

CANCER CARE IN CANADA

Report Card 2003 paints a disturbing picture of a country ill-equipped to cope with a growing cancer burden.

This year's report focuses on two important subjects: the human toll exacted by the chronic under-funding of provincial cancer agencies and the surprisingly close correlation between funding levels for cancer and mortality rates.

The charts, graphs and numbers contained in the report card confirm what many cancer care professionals have long sensed from direct personal experience. From 1979 to 1992, I was Director of the Hamilton Regional Cancer Centre in Ontario. I managed budgets that were consistently and considerably lower than those of the well-funded Tom Baker Centre in Calgary, which served an equivalent population size. In direct proportion Hamilton couldn't provide the services and treatments that Alberta cancer patients received.

Canada's failure to deal with our current cancer burden has ominous implications for the future. Ten years ago, 33% of Canadians were destined to get cancer during their lifetimes. Today, the risk has risen to 40%, making cancer our number one health threat and a chronic disease of epidemic proportions, one that threatens to break Canada's public health system.

The ultimate cancer paradox: a planeload of Canadians dies of cancer every day and a national strategy for cancer control is carefully crafted by a coalition of professionals desperately dealing with this burden. Yet their resultant effort, the Canadian Strategy

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CANCER CARE IN CANADA

EDITOR Beth Kapusta
**CACC EDITORIAL
 ADVISORY COMMITTEE** Bill Hryniuk, Colleen Savage
ART DIRECTOR Bob Wilcox
ASSISTANT EDITOR Susan Harrison

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.

Jan Capen (B.Comm Entrepreneurial Management) is a cancer survivor and advocate based in Victoria.

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

Stefan Glück MD, PhD, is a medical oncologist formerly of the Tom Baker Cancer Centre in Calgary and Professor of Oncology, Medicine, Pharmacology & Therapeutics and Deputy Head, Department of Oncology.

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.

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

Pat Kelly is a cancer survivor, President of the consulting firm PISGES, and a founding member of CACC.

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

Carol Loughrey MBA, FCA is a cancer survivor who co-founded the first breast cancer support group in New Brunswick and the New Brunswick Breast Cancer Network Inc., a former Chair and CEO of the Canadian Institute of Chartered Accountants, provincial Deputy Minister and a university professor.

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.

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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

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for Cancer Control (CSCC), is virtually ignored by the government, which gives them \$0.5 million to continue discussions. Meanwhile, a strategy for containing AIDS receives \$100 million per year for further study. AIDS kills one or two Canadians a week.

In meeting with newly diagnosed cancer patients, we hear story after story of unconscionable delays in staging and treatment. Nurses, oncologists of all specialties, psychologists and social workers echo their tales of frustration. But there is no national public outcry, no demand for better care, shorter waiting times or improved prevention. Why? Do most Canadians not realize that almost half of us will get cancer? Do we not care? Or do we, as advocates need to take a different tack in making our message clear?

Earlier this year, the Cancer Advocacy Coalition (CACC) met with politicians to try to understand why such a compelling cause has resulted in so little action. Politicians told us they aren't hearing from constituents who have experienced difficulties in getting diagnosed or treated. They hadn't heard that cancer incidence has reached epidemic proportions. In fact, they asked, weren't we winning the war? Didn't we know about the improvement in survival statistics or the latest breakthrough in unraveling the genetic code? One MP even told us that too much money is spent on tobacco control. He said that smoking doesn't cause cancer, that it's all just a "statistical association"! When we asked for the House of Commons Health committee to address the cancer problem, it was assigned a priority of 14 among 20 issues. West Nile virus, which killed 37 Canadians last year, was number one and AIDS was number two. That's when we realized we had a real problem on our hands.

And when the CACC met with MPs to point out the east-west gradient in cancer mortality correlated with dollars spent on cancer control, we were told that the relationship is simply due to a higher prevalence of smoking in the Maritimes where socio-economic status is lower. There is some truth in these statements, but we think there must be more to it than that.

In a separate cancer awareness effort (conducted by the recent National Cancer Leadership Forum) MPs and senators were surveyed and also reported that they had never heard from their constituents or cancer charities about the inadequate state of cancer care in Canada; nor had they ever been asked to take action on cancer control. Yet, after these same elected officials became aware of the looming crisis, about half said they would be willing to introduce or support a bill to establish a national cancer act, and many were supportive of an accelerated process for implementation. Furthermore, when two MPs were fully informed, they said they were more than willing to work to address the cancer problem. We were greatly heartened by this response.

Clearly, there is a need for more effective advocacy. The CACC remains committed to raising cancer control to the top government health priority, taking advantage of our not-for-profit, non-charitable status to lobby politicians, find out what they are thinking, and devise ways to make change. In a government-run health-care system this kind of action is essential. We must not

only point out the problem to them, but we should also suggest the way forward.

In the first place, there must be focus on applying what we already know, as detailed in the Canadian Strategy for Cancer Control. Thus, the areas that have so far have been successful (wider application of better local and systemic treatment, screening, improved general medical practice, smoking cessation, and possibly improved nutrition) need to be more scrupulously implemented. But even as we do this, it becomes plain that the cost of this strategy is rising faster than the 3% annual increase in caseload. As detailed elsewhere in this Report Card, available data indicate that provincial cancer agency funding is growing at the rate of 11–19% compounded annually. Still, we have no choice: we must implement these better treatments and improve care of the patient as a person.

However, it is also essential that we stop the epidemic in its tracks. Cancer incidence, expressed per 100,000, is actually increasing. (Using the usual method of age-adjusted population it appears to be stable). While it is possible that the genetic revolution may somehow put an end to the current epidemic, it is looking less and less likely that this will happen in a timely fashion. It is no longer prudent to bet that a breakthrough is just around the corner. Yet, most of the research money still goes to laboratory-based research (using “models,” i.e. tissue cultures and animals studied under artificially devised conditions). Meanwhile, the successful efforts listed earlier receive only a small fraction of the research budget. Especially important is the need to determine what lifestyle changes can prevent invasive cancer from first appearing (primary prevention) or reappearing in cancer survivors (tertiary prevention). Regrettably, just as the knowledge emerges as to what lifestyle changes might be tested in tertiary prevention, cancer centres are discontinuing follow-up of survivors after initial treatment has been completed.

But how can such a complex sequence of concurrent events be orchestrated, especially the prioritization of the research-to-policy-to-practice links necessary for improved cancer control?

Faced with the federal-provincial system, regional disparities and system disconnects complexities and constraints, we have reluctantly become convinced that nothing less than a national cancer act and a national cancer agency are required to orchestrate the necessary strategies. A national cancer agency with a mandate embedded in law could foster implementation of the Canadian Strategy for Cancer Control, align

Ten years ago, 33% of Canadians were destined to get cancer in their lifetime. Today, the risk has risen to 40%.

research efforts with societal priorities and monitor progress in cancer control. At the moment no agency is empowered or able to do any of these things.

All of this begs the question: how can we arouse the political will to address the problem? First, as cancer organizations and professionals, we must work together. The lesson learned from AIDS groups is clear: it is important to overcome the clashes that inevitably occur when passionate and dedicated people attack the same objective from different directions. Then, acting in a unified manner, we should be approaching politicians from two different directions simultaneously. First, advocacy groups must continue to engage politicians in public dialogue. The National Cancer Leadership Forum with its new Leadership Team is a major step in the right direction. At the same time we have to get voters into the act by encouraging them to meet individually with their MPs and MPPs.

Cancer survivors and those personally affected by cancer may well be willing to take this step. It is up to us to give them the necessary information, to encourage them to tell their personal stories and to assure them that individual meetings with their elected representatives will make a difference. This two-pronged strategy: advocacy groups approaching politicians publicly and citizens approaching them privately – could well be the key to a constructive solution. ●

BY BILL HRYNIUK

REPORT CARD

2003

Since the year 2000, the Cancer Advocacy Coalition of Canada (CACC) has been asking for hard facts on the issues that matter most to the country's cancer patients. Year by year, our mantra has been, "We cannot manage what we cannot measure."

This year, we assessed each province based on its performance in a number of areas: mortality (the rate at which people die of cancer), waiting times (a good measure of system efficiency and responsiveness), per capita cancer-agency funding levels (where possible), yearly increases in cancer-agency budgets, and provincial government budgetary allocation to cancer agencies measured against their means, as judged by their per capita income. As well, we have now had considerable experience in dealing with the various provincial agencies and are able to assess their accountability and transparency. From these complex factors we have ranked the provinces to find out who delivers the best care, and why.

