Are you ready?

Canadians take comfort in the belief that our public healthcare system will be there in our time of need, but long before the current economic woes, governments began to retreat from payment of cancer drugs. More and more of us have to rely on private insurance plans to cover the cost of expensive, potentially life-saving treatments. The trend has taken hold of half the country and will increase, as newer drugs come in oral form and appear on the market in waves. While a pill is more convenient for the patient than infusion at a clinic, the cost for those “take at home” treatments are increasingly borne by private insurers or, in the absence of insurance, at great expense to the patient.

Can employers and citizens absorb the offloading by our governments? The answer is, it depends. Your eligibility for private insurance, the type of plan you have and how your insurer feels about paying for clinic infusions will directly impact your finances after a cancer diagnosis.

Canadians might wonder if this is fair. Where did medicare go? The rules are set out in the Canada Health Act, but lacking a definition of “medically necessary”, the provinces seem free to offload “out-patient” drug costs as they choose.
About the Cancer Advocacy Coalition of Canada

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

Our Vision for the Cancer System

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

Our Goals: to benefit cancer survivors and all Canadians

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

For years it has been known there is a west-east gradient in cancer mortality in Canada. In the last 10 issues of this Report Card we have documented the reasons for this gradient. Let us review the facts and factors that led to them, and consider what fixes might be needed.

The differences are almost perfectly correlated with the degree of provincial government funding for cancer control programs in each province. Cancer mortality is lowest in British Columbia and increases steadily as you go east. Coincidentally, the more money spent by each province, the lower the cancer mortality (Report Cards 2003, 2004).

Waiting times for treatment vary between and within provinces (Report Cards 2004, 2005), with delays reaching medically dangerous levels in some instances (Rayson, Report Card 2005). Repeated efforts to get pan-Canadian agreement on standard definitions of a waiting time have failed.

Public funding for cancer drugs is almost three-fold greater in the west and conversely, private expenditure is almost seven-fold greater in the Atlantic Provinces (Report Cards 2005–2008). As revealed in this issue, the off-loading of drug costs from public insurance to private insurance is increasing, particularly for take home cancer drugs. If this trend continues at its current rate the private sector will be paying more than the public sector across the entire country.

Medical guidelines for drug treatment vary greatly between provinces despite the fact they are based on the same scientific information. Some provinces do not even publish guidelines, while others perennially state theirs are in development (Report Card 2004). As a result, the standard of care varies. In this issue we examine the fact that medically necessary insured services in one province can be deemed not medically necessary in another. Canadian courts have protected the right of provinces to make such decisions.

Deployment of modern technology varies: access to PET scanning, an important diagnostic technique, differs among provinces by a factor of five- to 30-fold (Report Card 2006). We suspect this variation also extends to other modern diagnostic technology, e.g., digital mammography.

Of particular importance in optimizing cancer care delivery is the availability of accurate and timely information through use of electronic health records connecting distant communities to their regional cancer centres. This too is highly variable. In only three of the eight provinces surveyed this year were acceptable standards met for linking the sampled communities, and in four provinces the sampled communities had no electronic linkage at all.

As for prevention, the record is not much better. Consider how the new vaccine against cervical cancer has been deployed: the province with historically the lowest incidence of cervical cancer has introduced the highest vaccination rate, while the province with the highest cervical cancer incidence has one of the lowest rates of vaccination (Report Card 2008). Deployment of screening mammography, proven more than 20 years ago to reduce breast cancer mortality, still varies greatly: the percentage of the target population screened can vary two-fold from one province to another. No province reaches the target 75 per cent level (Report Card 2006).

These discrepancies between provincial efforts at cancer control probably explain why cancer mortality is not dropping in Canada compared to other jurisdictions.

Why are western provinces capable of better cancer control? Or to rephrase: why do western provinces devote more effort (money) to cancer control? We think the answer is in large part because they have better organization, and have established a different set of priorities. We also wonder if they have had leaders with different skill sets than those in the eastern provinces.

Regarding the importance of organization one has only to look at cancer mortality in provinces that have historically lacked a provincial cancer agency: PEI, New Brunswick, and Quebec. Their cancer mortality has been consistently well above the Canadian average (Report Cards 2003, 2004). In contrast, provinces with the best results have been served by organized cancer agencies with a combination of central funding, cancer centres juxtaposed to academic centres, and well developed networks of community clinics. Unfortunately the recent trend has been to reduce or dismantle these organized cancer agencies in the interests of reorganizing to achieve higher (nebulous) health system goals. This has already occurred in four provinces, including two in the west. One can predict that cancer control in those provinces may either stop improving, or worse, will begin to deteriorate.
The adverse effects of competing priorities can be seen resulting from competing interests in provincial politics, different cancer delivery systems vying for resources within the same province, vagaries accompanying governance of large populations, or the desire to meet societal needs more fundamental than cancer control.

As for leadership, the issues are more complex. This could be investigated as a possible factor determining the effectiveness of cancer control in the various provinces. Particular attention would then have to be paid to the process of selection of cancer agency heads and cancer centre directors.

The matter is urgent. Cancer will be the number one cause of death within three years. What fixes are required to ensure that Canadians have an equal chance of surviving this disease?

Firstly, organization of cancer control should not be subjugated to a preponderance of bureaucratic or ill-conceived considerations. Governmental deconstruction of cancer agencies or their relegation to lesser status should not be allowed to continue.

Secondly, forceful and concerted advocacy is required to elevate cancer control to higher government priority. Existing cancer organizations must ramp up their advocacy efforts. Charitable organizations must not continue to let government surveillance of their budgets, limiting them to 10 per cent for advocacy, in effect completely prevent their advocacy efforts. The media has a critical role to play but they can only be as effective as the information they receive, and only then when deterioration has reached near-crisis proportions.

As we discuss on the back page of this issue of the Report Card, doctors should take up their societal responsibility. So far, medical oncologists have not collectively voiced their concern on behalf of their patients in an attempt to improve access to the new blockbuster drugs. Instead, they remain publicly silent, while privately admitting they are delivering suboptimal treatment.

What was the good news?

Provincial health ministers are attempting to constructively address the process of drug approval and funding. This is ongoing under the watchful eyes of advocacy groups.

