority that in turn reports to a deputy minister. The BC Cancer Agency has produced the best results for cancer control in Canada: BC is the only province where the actual (not projected) cancer mortality is decreasing. It remains to be seen whether the Agency will have the ability to be strategic about cancer control and sustain its benchmark effectiveness for Canada now that its lines of communication to the Government and direct responsibility to the public have been fractured.

Manitoba

Manitoba Prostate Centre opened at CancerCare Manitoba, a multi-disciplinary Centre for prostate disease. All provincial urologists will have access to evidence-based treatment protocols and a large registry of prostate cases for research purposes.

Great-West Life Manitoba Breast Cancer Research Centre opened in Winnipeg, focusing on breast cancer research, with an emphasis on identifying biological markers in blood or urine that will aid in the early detection of breast cancer.

OTHER GOVERNMENT INITIATIVES

Progress Report on Cancer Control in Canada

Health Canada released a report outlining the urgency, the obstacles and priorities for effective cancer control. "Canada's approach to cancer control needs to encompass increased recognition of the value of health promotion and disease prevention, a greater commitment to broader integration of cancer control activities through better national and provincial planning, the promotion of greater participation in effective screening programs, use of evidence-based guidelines to inform clinical care and service delivery and an awareness of the value of palliative care and the need to increase palliative care capacity as our country's population grows and ages."

Compassionate Care

Beginning January 4, 2004, eligible Canadian workers who take time off work to care for a gravely ill family member can receive six weeks of employment insurance benefits over a period of six months. Their jobs will also be protected.

Public Health Agency of Canada

Led by Dr. David Butler-Jones, the new Public Health Agency of Canada (PHAC) will focus on more effective efforts to prevent chronic diseases, like cancer and heart disease, prevent injuries and respond to public health emergencies and infectious disease outbreaks. PHAC

is expected to play a major role in a Canadian network of expertise and research in public health, and will serve as a focal point for sharing Canada's expertise with the rest of the world and for applying international research and development to Canadian public health programs and policies.

Federal Funding for Health

Provincial First Ministers met in September and cut a new deal for health funding: \$41 billion over the next 10 years including:

- \$1 billion in 2004-05 and
- \$2 billion in 2005-06, closing the short-term "Romanow gap;"
- \$500 million in 2005-06, for progress on home-care services and catastrophic drug coverage;
- A new base and escalator for the Canada Health Transfer that will raise the federal transfer to provinces and territories to 45 percent by 2010;
- \$4.5 billion over the next six years, beginning in 2004-05, in the Wait Times Reduction Fund. In 2010-11,
- \$250 million ongoing will be added to the CHT base primarily for health human resources;
- \$500 million for medical equipment; and
- \$700 million over five years to improve the health of Aboriginal people.

A month later, the health ministers agreed to:

- Meet again in January 2005 to review progress on waiting times commitments;

- Develop and implement the national pharmaceuticals strategy and report on progress by June 30, 2006;
- Initiate work on public health goals and targets, which will address the broad determinants that lead to improved health outcomes for all Canadians;
- A new approach to ensuring a sufficient supply of medical and health professionals;
- A new Canadian Health Technology Strategy to assess the impact of health technologies and maximize their effective utilization; and
- The Integrated Pan-Canadian Healthy Living Strategy, focused initially on increasing physical activity, healthy eating and healthy weight.

Waiting for Waiting Times Progress

According to a recent Health Canada progress report, "provincial governments are engaged in various initiatives to improve access to health services and better manage wait times, (registries, posting of wait times), develop wait times protocols (prioritization tools, targets) and undertake public education. Health Canada and the four Western provinces are partners in the Western Canada Waiting List Project, a collaborative initiative of 20 partners that also includes regional health authorities, medical associations and research centres. The project developed and implemented prioritization tools in high-demand clinical areas. It is now adapting the tools for use

in primary health care and developing maximum acceptable wait times for key procedures.