Our findings suggest once again that we need to be able to measure more accurately in order to improve cancer care in our country, as too many question marks and too many "not comparable" footnotes persist. Our findings also strongly suggest that the more you spend on cancer the more lives you save, with British Columbia leading the country on both counts. As a patient advocacy organization we challenge every province in Canada to follow the Canadian Strategy for Cancer Control and set a five-year goal: to bring mortality rates in line with the outcomes of British Columbia, the province that has historically been the best organized and the most responsive in meeting patient needs. Can this be accomplished by increasing per capita funding to adequate levels – so that current knowledge regarding screening, prevention, treatment and care can be applied to all Canadians?

Year-End Final Report for 2002 for Canada's Provincial Cancer Control Programs

	MORTALITY (2002 RANKING)	WAITING TIMES * (2002)	PER CAPITA FUNDING (2002)	RATE OF FUNDING INCREASES (RANKING 1998-2003)	TRANSPARENCY & ACCOUNTABILITY ** (2002)	COMMENTS
BC	1	ACCEPTABLE	1	4	ACCEPTABLE	Does not collect data on waiting times for systemic therapy after referral; radiation guidelines in place and usually achieved. Compared to other provinces, waiting times are artificially low, due to exclusion of period for follow-up tests after referral.
ALB	2	UNACCEPTABLE	2	3	BORDERLINE	Did not provide data on 2002 waiting times, although historically has met recommended guidelines. Transparency on expenditures improves score.
SASK	4	UNACCEPTABLE	3	5	UNACCEPTABLE	Did not provide data on 2002 waiting times.
MAN	5	BORDERLINE	4	2	BORDERLINE	Very limited information provided on 2002 waiting times. Radiation waiting times within acceptable range.
ONT	3	UNACCEPTABLE	N/A	N/A	OUTSTANDING	All waiting times unacceptably long and worsening. Exceptional willingness to be transparent, open and accountable. Expenditures not comparable since a large portion of the province's cancer care is provided outside CCO.
QUE	8	UNACCEPTABLE	N/A	N/A	UNACCEPTABLE	Did not provide data. No cancer agency in place. Long-term planning process underway. Historically, significant burden of cancer compared to other provinces.
NB	7	UNACCEPTABLE	N/A	N/A	UNACCEPTABLE	No data collected. No cancer agency in place. A significant cancer burden compared to other provinces requires priority attention.
NS	10	UNACCEPTABLE	6	N/A	ACCEPTABLE	Data submission missed publication deadline except for 2002 financial data. A significant cancer burden compared to other provinces requires priority attention.
P.E.I.	6	BORDERLINE	5	N/A	BORDERLINE	Much improvement in availability of waiting times information; did not disclose expenditure data.
NL	9	UNACCEPTABLE	N/A	1	ACCEPTABLE	Improving rapidly – largest rate of increase in cancer budget of all provinces should help address significant waiting times problems. Significant cancer burden compared to other provinces.

* Based on ability to meet Canadian Association of Radiation Oncologists recommendations.

** Measures responsiveness and timeliness of meeting requests for data on waiting times and financial data and/or availability of annual report information.

N/A Not available.

BENCHMARKING CANADA'S CANCER CARE SYSTEMS

In 2000, the subjects the CACC could report on were extremely limited. We asked all ten provinces how many people were currently living with a cancer diagnosis, and received numbers from five (Manitoba, BC, Ontario, Nova Scotia and Saskatchewan). We asked about five-year survival times for the major cancer sites: we got four reasonably comparable answers (from BC, Alberta, Ontario and Nova Scotia). We were able to obtain only anecdotal information on waiting times, and no clear sense from any province as to how much was spent on cancer control and care.

Over time, we were able to put together a more comprehensive composite image of cancer across the country. In 2001, information obtained directly from cancer registries on incidence and mortality revealed a disturbing trend: Canada was falling behind many areas of the US in outcomes.

Our 2002 Report Card showed a slightly clearer picture: incidence and mortality data were more complete, waiting time information was still sketchy except for BC, and we were able to obtain annual budgets from several of the provinces. However, these measured many different things and were far from comparable.

We began to speculate on the relationship between better outcomes and the presence of organized provincial cancer agencies – in a quest to find an explanation for the east-west gradient of outcomes across the country. This led to Report Card 2003, which begins to shed some light on the relationship between cancer funding and outcomes.

YOUR MONEY OR YOUR LIFE?

The 2003 Report Card finds us still pondering the enigmatic east-west gradient of outcomes across the country, this time with an eye to following the money. For some time it has been known that the further west you go in Canada, the lower the mortality from cancer. What has not been as widely appreciated is that the further west you go, the more money provincial governments transfer to their provincial cancer agencies for surveillance, screening, treatment and organization. Figure 1 shows this relationship for provinces which have agencies that have authority over cancer control and for which we were able to obtain complete financial data for 2002.

Although this is by no means a complete academic analysis of the cause-effect relationship between spending and mortality, we feel that the tight correlation we observed may be more than coincidence. In the provinces with comparable data we see without exception that the greater the per capita funding, the lower the mortality from cancer in that province. The relationship is consistent, whether we consider all cancers or exclude lung cancer (indicating that the relationship was not simply related to better tobacco control or socioeconomic status).

These observations should come as no surprise. Invasive cancer is a lethal disease if left unchecked. If every case is effectively treated, mortality will be lower than if not. And it costs money to screen, treat and manage effectively – factors that cumulatively should point to better outcomes. It would appear that the more money spent (within limits), the better the results. Professionals consistently echo this message in their anecdotal accounts. Is it your money or your life?

FIGURE 1: **MORTALITY RATES VS. GOVERNMENT SUPPORT, 2002**

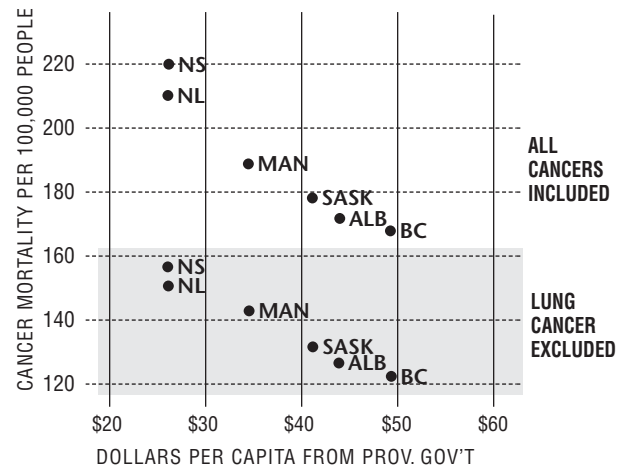


FIGURE 2: **OPERATING BUDGETS PER CAPITA BY CANCER AGENCIES**

	97	98	99	00	01	02	03
BC	\$27	\$29	\$33	\$36	\$44	\$49	\$55
ALB	\$25	\$26	\$27	\$30	\$38	\$43	\$50
SASK	\$28	\$26	\$27	\$32	\$35	\$41	\$45
MAN	\$13	\$18	\$19	\$23	\$29	\$34	\$36
NL	\$12	\$12	\$14	\$15	\$19	\$27	\$30

Figure 2 shows the 1997 to 2003 operating budget for the agencies that have full jurisdiction over cancer control in their respective provinces, and for which we were provided data (BC, Alberta, Saskatchewan, Manitoba, and Newfoundland). The analysis excluded funding for research, in-patient care, surgery, federal funding, and capital expenditures.

NAVIGATING A MAZE OF FACTS

There are caveats to the hypothesis arising from Figure 1, on page 7, – that mortality is linked to funding levels. Some we include in the following section. Additional facts, figures, charts and graphs are posted on the CACC website (www.canceradvocacycoalition.com).

First, it should be pointed out that better funding leading to more effective organization, screening and treatment cannot reduce mortality in the year of application. That is, efforts in 2002 cannot be the sole reason for reduced mortality in 2002. It takes about five years, at a minimum, for better treatment to reduce overall mortality, and even longer for screening benefits to take effect. We therefore studied the relationship between provincial funding levels and mortality for the provinces shown in Figure 1 for each of the last seven years. The results were the same: the higher the level of funding, the lower the mortality. In each year the relationship mirrored the 2002 data shown in Figure 1, and obtained whether or not lung cancers were excluded from the analysis. These data are shown in detailed tabular form appended to the electronic version of this report card on our website.

Other caveats bearing on the speculation that provincial funding levels determine outcomes include the possibility that cancer incidence, socio-economic status and smoking each contribute to the east-west gradient of better outcomes shown in Figure 1. While there is a slightly lower incidence of cancer in the western provinces than the eastern ones, the curve is

shallow and erratic. Socio-economic status and smoking are unlikely to account for most of the difference in outcomes because as is shown in Figure 1, the relationship between spending and outcomes obtains whether or not lung cancer is included.