Most importantly has been the creation of the Canadian Partnership Against Cancer (CPAC). CACC proposed and advocated strongly for the creation of a national cancer control body functioning at arm’s length from other government health agencies. CPAC was a result of these initiatives. We look to CPAC to facilitate achievement of high standards for cancer control.

The bioresearch establishment continues to produce major technical advances. That’s good. However, we are coming to the conclusion that the production rate of these new technologies and treatments has outstripped the capacity of the public system to absorb them; provincial health insurance systems can never completely cover the cost of new cancer drugs. Public and private insurance systems must therefore address the risk to the individual patient in a coordinated fashion rather than allowing continuation of the present disconnected mode. Quebec has required for some years that all individuals must have supplementary private drug insurance.

We have been advocating for a national forum to determine the means by which provincial disparities in access to treatment could be remedied, and have garnered the support of federal and provincial ministers and politicians for this idea. As a result, the Provincial and Territorial Health Ministers proposed that “Beginning in 2009, ministers will host a series of forums with governments, experts and stakeholders to advance collaborative work towards a sustainable health system that delivers excellent care at affordable cost.” We will press this initiative.

In the end, it will be the Canadian public that must demand inter-provincial disparities be minimized and high standards of care be provided to all Canadians. In this issue of the Report Card we propose that cancer patients have complete access to their own health record in electronic form. They can then determine if they are getting the right treatment from the right health professional at the right time. If they find they are not, some will be motivated to take matters into their own hands and advocate for change.

James D. Gowing, Chair, CACC
William Hryniuk, past Chair
TRIBUTE

James L. Connors, QC

December 8, 1955 – April 3, 2008

Look at that smile. Here is a man fully aware of the many blessings in his life and deeply grateful for every one of them: the happy family, a successful and satisfying career in law, a man loved by and committed to his community.

He golfed, he sailed, he traveled, he appeared before the Supreme Court of Canada and won his case, which is why we have TV cameras in our legislatures, by the way. Jim and his partner, opposite more than 40 lawyers from half a dozen provinces and the feds. It was a good day in the life of Jim Connors. Afterward, his innate humility would only let him say that he took the case, the hopeless, politically unpopular case, because “it just wasn’t right” to deny citizens a chance to watch their government at work.

Jim gave himself to civic duty, offering countless hours of service to innumerable community organizations. The litany of accomplishments could inflate a man of lesser virtue to unbecoming pride. But Jim told his friends that his dearly beloved wife Cathy was really the smart one. He was a devoted father to Paul, Lauren and Patrick, giving them a legacy of intelligence, humour and compassion.

How evil is cancer. Barely 50 years old, this champion of good was ambushed by a disease and a health system that he described as “the best of care and the worst of care”.

Jim reminds us how many cancer advocates evolve. He spent a lifetime fixing a wrong, working for a cause, helping the vulnerable. When Jim found that the Nova Scotia health system was unwilling to pay for his cancer drug, he worried about the other colorectal cancer patients in the province. He could pay for his treatments and he did, but what would become of the others? That question drove him to a new cause and to us.

Imagine Jim, past President of the Nova Scotia Conservative Party, dropping in on his old pal, the Minister of Health, to talk about the wicked perfidy of withholding drugs from cancer patients. But it didn’t work. Not until shortly after Jim Connors died did the Nova Scotia government decide to pay for the drug. Perhaps that reversal indicates remorse or respect – perhaps it was an effort to relieve the pain of waiting too long to do the right thing.

Cancer is everywhere; everybody knows this grief. We were fortunate to have Jim as a member of the Board and we honour his memory by persevering with compassion, integrity and knowledge.
**HPV Vaccination Programs in Canada**

**ARE WE HITTING THE MARK?**

ROSEMARY COLUCCI, WILLIAM HRYNIUK, COLLEEN SAVAGE

**Introduction**

In 2007 the federal government allocated $300 million over three years to the provinces and territories on a per capita basis to support the launch of a national vaccination program against human papillomavirus (HPV), the putative cause of cervical cancer. All of the provinces as well as the Yukon Territory responded by introducing vaccination programs targeting various cohorts of females between the ages of 9 and 17.

This article i) compares how each province and territory has designed their HPV vaccination program in response to this federal allocation, ii) reviews cost implications, with preliminary comments on cost effectiveness, and iii) explores possible future applications of HPV vaccines in preventing other HPV-related diseases.

**Background**

In July 2006, Health Canada approved a quadrivalent vaccine that protects against infection with two high-risk types of HPV (16 and 18) and two low-risk types (6 and 11). A second vaccine that protects against HPV 16 and 18 has been submitted to Health Canada and is awaiting approval, and therefore is not included in this article. HPV types 16 and 18 cause approximately 70 per cent of cervical cancers, while HPV types 6 and 11 cause approximately 90 per cent of ano-genital warts. The quadrivalent vaccine is very effective in preventing HPV infection and the associated pre-invasive changes in the cells of the cervix.\(^1\) It is assumed that, as a result, invasive cancer of the cervix will also be prevented.

The development of the vaccine to help prevent cervical cancer demonstrates how basic research can make a difference. Dr. Harald zur Hausen was recently awarded the 2008 Nobel Prize in Medicine for finding there are multiple HPV genotypes, for molecularly cloning HPV 16 and 18, and for demonstrating that HPV DNA is present in a majority of cervical cancers. He was able to implicate HPV 16 and 18 as the principal viral oncogenes and suggested their continued expression con-

---

**TABLE 1** Recommendations by the National Advisory Committee on Immunization (abridged)\(^1\)

**Females 9-13**

Recommended – before the onset of sexual intercourse, efficacy would be the greatest.

**Females 14-26**

Recommended—even if they are already sexually active, may not yet have been infected and very unlikely to have been infected with all four HPV types.

**Females 14-26 who have had HPV infection, cervical cancer, or genital warts.**

Recommended—these women are unlikely to have been infected with all four HPV types.

**Females > 26**

No recommendation at this time. Studies are ongoing. Can be considered on an individual basis.

**Females < 9**

Not recommended.

**Males**

Not recommended at this time. Immunogenicity data are available but the efficacy of this vaccine is as yet unknown.