The federal government's "five in five" proposal aims to significantly reduce waiting times over five years in five key areas—cancer, heart, diagnostic imaging, joint replacement and sight restoration, which are targeted as the areas of most concern to Canadians. The report states that governments will use comparable indicators to report to the public on health system performance, including timely access, in November 2004. The Health Council, promised in the Health Accord and established in December 2003, has formed a Wait Times Committee and will report on wait times as one of the Council's priorities. The information is intended "to give Canadians a fair and accurate picture of the situation regarding waiting times."

Forum on the Canadian Strategy for Cancer Control (CSCC)

An important forum to enable a wide variety of stakeholders to understand and give feedback on the Canadian Strategy for Cancer Control strategy will be held Jan 27-29, 2005 in Aylmer, Quebec.

WHAT TO DO WHILE WAITING

Federal/provincial efforts to improve waiting times will take some time to kick in. Meanwhile, what does a cancer patient do?

STRESS RELIEF. Cancer agencies and hospitals with a specialty cancer service offer a range of support services to help patients deal with fears. Services take the form of professional psychosocial counseling, spiritual counseling and education in relaxation techniques. Everything helps.

COMMUNICATING WITH YOUR CANCER SPECIALISTS. Plan for the best ways to use your appointment time with health professionals; think about your questions in advance and write them down. Take a friend or relative with you, or talk to the hospital about arranging for a patient representative, volunteer or advocate to attend with you. The “extra set of ears” is so important that CancerCare Manitoba encourages patients to bring along a tape recorder and replay the entire conversation later.

INFORMATION ABOUT CANCER. The Canadian Cancer Society’s cancer information service is accessible by toll-free telephone 1-888-939-3333, open from 9 a.m. to 6 p.m. anywhere in Canada, offering advice in English, French and Chinese.

INTERNET VIGILANCE. Credible web sites for information about your disease include your provincial cancer agency, Health Canada (www.hc-sc.gc.ca) and the Canadian Cancer Society (www.cancer.ca). CCS can refer patients to education and support services near home. Check your phone book for local cancer groups.

CACC selected this brief list of international web sites for patients who want more. These are provided for information only and are not intended to replace medical advice. Sites originating from outside Canada may contain information about therapies, screening methods, etc., which may differ from those offered in your clinic. CACC assumes no liability for the content of these sites.

Action on Smoking and Health: information on tobacco control (www.ash.org.uk)

American Cancer Society: general information for U.S. patients (www.cancer.org)

American Institute for Cancer Research (www.aicr.org)

Cancer Index: a guide to internet resources for cancer (www.cancerindex.org)

Cancer Literature (www.cancer.gov)

Karolinska Guide: a general guide to the web regarding diseases (www.mic.ki.se/diseases/index.html)

National Comprehensive Cancer Network: detailed guidelines for patients and doctors (www.nccn.org)

National Institutes of Health Library and Literature Resources (www.nih.gov/science/library.html)

Nutrition Action: practical up to date guide to healthy living (<http://www.cspinet.org/nah/>)

Oncolink: a good source for breaking news (www.oncolink.com)

Physician Data Query: summaries for patients/health professionals (www.suttercancer.org)

Pubmed: a portal for searching medical literature (www.cancer.gov/search/pubmed)

CACC believes in advocacy and is committed to speaking openly about cancer issues, to highlight the concerns of patients and families, and to press governments for a more effective response to the enormity of the cancer problem in Canada. We forego charitable status to retain this freedom. Through the generosity of sponsors and donors, we use unrestricted grants to collect information, consult with cancer experts and families, and lobby governments for improvements. Sponsorship guidelines can be found on our web site.

If you are one of the millions of Canadians concerned about the state of cancer care, tell your federal MP and your provincial MPP/MLA. Make sure the people you elected to govern know that cancer is a priority to you and should be for them.

CANCER ADVOCACY COALITION OF CANADA

60 St. Clair Ave. East, Suite 204, Toronto, Ontario M4T 1N5

Tel: (416) 538-4874 Toll Free: 1-877-472-3436

canceradvocacy@on.aibn.com www.canceradvocacy.ca