More detailed analysis of the interaction of these various factors must be undertaken before we can determine precisely how much the level of funding determines cancer mortality. Nevertheless, the startlingly close relationship shown in Figure 1 suggests to us that while funding levels may not be the only explanation they may be an important one. And they should be the most easily rectifiable.

If, in fact, funding levels from government have a major impact on cancer mortality, we may have stumbled upon a very important piece of quantitative information. Over the period of interest, 1997–2003, among the provinces studied, BC was the only one to show a consistent and sustained decline in cancer mortality. The others in the group had no change or an increase in mortality levels. Thus, the per capita funding for cancer control received by the BC Cancer Control Agency might provide a benchmark for other provinces to follow, giving them an indication of what level of support they would need in order to lower death rates to those already achieved in BC. Such a benchmark, if accurate, would be an invaluable aid in planning cancer control for Canada.

Unfortunately, we cannot analyze the results from the two largest provinces with the same precision that we could those shown in Figure 1. Quebec has a largely separate system, and data from that province are not likely to be forthcoming in the near future. Ontario's hybrid system of control over cancer services also

makes it difficult to get an apples-to-apples comparison of how Ontario is doing relative to the other provinces. Because Cancer Care Ontario (CCO) delivered only a portion of the province’s cancer care, its numbers are not strictly comparable to the other provinces’ cancer agencies. Nevertheless, CCO does fund the major regional cancer centres in each of the cancer-planning regions of the province, and these serve much of the needs of cancer patients outside the greater Toronto area.

To get some approximation of the rate of growth of funding levels, we examined in more detail the increases in provincial government funding for the period from 1997–2003 for each of the provinces in question, including CCO. These data are attached to the electronic version of this report card on our website. With the exception of Newfoundland, where the funding started to increase only in the last five years, for each of the other provinces the year-over-year increase in funding was remarkably constant.

As shown in Figure 3, on this page, the provinces had *compounded* annual increases in funding from their respective governments varying from 12% to 19%, while CCO’s budget grew at only 11% per year. This suggests that Ontario’s regional centres are funded well below the levels of their western counterparts, a suggestion that could easily be investigated if access were provided to the necessary data. The suggestion is also consistent with the recent report that, in terms of 2001 health spending as a percentage of provincial gross domestic product (source: Canadian Institute for Health Information), Ontario is next to last, while it is first in terms of private-sector health spending, presumably out of necessity, with individuals making up the shortfall out of their own pockets.

FIGURE 3: RATE OF INCREASE OF CANCER AGENCY OPERATING BUDGETS

PROVINCE	DOUBLING TIME	RATE OF INCREASE COMPOUNDED ANNUALLY	RANKING
Newfoundland	3.8 years	19%	1
Manitoba	4.3 years	17%	2
Alberta	5.0 years	14%	3
British Columbia	5.2 years	14%	4
Saskatchewan	6.0 years	12%	5
Ontario	6.5 years	11%	6

Figure 3 ranks increases in operating budgets for provinces with available information on the rate of this increase. The data are expressed both in terms of doubling time (the number of years it takes for cancer budgets to double at present rates of increase) and the percent rate at which budgets increase (compounded annually).

WAITING TIMES: LONG WAITS, DIFFERENT MEASURES, LACK OF INFORMATION

The CACC's questions about waiting times revealed three issues of ongoing concern: in many provinces waiting times exceed recommendations, with no mechanisms in place obliging provinces to meet them; there is a lack of standardized measurement across the country, and few provinces can complete information on how many patients receive prompt treatment.

To help ensure comparability of the data for the calendar year 2002, we asked for information on newly-diagnosed patients with the most common cancers: breast, prostate and lung. We asked for information on the length of time a patient waits between a request for an appointment at a cancer centre until the patient sees a medical or radiation oncologist, and then the time to the start of radiation or chemotherapy treatment. The Canadian Association of Radiation Oncologists recommends that the time between

referral and consultation should not exceed two weeks, and between consultation and beginning of treatment should not exceed an additional two weeks.

No province meets these standards for radiation treatment. British Columbia which has the lowest cancer mortality does meet its own stated standards.

Alberta, Saskatchewan, Quebec, and New Brunswick provided no 2002 waiting time data in response to our requests. The reasons given were various. In order to fill information gaps, CACC will follow up on these requests with a freedom of information request, the results of which will be posted on the CACC web site.

On the other end of the spectrum, Ontario presents an interesting challenge. Cancer Care Ontario's October 2003 Quality Council Report is an extraordinarily candid and self-critical document that details a disturbing situation in Ontario: it chronicles its own deteriorating performance results. Median waiting times from referral to start of radiation have increased from a low of about five weeks in 1996 to over seven weeks in 2002, and waiting times to access chemotherapy have increased at an average rate of four days per year since 1999.

**FIGURE 4:
WAITING TIMES
FOR BREAST,
PROSTATE AND
LUNG CANCER,
2002**

1 Does not include interval required to determine whether the patient is medically able to receive treatment.

2 From correspondence from Manitoba Cancer Agency – “No waiting lists for systemic therapy. Some waiting time for first appointments for some of the bigger disease site groups – times vary.”

3 May not include time from referral to first seeing oncologist.

4 Source: “Strengthening the Quality of Cancer Services in Ontario,” Ed. by T. Sullivan, W. Evans, H. Angus, A. Hudson

5 Although Quebec has data on waiting times for radiotherapy and surgical oncology, the information is being standardized and waiting time information will not be available until this work is complete.

6 Does not include interval between request for appointment and seeing radiation oncologist.

7 Includes delays due to surgery and chemotherapy.

		INTERVAL BETWEEN REQUEST TO SEE ONCOLOGIST TO START OF TREATMENT (NUMBER OF DAYS)					
		Systemic Therapy			Radiation		
		BREAST	PROSTATE	LUNG	BREAST	PROSTATE	LUNG
BC	2001	28 ¹	28 ¹	28 ¹	28 ¹	28 ¹	28 ¹
	2002	N/A	N/A	N/A	31 ¹	31 ¹	19 ¹
ALB	2001	28 max	28 max	28 max	28 max	+28	28 max
	2002	N/A			N/A		
SASK	2001	N/A			N/A		
	2002	N/A			N/A		
MAN	2001	No wait except for more common cancers.			28 to 35 ^{1,3}		
	2002	No wait except for more common cancers. ²			28 to 35 ^{1,3}		
ONT⁴	2001	69			56	56	24
	2002	73			63	76	23
QUE	2001	N/A			N/A		
	2002	N/A ⁵			N/A ⁵		
NB	2001	N/A			N/A		
	2002	N/A			N/A		
NS	2001	N/A			N/A		
	2002	N/A			33 ⁶		
PEI	2001	N/A	N/A	N/A	N/A	N/A	N/A
	2002	14	6	5	73 ⁷	N/A	21
NL	2001	35 to 42			70 to 84		
	2002	30	17	21	53 to 60	51 to 58	34 to 41

EXPECTATIONS AND REALITY: PUTTING THE DOLLARS IN CONTEXT

We thought we'd wrap up the financial data in Report Card 2003 with a little exercise that would address one of the nagging questions it has raised – why do some provinces spend so much more per capita on cancer care than others? We speculated that it might have something to do with the base wealth of the provinces, so we undertook a comparison of means and spending. One might expect that the wealthier the province, the higher the level of per capita spending on cancer. However, this is not the case. BC, the province that spends the most per capita on cancer, ranks third in terms of per capita income. Alberta, on the other hand, spends the third most on cancer. Although it is difficult to pin down an expenditure number per capita (as we have defined it) for the wealthiest province, Ontario, by self-admission it

FIGURE 5: PER CAPITA INCOME VERSUS PROVINCIAL SPENDING ON CANCER

	2002 RANKING INCOME PER CAPITA	2002 RANKING SPENDING PER CAPITA
Alberta	1	3
Ontario	2	
British Columbia	3	1
Quebec	4	
Manitoba	5	4
Nova Scotia	6	
New Brunswick	7	
Saskatchewan	8	2
Prince Edward Island	9	
Newfoundland	10	5

Source: Average Personal Income by Province, calculated from StatsCan Table 384-0012 and Table 051-0001

seems to be truly struggling in all measurable aspects of cancer care delivery. We strongly suspect it spends much less than it could or should. **CACC**

METHODOLOGY

Information for this report was collected first by approaching CAPCA (Canadian Association of Provincial Cancer Agencies) for information on waiting times. In an effort to illustrate the quality of cancer care across the country, the Cancer Advocacy Coalition of Canada researched provincial government expenditures to cancer agencies, incidence and mortality rates, and wait times for care.