**Immunocompromised persons**

Can be administered to persons who are immuno suppressed as a result of disease or medications; however, the immunogenicity and efficacy in this population are not known. Immune response to the vaccine might be less than that in persons who are immunocompetent.

**Pregnancy**

Not recommended. Data limited. If a woman is found to be pregnant after initiating the vaccination series, completion of three-dose regimen should be delayed until after pregnancy.
tributed to the tumorigenic phenotype. Earlier this year, he was also awarded the Canadian Gairdner Award in recognition of his work.

**Current Recommendations for the Vaccine**

The vaccine is given as three separate 0.5 mL doses, using a zero, two and six month schedule. The minimum interval between the first and second dose is one month.¹

**Provincial Vaccination Programs**

Table 2 summarizes the provincial vaccination programs. It includes the year the program started, the ongoing female cohort immunized, and the short-term catch-up of female cohorts (if any). In all provinces and one territory, the HPV vaccination program offers free HPV vaccine to all females in at least one of grades 4 to 9 through school-based clinics administered by local public health units.

Newfoundland and Labrador, Prince Edward Island, Nova Scotia and Ontario implemented an HPV vaccination program in September 2007, each targeting one age group of pre-adolescent females. In 2008, Newfoundland and Labrador increased their program to include a second cohort in grade 9. The remaining six provinces and the Yukon Territory commenced their programs in the 2008-09 school year.

As can be seen in the table, the dissemination of the vaccine by age and grade varies widely across the provinces. Quebec, with the most comprehensive program, started vaccinating girls in grades 4 and 9 as of September 2008. Girls up to the age of 18 can also be vaccinated upon request. If the girl is under 14, her parents will have to sign a consent form.

Prince Edward Island, Nova Scotia, Ontario and Manitoba have the most restrictive programs, vaccinating only one grade of girls but Prince Edward Island, Nova Scotia and Ontario initiated their program one year earlier in 2007 thus capturing an additional age group of girls.

**Table 2 Provincial and Territorial HPV Vaccination Programs**

<table>
<thead>
<tr>
<th>Provl</th>
<th>Year Implemented</th>
<th>On-going Female Cohort Immunized</th>
<th>Short-term Catch-Up of Female Cohorts</th>
</tr>
</thead>
<tbody>
<tr>
<td>NL</td>
<td>2007-08</td>
<td>Grade 6</td>
<td>Grade 9, 2008-10</td>
</tr>
<tr>
<td>PEI</td>
<td>2007-08</td>
<td>Grade 6</td>
<td></td>
</tr>
<tr>
<td>NS</td>
<td>2007-08</td>
<td>Grade 7</td>
<td></td>
</tr>
<tr>
<td>ON</td>
<td>2007-08</td>
<td>Grade 8</td>
<td></td>
</tr>
<tr>
<td>NB</td>
<td>2008-09</td>
<td>Grade 7</td>
<td>Grade 8, 2008-09</td>
</tr>
<tr>
<td>PQ</td>
<td>2008-09</td>
<td>Grade 4 – receive 2 doses and a third dose in Grade 9</td>
<td>Grade 9 catch-up (receive all three doses) Under 18 may also receive free vaccine from their doctor</td>
</tr>
<tr>
<td>MB</td>
<td>2008-09</td>
<td>Grade 6</td>
<td>Grade 7, 2008-09</td>
</tr>
<tr>
<td>SA</td>
<td>2008-09</td>
<td>Grade 6</td>
<td></td>
</tr>
<tr>
<td>AB</td>
<td>2008-09</td>
<td>Grade 5</td>
<td>Grade 9, 2009-12</td>
</tr>
<tr>
<td>BC</td>
<td>2008-09</td>
<td>Grade 6</td>
<td>Grade 9</td>
</tr>
<tr>
<td>YU</td>
<td>2008-09</td>
<td>Grade 5</td>
<td>Grade 6 and 7, 2008-09</td>
</tr>
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</table>

Source: Public Health Agency of Canada, Publicly Funded Immunization Programs in Canada—Routine Schedule for Infants and Children (including special programs and catch-up programs), Updated May 13, 2008, available online at www.phac-aspc.gc.ca/im/ptimprog-progimpt/table-1-eng.php

Table 3 illustrates the percentage, as per Statistics Canada data, of the female population aged 9 to 17 years in 2007 (the year the vaccine was introduced) that will be included in the provincial/territorial vaccination programs. Note that participation in the vaccination program is voluntary; these numbers represent eligibility, not actual immunization and assume that the programs will continue beyond the three year federal funding allocation.

Quebec offers the most comprehensive program, eventually available for 100 per cent of the target population, while Manitoba will include only 32 per cent, followed by Prince Edward Island with 41 per cent, Saskatchewan with 42 per cent and the Yukon Territory

**Table 3 FEMALES ELIGIBLE FOR VACCINATION PROGRAM AND INCIDENCE OF CERVICAL CANCER**

<table>
<thead>
<tr>
<th>Province/Territory</th>
<th>QC</th>
<th>ON</th>
<th>BC</th>
<th>NL</th>
<th>AB</th>
<th>NB</th>
<th>NS</th>
<th>YT</th>
<th>SA</th>
<th>PEI</th>
<th>MB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of females 9–17 included in the program**</td>
<td>100</td>
<td>66</td>
<td>65</td>
<td>63</td>
<td>54</td>
<td>53</td>
<td>53</td>
<td>43</td>
<td>42</td>
<td>41</td>
<td>32</td>
</tr>
<tr>
<td>Estimated Annual Incidence of Cervical Cancer per 100,000 females***</td>
<td>6</td>
<td>7</td>
<td>6</td>
<td>7</td>
<td>10</td>
<td>8</td>
<td>11</td>
<td>N/A</td>
<td>8</td>
<td>10</td>
<td>7</td>
</tr>
</tbody>
</table>

*There is no school-based program for females 15 to 18 years of age, but these females may receive the vaccine free from their doctor.
** Calculated using 2006 Statistics Canada Population Data
with 43 per cent included in their programs.

Table 3 also lists the estimated incidence of cervical cancer per 100,000 females in each province based on 2008 Canadian Cancer Statistics (data not available for the Yukon Territory). The inclusion of this data provides a comparison of the relationship between the incidence of cervical cancer by province and the rate of vaccination for the target population of females aged 9 to 17 years. There appears to be no relationship between the programs being implemented in each province and the rate of cervical cancer in that province.