Where possible, government expenditures are from each agency's audited financial statements. In general, these expenditures made up the provincial government contribution towards the general operating budget and do not include major capital expenditures, or costs of research in patient care, surgery or federal funds.

Mortality rates are from the 1997–2003 publication *Canadian Cancer Statistics* produced jointly by the Canadian Cancer Society, NCIC, StatsCan, Provincial-Territorial Registries and Health Canada. These figures are estimates based on modeling trends in cancer and population data since 1986 for both cancer incidence and mortality.

Each cancer agency was also surveyed to determine relative waiting times for the calendar year 2002. The CACC asked the following questions for new cases of breast, prostate, lung and colorectal cancer:

1. The length of time a patient waits between a request for an appointment at a Cancer Centre until the patient sees an oncologist.
2. a) The length of time between the patient's appointment

with an oncologist to the time tests are conducted.

b) The length of time between the tests and treatment beginning.

or if a) and b) are not available as separate figures:

c) The time between the first appointment at the cancer centre to the time treatment begins.

Each Agency is unique in its calculations, including different information within the scope of their funding. Here are a few examples of some of the challenges:

Some provincial governments give one general grant while others include a general grant and a 'restricted' grant (often for capital, research). We excluded any 'restricted' grants from our research and only included general funding. The problem this creates is that there may be some overlap from provinces that just have general grants particularly in terms of research.

Similarly, some provincial Agencies receive funding from more than one ministry of the government – again often for research or one time drug costs. In the case of Alberta this was often the case, and funding from Ministries other than Alberta Health were excluded since the Cancer Agency did not respond to requests for clarification due to time constraints on their end. We may have therefore underestimated Alberta's funding or private oncology practices.

Also, Ontario numbers do not include Princess Margaret and therefore leave out a significant provincial expenditure for direct clinical care.

ONE PLAN, MANY VOICES

A Plea for Political Courage

BY PAT KELLY

Patient advocate Pat Kelly reports on an advocacy meeting aimed at mobilizing public support and political action around a national cancer plan.

If you think Canada's cancer control system is a complicated web of institutions, bureaucratic committees, funding sources and medical jargon – you're right. If you think that means that cancer patients, caregivers, families, charities, citizens and advocates should not tackle the system problems of cancer, you're wrong. And if you think our elected officials will provide the necessary leadership for us, you're dead wrong.

Here's what happened in December 2003, when 92 Canadians representing more than 28 major cancer groups met at a National Cancer Leadership Forum (NCLF) held in Aylmer, Quebec. Prior to the Forum, the steering committee sponsored a survey of cancer organizations and federal elected officials to determine their attitudes and goals for the forum. Recommendations included:

- An action plan for implementing a national cancer strategy
- Identifiable leaders
- Advocacy tools
- Trust and understanding among groups
- Public awareness

A survey of MPs and senators found that cancer was either a very important or an urgent issue for their constituents, however they recognized that cancer was not a major government priority like AIDS or diabetes. They had definite ideas about how to give cancer a higher federal profile, including:

- More media attention
- More charities and patient groups speaking out
- A national inquiry such as a Royal Commission or a Senate Report
- Public opinion surveys

MPs argued that co-ordinating cancer organizations and charities to represent cancer-related issues with one voice would be more effective than current competing and confusing efforts. Prior to briefings for the forum, none of the MPs had been aware of the Canadian Strategy for Cancer Control (CSCC), and many were shocked to learn that as much as one-half the Canadian population would be diagnosed with cancer.

In the face of these challenges, delegates created an advocacy action plan and voted for a new leadership team led by BC Cancer Agency President Dr. Simon Sutcliffe, with an advisory council chaired by Dr. Bill Evans. Four sub-committees include: Public Engagement (Geoff Eaton, chair), Government Relations (Dr. Bill

Hryniuk, chair), Stakeholder Relations (Elizabeth Ross, chair) and Resources (David Tremblay, chair). Delegates agreed to focus their energies on a 12-month collaborative advocacy effort, culminating in a second National Cancer Leadership Forum in December, 2004.

Following the forum, representatives from the Leadership Team met with Liberal MPs Carolyn Bennett (St. Paul's/Toronto) and Nick Discepola (Vaudreuil-Soulanges). As an indication of their strong commitment to advancing cancer control with the new government, the MPs committed to the following efforts, agreeing to try to:

- Have cancer identified in the throne speech
- Increase CSCC funding to \$3M for 2004
- Put the CSCC on the agenda of Federal/Provincial Task Force Health Ministers
- Create a higher profile for the CSCC within Health Canada

They have pledged to champion cancer control in caucus, and will actively support NCLF federal and provincial legislative forums for building awareness/support for cancer control among elected officials, the media and the public. They will also stand behind efforts to undertake a parliamentary and/or senate inquiry or hearings into cancer control.

Providing an efficient, compassionate, comprehensive cancer control system starts with the idea that every person in Canada has the right to timely, evidence-based care. The federal government must guarantee that right and provide the resources to ensure it. The NCLF is a call for focused political leadership in cancer control – for more money, better spent; resulting in more people being better served. It is also a call for more political courage: more advocacy, more lobbying and more lives saved. ●

“You seem to be following a strategy guided by an anxiety about making waves. It is your turn.... Something transforming occurs when people band together out of concern for those whose health is fragile, or to protect the environment or to seek redress for people denied justice. There is exhilaration in working for a uniting cause, and none of you want to miss an opportunity to experience the sheer joy of it.”

—A call to action from June Callwood, journalist, activist and NCLF keynote speaker

THE VIEW FROM INSIDE

What the experts are saying about Human Resources, Research, Compassionate Care, and Organizing Cancer Systems

The CACC approached some of Canada's leading experts to talk about developments in their fields. Andy Padmos provides an overview of cancer workforce shortages. Tony Miller looks at the future of cancer research. Zeev Rosberger argues for increased numbers of psychosocial professionals and improved integration of psychosocial services. Brent Schacter examines how cancer treatment is affected by the rising burden of cancer. Finally, Bill Evans explains recent changes at Cancer Care Ontario and the challenges faced by organized cancer agencies.

THE CANCER WORKFORCE IN CANADA

BY DR. ANDREW PADMOS

Between 2001 and 2015 the annual incidence of new cancer cases in Canada will increase by 70%. Serious and repetitive cancer workforce shortages limit cancer system capacity and sustainability, threatening patient safety, service quality, education programs and research. Many cancer programs in Canada operate with inadequate staffing in the face of relentlessly increasing caseloads, resulting in patient distress and staff demoralization. The inexorably rising cancer caseload is driven by an aging and growing population, expanded indications for treatment for increasingly prevalent cancer survivors, and the growing expectations of cancer patients and their families.

The Human Resources Policy Advisory Committee of the Canadian Association of Provincial Cancer Agencies and the Human Resources Action Group of the Canadian Strategy for Cancer Control operate together. Their initial approach included snapshot surveys of core job categories in Canadian Cancer Treatment Centres, including Medical Oncology, Radiation Oncology, Medical Physics and Radiation Therapy. Although the data from such surveys is of limited value, it confirmed that more than 10% of positions in the complements of these core disciplines are vacant, although the absolute number of positions has increased steadily with expansion and the opening of new cancer centres. The focus of the HR planning groups has now shifted to support the development of a robust HR Planning Information System (HRPIS) to provide a model that can forecast cancer HR requirements in terms of population needs, using data derived from provincial cancer registries. The HRPIS is now in pilot testing with data from several provinces.

Our present focus in the cancer workforce is on the creation of a National Cancer Workforce Strategy and Bureau to support and sustain the HRPIS. We feel that the cancer system is uniquely positioned and well resourced to develop and implement Canada's first model to forecast the future requirements of human resources based on population needs.

The work of the cancer HR Action Group is now channeled into four task forces:

- (1) To describe the nature and severity of cancer workforce shortages in Canada and to devise advocacy strategies to address them
- (2) To study and improve the supply of cancer health professionals from Canadian training programs and educational institutions
- (3) To compile and analyze information on staff planning ratios used in cancer treatment programs and to examine new models of service delivery

(4) To continue the development and pilot testing of a cancer HR Planning Information System based on population needs

The Cancer Human Resources Action Group has made application to Human Resources Development Canada and the F/P/T Advisory Committee on Health Delivery and Human Resources to conduct a labour market sector study on the cancer workforce in Canada. The object is to build a stronger platform for the further development of policy and programs in this vital area. ●

Andrew Padmos, BA, MD, FRCPC, is Chair, Human Resources Planning Advisory Committee for the Canadian Association of Provincial Cancer Agencies; Chair, Human Resources Action Group for the Canadian Strategy for Cancer Control; and Commissioner, Cancer Care Nova Scotia.