**Coverage Rates**

In addition to examining the programs being offered, it is important to consider the vaccine uptake or coverage rate in each province and territory to determine the effectiveness of the vaccine programs. In the first year of the program, Newfoundland achieved an 85 per cent coverage rate and the rate for the Atlantic Provinces was approximately 80 per cent. Ontario achieved a coverage rate of 53 per cent for the first dose. Québec achieved a coverage rate of 84 per cent for grade 4 and 87 per cent for grade 9 for the first dose.

**Safety of the Vaccine**

Safety of the vaccine along with religious beliefs may be factors that would impact overall uptake of the vaccine. Although these factors have not been accounted for in this article, it is worth mentioning that in Canada, as of December 31, 2008, the Public Health Agency of Canada (PHAC) has received 321 reports of adverse events, the majority of which have been minor such as injection site reactions. There has been a single report of Guillain-Barre Syndrome, a rare disorder that causes muscle weakness.

**Cost Considerations**

The national cost of the vaccination program for one age group between the ages of 9 and 18 (representing approximately 200,000 females based on 2006 Statistics Canada data) is estimated to be $80 million, based on an average vaccine cost of $400 for three doses). This estimate does not include the costs of administering the vaccine or associated public education programs.

According to a recent Canadian study, vaccinating 12-year-old girls at a cost per course of $400, and assuming a 95 per cent efficacy with no waning of protection, the cost would be $21,000 to gain one quality adjusted life year (QALY). Estimations of results were shown to be most sensitive to age at vaccination, duration of vaccine protection, vaccine cost and QALY’s lost due to genital warts, and were least sensitive to medical costs. The study concluded that vaccinating adolescent girls against HPV is likely to be cost-effective.

A QALY (quality adjusted life year) is defined as a year of life adjusted for its quality or its value. A year in perfect health is considered equal to 1.0 QALY. The value of a year in ill health would be discounted. For example, a year bedridden might have a value equal to 0.5 QALY. QALYs provide a common currency to assess the extent of the benefits gained from a variety of health interventions. When combined with the costs of providing the interventions, cost-utility ratios result; these indicate the additional costs required to generate a year of perfect health (one QALY).

Studies are also available from other countries providing cost-effectiveness models for use of the HPV vaccine.

**The Magnitude of HPV Infection as a Health Hazard**

In Canada, there are approximately 1,400 new cases and 400 deaths from cervical cancer each year. In addition to causing cervical cancer, HPV 16 and 18 infections are the primary cause of anal, penile, vaginal, and vulvar cancers and have been now observed among an increasing fraction of head and neck cancers. HPV 6 and 11 infections are the primary cause of anogenital warts and recurrent respiratory papillomatosis. Extrapolating from recent estimates in the United States in 2007, approximately 50,000 men and women in Canada have been diagnosed with anogenital warts. The vaccine has been shown to reduce the risk of anogenital warts and pre-cancerous lesions by 90 per cent in men. An application to the FDA for approval for use in males was filed in late December 2008.

**Discussion**

The federal allocation of $300 million over three years on a per capita basis provided the provinces and territories with an equal opportunity to design and implement a vaccination program for young females. This begs the question: why are the vaccination programs across the provinces so varied with some provinces implementing a program that only covers one age group of females, while others are covering a second age group as a catch up and including all females under the age of 18?

Newfoundland, for example, is able to implement a program with greater than 85 per cent uptake for a total of five cohorts in a three year period while Ontario will cover only three age groups with an uptake estimated at 53 per cent for the first year.

Our research also reveals that the vaccination programs bear no relationship to the risk of cervical cancer in each jurisdiction. For example, Quebec and BC with the lowest incidence rate of cervical cancer at six per 100,000 females, have two of the best programs capturing 100 and 65 per cent of females aged 9–17 years, respectively. Provinces with the highest incidence rates such as Nova Scotia with only 11 and Prince Edward Island with 10 cases per 100,000 females are only capturing 53 and 41 per cent of females in their programs. If not on incidence, on what basis were program decisions made?
The question arises whether to vaccinate males. The vaccine is not currently approved for use in men in Canada or the US. It is licensed for use in males aged 9 to 15 in Europe and Australia. In these jurisdictions, males are not included in the public program but can be vaccinated at their own cost. In the UK, the vaccine is being given to homosexual men “off-label” to help protect against genital warts, anal and penile cancers.12

What role should the family physician play in the HPV vaccination program? The recommendations listed in table 1 represent the standard of care for vaccinating against HPV. Therefore, it is the responsibility of each family physician to recommend that females between the ages of 9 to 26 who will not be included in the public vaccine program be vaccinated, and to inform parents of the advantages and risks of vaccinating their daughters who are eligible for the public programs.

While it is commendable that the provinces and the Yukon Territory have initiated HPV vaccination programs, CACC recommends that cervical screening continue to be offered and promoted as a necessary component of a cervical cancer prevention program.

Conclusions
We have repeatedly observed large differences in cancer screening, care delivery and mortality between provinces. This is the first time we have been able to document the same inter-provincial variability as it relates to cancer prevention through vaccination. In this case, Quebec’s program offers the broadest coverage.

The differences in each provincial program may eventually result in differences in effective control of cervical cancer and the other diseases prevented by the vaccine in that province. These differences will not be known for several years.

The examination of Provincial/Territorial HPV vaccination programs may be an area of interest for the Canadian Partnership Against Cancer—Primary Prevention Action Group, to help determine the most effective programs moving forward in reducing the risk of cervical cancer and other HPV-related diseases.

Recommendations
• Additional research should be conducted to determine how health care system programs such as cervical screening and follow-up will be impacted by the introduction of the vaccine.13
• Research regarding vaccinating males should be monitored to determine whether it would be effective in:
  • controlling other conditions caused by HPV such as anal and penile cancers, ano-genital warts, and head and neck cancer, and
  • further reducing HPV-related diseases in the female population, since it appears that males are among the vectors carrying the virus

The Magnitude of HPV Infection as a Health Hazard

In Canada, there are approximately 1,400 new cases and 400 deaths from cervical cancer each year.9 In addition to causing cervical cancer, HPV 16 and 18 infections are the primary cause of anal, penile, vaginal, and vulvar cancers and have been now observed among an increasing fraction of head and neck cancers. HPV 6 and 11 infections are the primary cause of anogenital warts and recurrent respiratory papillomatosis.10 Extrapolating from recent estimates in the United States in 2007, approximately 50,000 men and women in Canada have been diagnosed with anogenital warts.11 The vaccine has been shown to reduce the risk of anogenital warts and pre-cancerous lesions by 90 per cent in men.12 An application to the FDA for approval for use in males was filed in late December 2008.

References
Cancer Care in Smaller Communities

A SAMPLE OF COMMUNITY CLINICS ACROSS CANADA

WILLIAM HRYNIUK, NORM ARCHER, ROSEMARY COLUCCI, DANIEL GILLESPIE AND DAVID SALTMAN

Introduction
Six million Canadians, about 20 per cent of the country’s total population, live in small towns. While the major urban centres have large cancer centres and comprehensive care in their midst, people living two hours away in a smaller community have a very different reality.

Management of cancer requires, in virtually every case, multidisciplinary treatment delivered by a large number of health care personnel based in different locations.

Until recently, delivery of cancer treatment and care has been coordinated under the jurisdiction of provincial or regional cancer care programs in most provinces. In British Columbia, Alberta, Saskatchewan, Manitoba, PEI, Newfoundland/Labrador and Nova Scotia coordination of the activities in many community oncology cancer clinics falls in the provincial category. In Ontario and New Brunswick they are part of a regional cancer care program. Under these circumstances, use of an Electronic Health Record would seem to be uniquely appropriate for optimizing treatment and care. It might even be viewed as a critical component of any provincial or regional program when toxic chemotherapy prescribed by specialists at the tertiary centre must be delivered in distant communities by non-specialists.

With these considerations in mind, CACC conducted a cross-Canada survey to sample the use of EHRs and the resources available to community cancer clinics, specifically where patient treatment with cytotoxic drugs occurs in communities at a distance from, but still within the jurisdiction of, large tertiary centres.

Methods
For the survey, we selected communities from across Canada that were more than a two hour drive from the regional tertiary centre, and were of a population size usually unable to justify a permanent medical oncologist. The communities were selected by perusal of regional maps, with no prior knowledge of their service patterns or access to an EHR. PEI and Quebec were not included in the survey, the former because of its size and the latter because of its heterogeneous jurisdictional configuration.

Respondents were administrative personnel at each tertiary centre who were responsible for some measure of administrative support for the selected community sites. In most cases, answers were verified with separate follow up communications with the survey respondent; and in two cases additional interviews were conducted with health professionals at the community sites.

<table>
<thead>
<tr>
<th>Distant Community</th>
<th>Pop.</th>
<th>Distance to Regional Cancer Centre (Km)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>&lt;10,000</td>
<td>300</td>
</tr>
<tr>
<td>2</td>
<td>&lt;10,000</td>
<td>350</td>
</tr>
<tr>
<td>3</td>
<td>&lt;10,000</td>
<td>280</td>
</tr>
<tr>
<td>4</td>
<td>10–25,000</td>
<td>475</td>
</tr>
<tr>
<td>5</td>
<td>10–25,000</td>
<td>220</td>
</tr>
<tr>
<td>6</td>
<td>10–25,000</td>
<td>760</td>
</tr>
<tr>
<td>7</td>
<td>10–25,000</td>
<td>250</td>
</tr>
<tr>
<td>8</td>
<td>10–25,000</td>
<td>690</td>
</tr>
<tr>
<td>9</td>
<td>10–25,000</td>
<td>230</td>
</tr>
<tr>
<td>10</td>
<td>25–50,000</td>
<td>370</td>
</tr>
<tr>
<td>11</td>
<td>50–75,000</td>
<td>790</td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td><strong>19,927</strong></td>
<td><strong>429</strong></td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td><strong>13,200</strong></td>
<td><strong>350</strong></td>
</tr>
</tbody>
</table>

As shown in Table 1, a total of 11 communities populated by approximately 220,000 Canadians were included in the survey. The communities were an average distance of 430 km from the coordinating provincial or regional (tertiary) cancer centre.
PART 1: The Use of an Electronic Health Record in the Provision of Cancer Services

An Electronic Health Record is a digital version of an individual’s health record. It may contain a person’s full health and medical record, or it can include only certain records, such as those related to management of a particular condition, e.g., cancer, or to laboratory results that can be used in conjunction with more traditional paper-based patient charts.

An EHR is particularly effective when it is accessible online through an interoperable network. By facilitating the retrieval of information about patients when and where it is most needed by practitioners concerned with the patient’s care and by gathering the scattered notes in doctors’ offices, clinics, test centres, laboratories and hospitals, the EHR can provide full details about each case, easing referrals among different facilities. Such coordination can lead to optimal and timely treatment, reducing errors resulting from mislaid or missing information, unnecessary delays, duplication of effort, and unnecessary costs.

Canada Health Infoway, a federal organization, in collaboration with Canadian provinces and territories, strategically coordinates and funds projects to build standardized EHRs for patients. Infoway also supports extensions of these systems. The objective is to link records containing critical health information across sources of care delivery within a jurisdiction, as the basis for delivering healthcare in Canada. Its ambitious goal is to have EHRs accessible for 50 per cent of Canadians by 2010. The specific EHR data elements required for cancer treatment and care go beyond those for standard clinical applications.3

Canadian Medical Association (CMA) President, Dr. Robert Ouellet, noted recently in his inaugural address that among major industrial nations, “Canada has the dubious honour of ranking last in the use of electronic patient files”. Despite concerns regarding patient privacy, the Canadian Medical Association (CMA) has been a strong advocate in favour of a fully interoperable, pan-Canadian EHR to improve patient outcomes and health system efficiency and accountability. According to the CMA, the benefits of an investment of $570 million over five years could include an estimated savings of $6.1 billion in transcription costs as well as less duplication of medical test requisitions and fewer adverse drug reactions.4

In a recent national survey of Canadian hospitals5, slightly more than half (54.2 per cent) reported having some sort of EHR in place; however, 97.6 per cent indicated that the EHR was not the sole method for recording patient information. Very few institutions had predominantly an electronic record; most commonly hospitals had records that were 11 to 50 per cent electronic. The survey results suggested the adoption of EHRs by Canadian healthcare institutions is in its infancy.