HOW INDIVIDUALS CAN ADVANCE CANADA'S RESEARCH AGENDA

BY DR. ANTHONY B. MILLER

To prevent cancer we need to know its causes, and to cure cancers we need good treatments. Cancer research is the process by which we acquire such knowledge. Research takes many forms, from the laboratory-based basic sciences through population-based epidemiology. The former has been responsible for our increasing understanding of the way cells become cancerous, the latter for identifying the association of smoking, diet, occupation and sunlight with cancer occurrence. Oncologists interested in improvements in cancer treatment evaluate new treatments in clinical trials; epidemiologists interested in early detection evaluate screening through screening trials.

Although relatively few cancers are inherited, the function of the genetic material in cells turns out to be intimately related to cancer occurrence. With the decoding of the human genome, many researchers are anticipating new ways to diagnose and treat cancer, and identify its causes. This has led to a flurry of new research discoveries, though few have so far made any immediate impact upon cancer management or the possibility of cure. However, new treatments are in the pipeline and some hold great promise.

Prevention is an under-explored domain that also holds promise in reducing the future burden of cancer. In the last two years international agreement has been reached that even moderate physical exercise and avoidance of obesity are protective for breast and col-

orectal cancer. Our knowledge of how dietary changes may protect against cancer is improving as results of a study of over 500,000 people in ten European countries are reported. Last year that study showed that high dietary fibre affords significant protection against colorectal cancer, and high fruit intake helps to protect against lung cancer (though it is far less important than not smoking). In addition, a Canadian-led clinical trial has shown that the drug letrozole helps to protect against recurrences of breast cancer post surgery.

We need to recognize, however, that the process of establishing the validity of promising research findings is relatively slow. For example, a blood test for prostate cancer (PSA) was introduced 20 years ago, but we still do not know if use of this test reduces prostate cancer deaths. Two large trials currently in progress may give us this answer, though we may have to wait five or more years before they report their results.

Two actions by individuals will further the effectiveness of the research agenda in Canada. First, if you have the opportunity to participate in a cancer research study, agree to do so. In the last two decades, thousands of Canadians have participated in such research. Second, support the efforts of Canadian researchers to maintain access to potentially sensitive data for research, with full preservation of confidentiality. Researchers are aware of the need for data protection, but without access to data currently stored in cancer registries, for example, our ability to learn the causes of cancer will be severely impaired. ●

Anthony Miller is Professor Emeritus, Department of Public Health Sciences, University of Toronto.

2003: THE YEAR IN PSYCHOSOCIAL ONCOLOGY

BY DR. ZEEV ROSBERGER

The psychosocial care of cancer patients and their families continues to rank low on the list of priorities of cancer care in Canada, despite evidence that quality of life is vital along the continuum of cancer care, from prevention to palliation. The data continue to show that 35% to 45% of cancer patients will experience significant distress requiring intervention.

Few cancer centres in Canada come close to providing adequate psychosocial care. These specialized services are not available in the community, and those that are available are private and not covered by provincial health plans. Without integrated psychosocial care we

cannot address the increasing prevalence of cancer.

A recent comprehensive review of cost-offset research studies by Linda Carlsen and Barry Bultz (*Psychology Exchange*, Fall 2002) concluded that investment in professional psychosocial services reduces distress, improves quality of life and reduces other medical costs by three to five times.

Clinical Services

Attempts continue to increase the number of psychosocial health professionals. The Standards published by the Canadian Association of Psychosocial Oncology (CAPO) have been useful in influencing policy-makers to increase the number of psychosocial professionals in some areas, however despite the evidence of benefit, less than 2% of operating costs of cancer centres is directed toward psychosocial care.

Often, the largely volunteer and non-professional support services supplied by various local, provincial and national agencies are cited as evidence for the adequacy of care. These services provide many important supports, but are unable to offer professional diagnostic and treatment services. Patients suffering significant levels of distress require the intervention of psychologists, psychiatrists, social workers and other licensed, trained psychosocial oncology specialists.

The Canadian Strategy for Cancer Control (CSCC) is an important initiative that needs immediate implementation. Its commitment to "rebalance focus" will promote a reorientation to comprehensive and integrated care, including psychosocial and supportive care services.

Research

The research climate has improved for psychosocial research. The Institute for Cancer Research of the Canadian Institutes of Health Research has made psychosocial and supportive care research (broadly defined under the name "palliative care") one of six priorities over the next few years. The Canadian Breast Cancer Research Alliance will focus on greater opportunities for psychosocial oncology research. The Sociobehavioural Cancer Research Network of the National Cancer Institute of Canada (NCIC) is looking for ways to improve the transfer of research findings to the clinic and community to provide a greater evidence base and accountability for psychosocial interventions. Other research initiatives include the Canadian Prostate Initiative. CAPO is assuming a larger advocacy role in many areas, with increasing visibility in organizations such as the Canadian Association of Provincial Cancer Agencies (CAPCA).

Summary

In advocating for improved care for patients and families, CAPO's greatest challenge remains the need for

increased professional psychosocial resources. The implementation of the CSCC will be a marker for these advances. Until then, however, advocacy groups need to focus and unite their energies to influence policy-makers to effect the integrated care that cancer patients and their families across Canada want and deserve. ●

Dr. Zeev Rosberger, PhD is President of the Canadian Association of Psychosocial Oncology, and Director and Associate Professor, Psychology Division, SMBD- Jewish General Hospital & Psychosocial Oncology Program, McGill University

TREATMENT CHALLENGES

BY DR. BRENT SCHACTER

Effective treatment is the cornerstone of cancer control. Approximately 52% of all 139,960 new cases of cancer in Canada in 2003 will be cured by treatment with surgery, radiation therapy, and chemotherapy/systemic therapy or a combination of those modalities of treatment. Cancer treatment also has a major impact on the burden of cancer by improving the quality of life and prolonging survival for those patients with incurable cancer.

There are some positive results to report: in men, the age-adjusted cancer mortality rate for all cancers combined has declined by 12% since 1988; amongst women, if lung cancer is excluded, there has been a 21% decline in mortality rates since 1974. However, primarily due to population growth and an aging population, the total number of new cancer cases and deaths in Canada continues to rise. Between 1990 and 2010, the number of new cancer cases occurring each year will have more than doubled, and it is estimated that by 2010 cancer will be the leading cause of death in Canada.

Cancer treatment in Canada is affected by the rising burden of cancer in a number of ways. In Manitoba, for example, the annual increase in cancer incidence (2.3%) has resulted in increases in new patient visits, (6.1%) treatment visits for systemic therapy (14.6%) and oncology drug costs (37.4%) larger since 1999. Similarly, Ontario reports that the use of systemic therapy for patients is increasing at an annual rate of 11%, much greater than the overall increase in cancer incidence

The impacts of the growing burden of cancer on treatment are also experienced with other modalities of care. The Canadian Association of Radiation Oncologists recommends that the average waiting time from referral to start of radiation therapy treatment should not exceed four weeks assessed comprehensively in Canada.

The Cancer Quality Council of Ontario Report for 2003 notes that access to radiation therapy in that province remains inadequate and inequitable among regions, because of increasing demands due to population growth, aging of the population and new indications. The median waiting time for radiation therapy at all Cancer Care Ontario sites has increased from five weeks to over seven weeks in the period 1992 – 2002.

The Department of Surgical Oncology at CancerCare Manitoba has compiled waiting times in 2003 from the date of decision to operate to the procedure date and has shown waits of from 30 days (melanoma) to 100 days (thyroid), with breast cancer and head and neck cancer at approximately 35 days. The targeted accepted standard for surgical waiting time is 14 days. Waiting times for cancer treatment vary from province to province, but it is clear that attention and resources need to be applied to this issue, which is destined to become worse as the burden of cancer inexorably increases with time.

The issues of access, drug costs and the need to increase training for human resource needs are all underlined by the increases in the number of cancer cases in Canada. It is abundantly clear that more attention to these needs is required, and that the Canadian Strategy for Cancer Control must be implemented to ensure the sustainability of the cancer treatment and cancer control systems in Canada. ●

Dr. Schacter, M.D., FRPCP is the Chief Executive Officer of the Canadian Association of Provincial Cancer Agencies (CAPCA), Chair of the Standards Action Group of the CSCC and Professor in the Department of Internal Medicine of the University of Manitoba.

CANCER CARE SYSTEMS: TRANSFORMATION AND TRANSPARENCY

BY DR. BILL EVANS

Cancer Care Ontario (CCO), an agency that is accountable to the provincial government, currently administers most of Ontario's cancer care. In the past year and a half, CCO has taken dramatic steps to address two key areas of concern for cancer patients: timely access to care and fragmentation of cancer services.