Methods

We considered that the EHR should be:

- headedquarter at the regional or provincial tertiary centre
- internet-based
- secure
- integrated
- accessible to the community clinic personnel
- configured to allow community personnel to enter as well as extract data
- have EHRs accessible for 50 per cent of Canadians by 2010
- include only certain records
- allow physicians to enter drug orders directly, or at least allow the use of standardized pre-printed orders
- checkpoints to prevent inappropriate drug treatments from being ordered
- protocols for managing treatment complications
- nursing processes
- list of all prescribed medications and treatments administered

We also asked for an estimate of the population in these distant communities who would be covered by the EHR system currently in place.
TABLE 2  **EHR Link Between Tertiary and Community Centres**

<table>
<thead>
<tr>
<th>Distant Community</th>
<th>Is the EHR in the Regional Cancer Centre Integrated with the Community</th>
<th>Population Covered by an Integrated EHR in the Region (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td>76-100%</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
<td>76-100%</td>
</tr>
<tr>
<td>3</td>
<td>Yes</td>
<td>51-75%</td>
</tr>
<tr>
<td>4</td>
<td>Yes</td>
<td>51-75%</td>
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<tr>
<td>5</td>
<td>Yes</td>
<td>76-100%</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Yes</td>
<td>76-100%</td>
</tr>
<tr>
<td>11</td>
<td>Yes</td>
<td>76-100%</td>
</tr>
</tbody>
</table>

**Average 80.4%** (of the 7 with an EHR)

Blank indicates a response of “No”
N/A indicates no answer received

Seven of the 11 communities surveyed were linked to their tertiary centres by an EHR. In five of the eight provinces surveyed, the sampled communities were linked to the appropriate tertiary centre. In provinces with EHR systems in place, an average of 80 per cent of the region’s population was linked to the tertiary centre.

Table 3 indicates the extent to which the EHR contained the nine essential elements. None had all nine elements, the actual number varying from three to seven. The most comprehensive systems were those from Manitoba, Alberta, and New Brunswick with six to seven elements each. The remaining EHR systems contained three and four elements.

Many of the essential elements were particularly lacking in all EHRs.

- drug protocols were present in only four of seven
- three of seven had capability for order entry
- two of seven had safety checkpoints on chemotherapy orders
- one of seven had protocols to guide treatment of complications
- one of seven had allowance for nurses’ notes
- two of seven had a list of all medications for all conditions

Table 4 indicates the degree of access to, and the mode of interaction with the EHR system available to health care professionals at the community level. While doctors had some degree of access in all seven instances where there was an EHR, nurses and pharmacists had access in only four instances.

Of the seven communities linked to the regional centre, community professionals were able to enter clinical data relating to the patients’ care in only three. In the remaining four, they had read-only access, i.e., the system did not allow entry of clinical information from the community professionals treating and taking care of the patients to enable tracking of treatment progress and complications by oncologists at the tertiary centre.

TABLE 3  **Information Included in the Electronic Health Record**

<table>
<thead>
<tr>
<th>Distant Community</th>
<th>General Medical Info</th>
<th>Lab &amp; Imaging</th>
<th>Pathology</th>
<th>Drug Treatment Protocols</th>
<th>Order Entry</th>
<th>Drug Treatment Checkpoints</th>
<th>Protocols for Managing Complications</th>
<th>Nursing Processes</th>
<th>All Meds</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
<td>✅</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6</td>
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<td>4</td>
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</tr>
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<td></td>
<td></td>
<td></td>
<td>3</td>
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<td>11</td>
<td>✅</td>
<td>✅</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

Blank indicates a response of “No”
of studies suggest that when such a system is operational and is interactive, other important aspects are impacted. For example, fewer medication errors occur, resulting in a reduction of adverse drug events, increased adherence to guideline-based treatment occurs in favor of the patient and efficiencies are introduced in the form of decreased utilization of care. When combined with more accurate charting, important drug-drug interactions may also be readily detected and, where necessary, adjustments can be made.

A particularly dramatic example of the utility of the EHR occurred in the city of New Orleans after Hurricane Katrina. When records were in an electronic format, only three per cent of oncology patients had difficulty obtaining their records when they returned six weeks after the hurricane, whereas 100 per cent of those without such a record stated they had difficulty. Perhaps the best example of the use of the EHR is the initiative taken by the Veteran’s Administration (VA) in the US. A system (www.myhealth.va.gov/) has been developed enabling veterans to tap into their personal health records including medical history, lab results and appointment scheduling. Secure messaging with physicians is also allowed, and those messages are posted to the EHR as progress notes.

My HealtheVet is a model for empowering patients to take an active role in their healthcare and for improving care while lowering costs. The configuration provides feedback and encourages positive behavior. The secure messaging strengthens relationships between physicians and patients and streamlines work-

### TABLE 4  Community Clinic Staff with Access to the EHR

<table>
<thead>
<tr>
<th>Distant Community</th>
<th>Physician</th>
<th>Onc Nurse</th>
<th>Other Nurse</th>
<th>Pharmacist</th>
<th>Clerk</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>☑</td>
<td>☑</td>
<td>☑</td>
<td>5</td>
</tr>
<tr>
<td>2</td>
<td>No Integrated Electronic Health Record</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>GP**</td>
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<td>☑</td>
<td>☑</td>
<td>☑</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>GPO#*</td>
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<td>☑</td>
<td>☑</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>Internist*</td>
<td>GPO#*</td>
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<td>☑</td>
<td>☑</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>Internist*</td>
<td>GPO#*</td>
<td>☑</td>
<td>☑</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>No Integrated Electronic Health Record</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>No Integrated Electronic Health Record</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>No Integrated Electronic Health Record</td>
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</tr>
<tr>
<td>10</td>
<td>Internist*</td>
<td>GPO#*</td>
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<td>2</td>
</tr>
<tr>
<td>11</td>
<td>Onc MD*</td>
<td>GPO#*</td>
<td>☑</td>
<td>☑</td>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>

Blank indicates a response of “No”
* Read-only access
** Trained in chemotherapy administration
GPO # = general practitioner with special training in oncology

### Discussion

It might be argued that the EHR should, in the first instance, contain all clinical information related to all the conditions of the patient. We have taken the position that treatment of cancer is so complex and influenced by so many different factors that, as a first step, it is necessary to have an EHR uniquely configured for delivery of cancer treatment, care, and follow-up. Also, we considered it should be readily accessible to all of the physicians and allied health care personnel responsible for care of the patient, not just the specialists at the tertiary cancer center.