In October 2002, the provincial government announced the creation of the Cancer Quality Council of Ontario to ensure that quality of services remains high and continually improves. The Council monitors and assesses cancer system performance and drives improvements, working towards a co-ordinated,

patient focused and seamless care system.

The Council has undertaken three initiatives during its first year. First, it produced *Strengthening the Quality of Cancer Services in Ontario*, a book that documents strengths and areas for improvement, including the need for data to assess the performance of the cancer system in areas that were previously outside of CCO's mandate of operating cancer centres. Second, the Council hosted an event on colorectal cancer, which focused on the need to implement colorectal screening in Ontario. A third initiative in process is the development of a menu of system indicators that will allow the Quality Council to report publicly on the performance of the cancer system and the quality of care in Ontario. Among the proposed indicators are the proportion of cancer patients *staged*, consistency of practice relative to guideline recommendations, and waiting times.

Beginning in 2004, CCO will restructure its delivery of services, and Ontario's regional cancer centers will be managed as Integrated Cancer Programs of host hospitals. This step will overcome some of the difficulties faced by patients dealing with two separate organizations at one location. Through planning efforts now underway for the Greater Toronto Area and the province, a cancer plan will be presented to government covering the full spectrum of cancer services – from prevention and screening through diagnostics, treatment and supportive/palliative care.

CCO now posts wait times for radiation therapy on its website, presented according to disease site and treatment centre. This information may enable patients and providers to exercise choice in the location of care, particularly in southern Ontario, and could act as an incentive to providers to improve access to care, especially if wait times are excessive relative to other facilities in the province.

As other quality indicators are developed and reported, patients will see a more complete picture of cancer services available to them. At the same time, quality and performance indicators will help cancer system managers pinpoint areas that need increased resources or innovative approaches to service delivery. This focus on transparency, accountability and innovation will enable CCO to advance its vision of creating the best cancer system in the world. ●

Dr. W.K. (Bill) Evans, MD, FRCPC is Vice-Chair, Cancer Quality Council of Ontario and Chief Medical Officer of Cancer Care Ontario.

For a synopsis of *Strengthening the Quality of Cancer Services in Ontario* go to

http://www.cancercare.on.ca/pdf/Synopsis_CQCO_Report.pdf. The full document is available for \$49.95 from CHA Press, 17 York Street, Ottawa, Ontario, K1N 9J6.

Lung cancer kills more Canadians than any other cancer – more than breast, prostate and colorectal cancer combined. So where are the research projects, the diagnostic tools, the effective treatments, the screening and support programs?

LUNG CANCER

Who Cares?

BY COLLEEN SAVAGE

A cloud of silence hangs over lung cancer, even though one new case is diagnosed every 25 minutes and one patient dies every 28 minutes. Only 14% of lung cancer patients will survive five years, compared to 85% of breast cancer patients. The biggest cancer killer in the country – in the world, in fact – gets such a meagre share of research attention that the mortality rate has not changed for decades.

Where is the public outcry? Where are the runs for the cure (there isn't one), the exciting research developments and new treatments that will save lives (there aren't many), the effective screening programs (there are encouraging technologies, such as spiral CT, but they are not being evaluated in Canada) and the public-education programs to "talk to your doctor?" When will we have lung cancer month? Where are the patient advocates?

This year, the Cancer Advocacy Coalition of Canada (CACC) set out to take a closer look at the sorry state of lung cancer control in Canada. Here's the story.

SURVEY FINDINGS ON LUNG CANCER CONTROL IN CANADA

The CACC surveyed 19 Canadian cancer centres last year to get a sense of how the unique needs of lung cancer patients were handled. We found disturbing patterns of referrals, which indicate that many lung patients are dying without specialized care, treatment or diagnostic equipment, unable to take advantage of new treatment options or secondary prevention measures, and with a lack of support systems.

Failure to refer patients

Our survey uncovered low rates of referral (which means that few patients, upon diagnosis with lung cancer, are sent on to a cancer specialist or cancer

centre for more specialized care). Between 20% (Alberta) and 50% (Ontario) of newly diagnosed lung cancer patients are never referred to a cancer centre for treatment. While Ontario does provide cancer care outside the formal cancer system and the non-referral rates may be deceptively high, the rates for other provinces give testimony to the trend: 36% non-referral in British Columbia and Manitoba, 38% in Saskatchewan and 32% in Nova Scotia.

Lack of diagnostic equipment

Among the most effective procedures to determine whether lung cancer has spread, and whether surgery is appropriate, are pre-operative mediastinoscopy and PET scanning, but neither one is in widespread use in Canada. As a result, up to 50% of surgical attempts to cure lung cancer may be found to have been futile after the fact, due to the finding on the operating table that the cancer has spread. In those cases, the surgery can cause unnecessary morbidity and preclude the use of a life-prolonging combination of chemotherapy with radiotherapy.

At the time of the survey, only five PET scanners were available in Canada for diagnosis of any type of cancer. Private PET scanners have been available in Canada but were recently shut down because of failure to obtain appropriate federal approvals. PET scanners slated for installation at Ontario cancer clinics will be dedicated to research, like most of this equipment across the country, so a patient who is not in a clinical trial will not have access. Quebec is the only province in Canada to have decided (in December 2003) that PET scans will be publicly funded and available as an insured service.

By contrast, the US Federal Health Care Financing Agency approved funding for routine use of PET scanning in eight different situations for a variety of different types of cancer, and the first approved use, in 1995, was for pre-operative assessment of lung cancer patients. France has 47 PET scanners and has purchased

another 13. Belgium has 22, Germany has 100 and Turkey has 11.

No adjuvant chemotherapy

In no centre was adjuvant chemotherapy the standard of care, despite the report from the American Society of Clinical Oncologists (ASCO) plenary session in April 2003 that this form of treatment had a modest but definite benefit in prolonging the survival of selected patients after they had surgery for localized disease (see News section). There are no guidelines in place among Canadian cancer centres to adopt this approach as standard treatment although guideline review is underway in Ontario and Nova Scotia.

Lack of smoking-cessation programs

Of the 19 Canadian cancer centres we surveyed, only four had in-house smoking-cessation programs. This, despite evidence that fully 20% of recurrences of aerodigestive cancers are due to second primaries rather than a recurrence of the original tumour, and that continuing to smoke during therapy interferes with the effectiveness of treatment.

Lack of psycho-social support

Only two centres had a lung cancer support group, even though the incidence of depression in lung cancer patients is higher than in patients with other cancers.

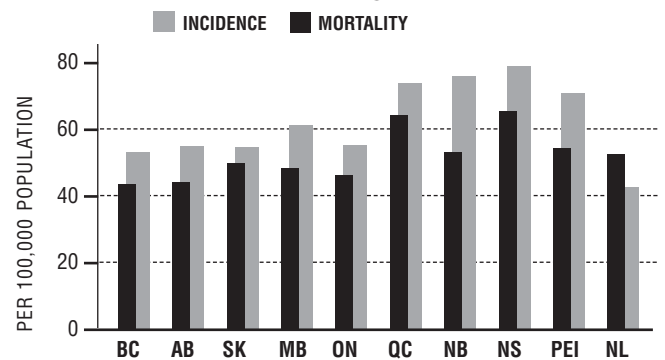
Lung cancer incidence and mortality across Canada

Across Canada, cancer incidence and mortality are lowest in the west and highest in the east. This is especially true for lung cancer, as shown in Figure 6. Because the lung cancer death rate is so high, lifestyle choices and socio-economic status are commonly given as explanations for the east-west gradient in overall cancer death rates.

As a correlate of lower SES there is a higher rate of smoking and therefore a higher rate of lung cancer. Because the lung cancer incidence rate is so high in eastern Canada, this was given as an explanation for the east-west gradient in overall cancer death rates.

It seemed to us too facile a story. The lung cancer gradient is nowhere near as well defined as the gradient for overall cancer mortality and, as shown elsewhere, that gradient exists whether or not you include lung cancer. In fact, our research suggests that the gradient for overall cancer mortality may be predominantly due to differences in the effectiveness of overall cancer control. If so, could this also be true for lung cancer? To address this we looked more closely at data from Ontario, a province with the lowest mortality rate from lung cancer and one of the highest levels of socio-economic status.