The present survey indicates the importance of detailed evaluation to accurately determine the true capabilities of EHRs, in instances where they are said to be present. The survey was conducted on relatively few communities but, as stated earlier, the results are in accord with other studies of the scant availability of EHRs in management of care. To ensure accuracy, the survey results were verified in most cases by the person who completed the survey and in two cases directly with a professional in the community.

The results of the survey indicate the very limited application of EHRs in managing the care of cancer patients in communities distant from major cancer centres. Only seven of the 11 community oncology clinics sampled had access to an integrated EHR system linking them to the tertiary centre. In those seven clinics, not all health care personnel could read the EHR, and in only three were clinic professionals allowed to enter clinical data into the record. It means the tertiary centre oncologists who originally devised the treatment plans were not able to follow whether treatment was being given, or what complications were encountered, and could not use the EHR’s real-time capacity to advise community personnel.

The most highly developed and user-friendly EHR system linking communities to a tertiary cancer centre was the one used in Manitoba and Alberta: the ARIA system, previously known as OPTX 2000. It was developed more than 10 years ago by the cancer agency in Manitoba, and has since been commercialized and taken over by an American firm for wide use in the US. None of the other provinces surveyed had the equivalent combination of capability, interactivity, and coverage of this system.

Although no statistical studies appear to have been done on the impact of EHRs on the final outcomes of cancer treatment in distant communities, i.e., effect on survival, a number
flow. Demand on the VA's Release of Information offices is reduced, as well as unnecessary trips to VA medical facilities by veterans who have difficulty traveling. Finally, the capability for online scheduling reduces the number of missed appointments and calls to the appointment desks.

A Canadian example would be the Odette Cancer centre at Sunnybrook Medical Centre in Toronto. Cancer patients have secure access to their electronic health records, are able to share this information with caregivers whenever they deem necessary, and can closely monitor their own progress.

If patients can access their bank statements from anywhere in the world, why not their health records? It can be expected that putting internet-based EHRs in the hands of individual patients will greatly improve cancer treatment and care. They will be able, in the comfort of their own homes, to become more aware of the delays arising in referrals and tests, can look up the implications of these delays, and better prepare themselves to become active participants in their own care during visits to their oncologists. Existing silos in cancer investigation and treatment will eventually be connected as a result of patient initiatives resulting in:

a. Uniformly higher quality of treatment and care for all cancer patients;

b. Improved quality of life as distress, due to lack of information, is reduced;

c. Improved timeliness of care and reduced waiting times especially by allowing patients to make their own appointments;

d. Improved safety by reducing accidents in administering chemotherapy drugs;

e. Stretching of oncology budgets by reducing wasteful repetitions of tests and x-rays;

f. Reduction in the myriad of costly systems necessary to maintain confidentiality of paper records during the sharing information among appropriate caregivers.

In addition to providing better patient treatment and care, deployment of an EHR facilitates system-oriented uses such as:

- Audits of treatment outcomes and complications in individual clinics;
- Post-market surveillance of newer cancer drugs to determine their true effectiveness in the general population;
- Rapid identification of patients who, in retrospect, may have been exposed to errors (e.g., recent problems with breast cancer tests);
- Screening patients who may be candidates for clinical trials;
- Linking health records to cancer registries to rapidly determine trends and the effects of improvements in cancer control.

**Barriers**

Choosing, implementing and integrating an oncology EHR system into a hospital system is resource-intensive. However, roadmaps are available from clinics that have successfully managed the transition. In a major community network involving 4,800 US physicians, electronic health records were linked among various clinics. Oncologists within the network quickly noted advantages from improved efficiencies and response speed. The salutary effects this could have on the prolonged waiting times bedeviling Canadian patients can only be imagined.

There have obviously been major barriers to developing and adopting an integrated interactive oncology EHR system in Canada, otherwise such a system would have been in operation long ago. Many were identified by respondents to the present survey (data not shown). We did not investigate these barriers, but the literature is replete with examples:

**Parochialism**

One of the biggest impediments; manifested as unwillingness to share clinical information. Includes reluctance to give universal access to capable and responsible users.

**Lack of funding**

Really a reflection of a lack of willingness by health care administrators to place a high priority on developing an integrated EHR. Lack of willingness is partly a failure to appreciate the far-reaching implications of EHRs on treatment and care. Education of administrators could address this issue, combined with pressure by physicians and public pressure on governing institutional boards.

**Privacy and security regulations**

Often over-interpreted to an unreasonable degree. This stifles development. Application of newer security systems and common sense would be in order.

**Overblown concerns regarding the integrity of the system**

Higher priority given to the security concerns of IT personnel than to safe and efficient patient care. Witness the fact that even where they existed, the majority of EHR systems surveyed were read-only in the community clinics. Treating physicians were thus unable to interact with the system and inform their colleagues back at the tertiary centre about what they were doing. To overcome this barrier, greater participation is required by health care professionals, especially physicians, in development and oversight of institutional policies.

**Resistance to change**

Healthcare workers recalcitrant to the idea of electronic charts, or the need to upgrade and maintain their computing skills, or reluctant to participate in the data
entry process. To overcome these obstacles, leadership is required from health care professionals, particularly physicians, experienced in the use of EHRs.

**Incompatibility of different systems**
Community cancer clinics located in hospitals that have clinical information databases not readily accessible or compatible with their tertiary cancer centres. Again, greater participation by health care professionals is required in development of EHR standards, institutional policies, and resource allocation.

**Lack of a national strategy for the development of an integrated EHR in oncology**
The American Society of Clinical Oncology (ASCO) is striving to help cancer care providers in the US move towards medical and patient-accessible EHRs. ASCO has proposed a standard oncology EHR and holds an annual event where practitioners evaluate commercial EHR packages and discuss findings and conclusions about these systems.