FIGURE 6: **INCIDENCE AND MORTALITY OF LUNG CANCER, 1999**
Both sexes combined, All Ages



Lung cancer survival in Ontario

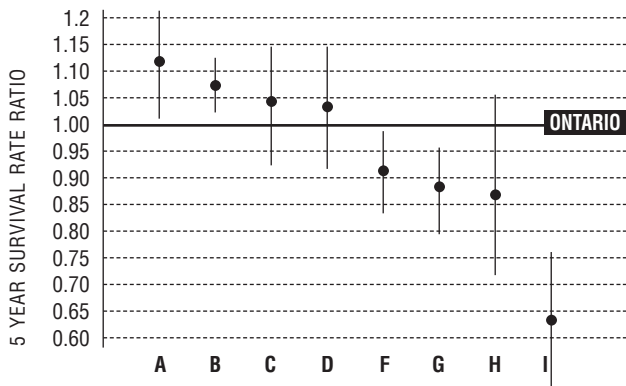
While mortality figures give an overall picture, survival after diagnosis may reflect the stage distribution at presentation and, when stage distributions are comparable, the effectiveness of medical management. With the assistance of Cancer Care Ontario investigators, we examined survival after diagnosis for lung cancer patients from Ontario's eight cancer planning regions, each of which is served by at least one regional cancer centre.

We analyzed five-year survival for the cohorts diagnosed from 1983 to 1987 and from 1993 to 1997. We also examined two-year survival for the cohort diagnosed from 1997 to 1999. Survival for each cohort in each region was expressed as a ratio compared to that of the whole province, taken as 1.00.

The results were identical for all three cohorts: survival of patients depended on which planning region they came from. The same planning regions consistently had the best or worst results, and differences were significant. The following chart shows data for the 1993–97 cohort. Patients in planning region A had a significantly higher five-year survival rate than those in planning region I. Survival of patients from planning regions F and G was consistently in between the best and the worst and did not overlap with the rates from either. We found only minor differences in referral of patients to the cancer centres serving these regions, so that referral patterns could not explain the findings.

Differences in survival of this magnitude deserve further investigation, especially when they occur among planning regions within the same provincial system and with the same treatment guidelines. The causes could include differences in stage at presentation, socio-economic status, and the degree of adherence to clinical-practice guidelines. If the differences were due to variations in practice, individual patients could be so informed and advised accordingly. As well, changes in medical management could be promoted to ensure best practice.

FIGURE 7: FIVE YEAR SURVIVAL IN ONTARIO
Following Diagnosis of Lung Cancer by Ontario Planning Region For Males and Females, 1993–97



(Survival Rate Ratio is the ratio of the five year survival rate for each region divided by the five year survival rate of Ontario)

Prevention ... and nothing else?

So what is being done to prevent lung cancer across the country? To their credit, governments and the Canadian Cancer Society spend millions of dollars on anti-smoking advertising and smoking-cessation campaigns, resulting in adults quitting in record numbers. However, the campaigns are having little effect on teenagers, although the recent provincial co-ordination of higher cigarette prices may be a catalyst in achieving this goal.

Smoking-cessation programs may be our best hope down the road, especially those targeting the 20-to-30-year-old age group, but there's a substantial lag before smoking reduction will have any impact on lung cancer incidence. Even if everyone in the country quit smoking right now, we would still have overwhelming numbers of new cases and deaths for 20 years.

Prevention is the best strategy for controlling lung cancer. But can you name one other cancer where prevention is almost the *only* strategy? Where research and support for screening, improved diagnostics and better treatments, are so often considered a waste of time and money? Across the country prevention means trying to eliminate tobacco use, with the one exception of British Columbia, where an innovative trial is underway to determine whether green tea helps former smokers prevent lung cancer.

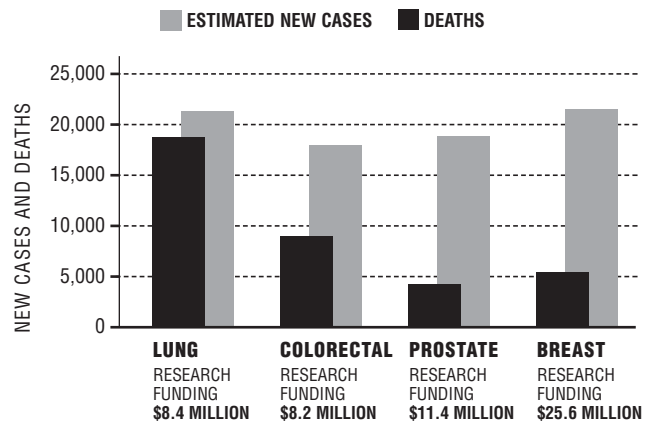
Lung cancer research disproportionately meagre

In cancer research generally, the more we invest in research, the lower the mortality rate for any given disease. Research also produces better screening and diagnostic techniques, along with an arsenal of treatment choices. The National Cancer Institute of Canada (NCIC) is the main source of cancer research funding in Canada, using donations made to the Canadian Cancer Society and the Terry Fox

Foundation. The distribution of NCIC research dollars in 2003 demonstrates the relationship between commitment to research and the associated survival benefit to patients with each of the major cancers, as depicted in Figure 8. The biggest killer, lung cancer, receives a disproportionately small share of research funding.

The low level of research activity in lung cancer is another indicator of the lack of interest that pervades Canadian society. It shows that the researchers are either not interested or know they have a better chance for funding if they study other types of cancer. But it also shows the power of patient advocates: the breast cancer movement has had a profound influence on public and political support, generating more media attention, more money and more research. And better survival. This country does not have one single fundraising event for research into lung cancer.

FIGURE 8: MAJOR CANCER KILLERS, 2003



How lung cancer measures up to other cancers: a comparison of new cases, deaths and relative research funding. NCIC-funded research is disproportionately low for lung cancer as compared to the other major cancer sites.

Lung specialists agree with us

We were invited to present our survey data as a scientific paper at the World Conference on Lung Cancer in Vancouver last year. At that conference, 205 lung specialists from 35 countries were surveyed by the Global Lung Cancer Coalition. Their insights provide useful milestones for lung cancer advocacy, including increased government funding, the creation of evidence-based guidelines, and increased research into effective detection. Their comments are represented here:

- More than three-quarters felt that lung cancer currently receives less government funding than other common cancers.

- A similar proportion thought that governments allocate more funding to diseases less serious than lung cancer.
- Nearly three-quarters felt that fear of receiving a diagnosis of lung cancer caused many people to delay seeing their doctor.
- Two-thirds believed that removing the stigma would encourage people to seek help earlier.
- Nearly nine in ten maintained that evidence-based guidelines would enhance the quality of care in lung cancer. (There are currently no internationally agreed guidelines for the diagnosis and treatment of lung cancer, which is not the case with many other diseases).
- When asked what could be done to improve survival in lung cancer patients, the first choice was more research into effective detection, followed closely by more government funding of effective lung cancer treatments.

Nobody deserves to die of lung cancer

In successfully stigmatizing tobacco use, governments have simultaneously stigmatized lung cancer and the lung cancer patient. Nihilism permeates any discussion about lung cancer. The resulting scarcity of research, diagnostic tools, screening and early diagnosis, support programs and effective treatments is grossly out of balance with the magnitude of the disease. While physicians wait for a patient advocacy movement to make a difference, patients hide and die because the stigma surrounding lung cancer and smoking shames people into isolation and denial.

Because of lung cancer's high mortality rate, there are few survivors to advocate for more attention. Since there is also a common perception that they have brought their untimely end upon themselves, relatives and friends may be unwilling to advocate their cause. The presumption of death following a diagnosis of lung cancer has also fostered an environment of therapeutic nihilism and neglect among physicians, governments and researchers.

Twenty years ago it was rude to say the word "breast" in public; today it is socially unacceptable to get lung cancer. Is it any wonder that millions of former smokers in this country are unaware of their risk for lung cancer, doing nothing to advocate for screening and diagnostic tests? Without any of these voices, few get around to thinking about lung cancer.

We know that advocacy makes a difference. What we don't know is where to find advocates. As the relatives of lung cancer victims will attest, no one deserves to die of lung cancer. Perhaps the same relatives, touched by lung cancer, can help. Let's start there. ●

LUNG CANCER FACTS

More than half (51%) of Canadians over the age of 45 are smokers or former smokers: 5,771,160 people. As many as one in seven (14%) will be diagnosed with lung cancer in the next decade, according to a study conducted at Memorial Sloan-Kettering Cancer Centre and published in the *Journal of the National Cancer Institute* last year. That could mean up to 807,962 new cases of lung cancer in Canada within a decade (and remember, these figures exclude lung cancers from second-hand smoke, airborne pollutants and exposure to asbestos).

In fact, Canada's baby-boomer generation will be particularly hard hit by the long-term risk caused by early smoking habits. In 1965 when most of them were in high school or college, 55% of males and 37% of females between the ages of 15 and 19 were smoking. In the same year, 69% of men and 50% of women between the ages of 20 and 24 smoked. Thirty years later, those youthful decisions had been revisited, and just under half had quit smoking. In 1995, for the age group 45 to 54, 25% of men and 24% of women were still smoking.

Lung cancer in women has more than quadrupled in the last 25 years and it now kills more women than breast cancer. And according to a recent US study, female smokers are *twice as likely* to develop lung cancer as their male counterparts.

NEWS

LUNG CANCER

Lung Cancer: Adjuvant chemo after surgery shows improved survival

A large international randomized study showed that adjuvant chemotherapy after surgery improved survival in patients with early-stage lung cancer. The degree of improvement was modest but at a sufficient level to warrant a change in practice in some cases.

BREAST CANCER

Breast cancer treatment significantly reduces likelihood of recurrence

Results of a large international trial indicate that letrozole improved disease-free survival when given to post-menopausal women who had completed five years of adjuvant tamoxifen. The improvement was so striking that the monitoring committee halted the trial to allow women in the placebo group to access the new treatment. Breast cancer patients (except those who are pre-menopausal) completing adjuvant tamoxifen should consult with their oncologists to see if they are eligible for the additional protection afforded by letrozole.

MRI recommended for high-risk breast cancer patients undergoing surgery

MRI has been shown to be more sensitive and specific than mammography for detecting early breast cancer. It is recommended that woman at very high risk (e.g. BRCA-positive) about to undergo surgery for breast cancer, should

first have an MRI of the other breast to rule out the possibility of undetected bilateral disease.

Jury still out on high-dose chemo with stem-cell rescue

Two reports in the prestigious *New England Journal of Medicine* regarding the results of high-dose chemotherapy with stem-cell (bone marrow) rescue for early breast cancer came to differing conclusions regarding the utility of this approach. The benefit of this treatment remains to be elucidated, particularly in women under the age of 50 who have many positive lymph nodes.

Dose-intensive adjuvant chemo regime shows better results

Adjuvant chemotherapy given every two weeks produced better survival than the same treatments administered every three weeks, with no increased toxicity observed as a side effect, according to the results of a recent study.

COLON CANCER

New application of therapy promising for colon cancer, caught in Catch-22

Good news and bad news in colon cancer, a disease for which the number of effective treatments is very limited. Oxaliplatin has been proven effective in treating colorectal cancer; however it has not been filed with Health Canada and cannot be marketed here. Canada does not acknowledge the manufacturer's intellectual property rights and the company won't file until that protection is in place, as it is in the

US and Europe. The drug is available through Health Canada's Special Access Program and covered by a number of provinces. Patient access is more difficult in Ontario and Alberta, where the provincial cancer boards will not reimburse the drug in the absence of a Notice of Compliance (NOC) from Health Canada. The manufacturer, Sanofi-Synthelabo Canada, is providing compassionate assistance to those patients, who can call: 1-866-356-9284 for details.

PROSTATE CANCER

Targeted radiation reduces side effects of prostate treatment

Prostate cancer patients should be aware of two important advances in radiation treatment of prostate cancer: conformal photon therapy and brachytherapy. As these techniques have been known for some time to reduce side effects of radiation therapy administered with the intention to cure prostate cancer, patients should ensure that their oncologists discuss these options even if they aren't able to deliver them in their centres. Conformal photon therapy uses CT scanning to carefully guide the external radiation beam to its target, while brachytherapy involves radioactive seeds implanted directly into the tumorous prostate gland.

CANCER SERVICES

More concerns over changes at Ontario's cancer agency

Cancer Care Ontario has relegated

control of Ontario's large cancer centres to their respective host hospitals, abandoning its management of direct patient services. The rationale for devolution cites the potential for more appropriate and effective regional decision-making. However, the cancer clinics are now grafted to the deficit-ridden Ontario hospital system, which could mean sharing in the persistent cost-cuts and service constraints required of all hospitals over the past several years.

Candid CCO report finds lengthening waits, lack of support, dramatic variations in treatment

To its credit, the Quality Council of Cancer Care Ontario recently published a report on the deteriorating performance of Ontario cancer services. The report was objective, comprehensive and generally critical of the province's ability to ensure timely, effective care, even though the authors were evaluating the performance of their own organization. (See *Strengthening the Quality of Cancer Services in Ontario*, at www.cancercare.on.ca for details.) The report could set the standard for evaluating other provincial cancer programs and serve as an instrument for improving government support and agency performance.

PALLIATIVE TREATMENT Surgery better than radiation for palliative patients with spinal cord compression

A recent study of patients with impending spinal cord compression

due to skeletal metastases showed that emergency surgery using a special approach and technique (anterior vertebral body resection) is better than radiation treatment in relieving pressure and preventing the devastating and permanent complications of paraplegia, immobility and incontinence. Those undergoing surgery had much better quality of life compared to the group receiving only radiation.

PREVENTION BC study looks at preventive capabilities of green tea

The BC Cancer Agency continues to lead the way in exploring the potential of alternative medicine, this time with the world's first scientific lung cancer prevention study using green tea. The prevention trial is recruiting former smokers, a group still at risk for lung cancer long after they have quit. Green tea's cancer prevention potential has been the focus of speculation for some time, however this is one of the first studies to bring eastern medicine into a western, evidence-based evaluation model. The study, open to volunteers from across BC, is part of a large lung cancer prevention study funded by the US National Cancer Institute. For information call 604.877.6190 (lower mainland) or 1.800.663.3333 x6190 (out of town).

Obesity linked to higher cancer risk

The *New England Journal of Medicine* recently reported that obesity is clearly associated with an increased

risk of death from cancer of the esophagus, colon, rectum, liver, gallbladder, pancreas, kidney, non-Hodgkin's lymphoma and multiple myeloma. In men, the risk increases for prostate and stomach cancer; in women for cancer of the breast, uterus, cervix and ovary. The authors conclude that current patterns of overweight and obesity in the United States could account for 14% of all deaths from cancer in men and 20% of those in women.

Nutrition, exercise and cancer

Patients can access three excellent articles – including an editorial, the “American Cancer Society Guide for Physical Activity and Nutrition,” and “Answers to Questions Often Asked by Cancer Survivors About Nutrition and Physical Activity” – by visiting the *CA Cancer Journal for Physicians* online at <http://caonline.amcancer.org/content/vol53/issue5/index.shtml>. The ACS guide is a comprehensive and thoughtful resource from an established agency that addresses lifestyle issues for cancer survivors (by selected cancer sites), despite the limited evidence available at this time.

Leadership in prevention

Ontario is showing leadership in strengthening cancer prevention efforts. Cancer Care Ontario has issued a comprehensive target list for preventing cancer and has appointed Dr Terry Sullivan, previous head of CCO's Cancer Prevention programs, as Director of Research for all programs.

ADVOCACY FOR CANADIANS

WHAT CAN ANYONE DO TO CHANGE THESE NUMBERS?

CACC believes in advocacy – to speak freely and openly about the issues, to highlight the concerns of patients and families, and to press governments for a more effective response to the enormity of cancer in Canada. This is a unique position. All of the cancer agencies and most of the associations in this country are constrained in their public activities; the former because they are government employees, the latter because their charitable status limits the amount of permissible advocacy.

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.

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.

CURRENT STATISTICS

Right now more than 710,000 Canadians are living with cancer: 312,280 men and 398,350 women

- Canada had an estimated 139,900 new cases of cancer and 67,400 deaths from cancer in 2003.
- Men have a 41% lifetime probability of developing cancer.
- Women have a 38% lifetime probability of developing cancer.
- One in four Canadians will die of cancer.

In 1999 cancer was the leading cause of premature death (Potential Years of Life Lost) for men and women: 932,000 potential years were lost as a result of cancer representing 31% of the PYLL from all causes of death.

THE COST OF CANCER

Health Canada produces reports on the economic burden of illness. Mortality costs represent the dollar value of lost production due to premature mortality.

- In 1998, the last year for which figures are available, the mortality cost of cancer to Canada was \$10.6 billion. In the same year, the cost of hospital care for cancer in Canada was \$1.8 billion.
- Among children and youth aged 0-19, cancer ranked as the sixth leading cause of PYLL after perinatal causes, congenital anomalies, motor vehicle accidents, other accidents and suicide. The total PYLL due to cancer deaths among Canadian children and youth (ages 0-19) in 1999 was 15,000 years.

SURVIVAL

- About a third of the women who develop breast cancer, and the men who develop prostate cancer, will die from it.
- Slightly more than half of the men or women who develop colorectal cancer will die from it.
- Nine out of ten people diagnosed with lung cancer will die from it.
- Overall the ratio of deaths to new cases is 48%, slightly higher in males than in females.

CANCER ADVOCACY COALITION OF CANADA

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

For further information please call our toll-free information line at 1-877-472-3436

e-mail us at canceradvocacy@on.aibn.com

or visit our web site at www.canceradvocacycoalition.com