An example of how barriers can combine to prevent the deployment of an EHR system to support community based cancer treatment is provided by the fate of a proposal to serve outlying communities in Ontario put forward almost twenty years ago. The proposal would have used the Oncology Patient Information System (OPIS), was approved in principle by the Ontario Legislature, the Ontario Medical Association, and the Board of the Ontario Cancer Research and Treatment Foundation (OCTRF). The then-Deputy Minister of Health asked for a plan to implement it. The plan was aborted due to internal considerations at the OCTRF.

### TABLE 5  Resources Available to the Community Oncology Clinic

<table>
<thead>
<tr>
<th>Distant community</th>
<th>Physician on site</th>
<th>Who administers drug therapy</th>
<th>Pharmacist</th>
<th>Psychosocial counseling</th>
<th>Nutrition counseling</th>
<th>Patient support groups</th>
<th>Designated oncology clinic</th>
<th>Designated area for drug therapy</th>
<th>Telemedicine</th>
<th>TOTAL</th>
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</thead>
<tbody>
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<td>IV Nurse</td>
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<td>✓</td>
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<td>3</td>
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Blank indicates a response of “No”
Results
Table 5 indicates the organizational readiness of the 11 sampled clinics to deliver cancer treatment and care, regardless of their access to an EHR system. Five of these community clinics met all nine of the clinical resource requirements we considered essential for community cancer care. Of the remainder, two had eight, one had seven, two had six and one had five.

Discussion
As judged from Table 5, the capabilities of the community clinics for delivering cancer treatments were quite impressive. However, the lack of an interactive EHR system in almost all of them raises the probability that patients’ treatment plans in these communities are not getting the input from the specialists at the tertiary centres that would obtain if they were in direct proximity to regional cancer centers. This, in turn, might mean that the patients in these communities are not getting the state-of-the-art treatments and tests they need.

Conclusions and Recommendations
• Health professionals at the community cancer clinic should be allowed to enter data into the EHRs.
• Physicians who have responsibility for day-to-day care such as family doctors, surgeons, and emergency room physicians should also have access to existing EHRs on their cancer patients.
• A national strategy should be devised and implemented to facilitate linking of oncology EHRs with community clinics in each province.
• Development of this national strategy should be facilitated by the Canadian Partnership Against Cancer (CPAC) in collaboration with Canada Health Infoway.
• Patients should be given immediate and continuing access to their own health record in conjunction with access to an electronic library of explanatory notes to enable them to make best use of the information in their record.
• Standard EHR specifications for cancer care should be adopted by Canadian institutions, to enable patient records to be interchangeable among different systems.
• Although such standards are necessary for exchanging EHRs, the terminology used may vary among practitioners. To accommodate differences in terminology, SNOMED CT (Systematized Nomenclature for MEDicine–Clinical Terminology) could be used. This is an internationally recognized and comprehensive multilingual clinical terminology tool which provides the information framework for clinical decision making for electronic medical records. SNOMED CT terminology is included with the standardized pan-Canadian EHR being supported by Canada Health Infoway.

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Rosemary Colucci is a consultant to the health sector in strategic planning, stakeholder relations and advocacy strategy.

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

David L. Saltman, MD, PhD, is Chair and Professor, Discipline of Oncology, at Memorial University of Newfoundland’s Faculty of Medicine. His current research interests include the oncology applications of telemedicine.

References
The Emerging Role of Biomarkers in Cancer

JOSEPH RAGAZ

Biomarkers profoundly impact the issue of access, cost, toxicity and overall value of newly evolving therapeutics for human cancer. Thus, biomarker research and adoption in clinical practice guidelines requires serious attention from the clinical community and funding agencies.

Biomarkers are tumour-associated proteins or genes identified from the primary tumour, circulating cancer cells, blood serum, or metastatic tissue that provide an indication of:

1. Risk and aggressiveness of disease at diagnosis (prognostic value)
2. Responsiveness to various therapies (predictive values)

Some biomarkers indicate which patients will benefit from a given treatment, e.g., estrogen receptors predicting responsiveness to hormonal therapy; Her2/Neu gene status to trastuzumab (Herceptin) therapy; c-kit molecule to imatinib (Gleevec), and so forth.

Some will identify patients who do not require a given therapy, e.g., ER negative status indicates no benefit from hormonal therapies in breast cancer; Her2/Neu—if not expressed—indicates no benefit from Herceptin or lapatinib in breast cancer; the presence of K-RAS mutation predicts no benefit from cetuximab (Erbitux) and panitumumab (Vectibix) in colorectal cancer, etc.

Biomarkers may also identify those who may require different types of treatment, e.g., a low Recurrence Score in the Oncotype Dx 21 gene test identifies breast cancer patients who may benefit from hormonal therapy alone and do not require the addition of adjuvant chemotherapy; the BRCA-1/2 genes identify women at high risk for breast and ovarian cancer who, in addition to chemopreventive strategy (tamoxifen, raloxifene), may also benefit from bilateral mastectomy and/or oophorectomy.

Biomarkers will lead to significantly improved quality of life by avoiding the toxicity of unnecessary therapy, while also lowering costs and contributing to overall societal benefit compared to therapeutic approaches not guided by biomarkers. While the process of identifying and testing new biomarkers is costly, the long-term benefit of avoiding unnecessary treatments more than justifies the investment.

More information on the principal biomarkers in current practice or under investigation, according to tumour site, with comments highlighting cost-benefits in quality of life and saved dollars can be found on the CACC website with other background relating to this Report Card (www.canceradvocacy.ca).

Challenges of Biomarker Research

Fiscal issues – One of the big problems with biomarker research is the slow rate of progress related to lack of funding. This could be overcome if longer-term fiscal gains were more clearly understood—in proportion to the strength of evidence from ongoing research.

Logistical issues – Some of these challenges will be more difficult to overcome. Specifically, there is increasing difficulty accessing tumour tissues from patients in a given trial to retest a preliminary observation, partially because tumour samples are small and many more tests per sample are now being contemplated.

Example: Herceptin resistance may evolve, identified by the expression of the molecules PTEN and c-myc, which are both potential biomarkers. The two preliminary reports on this subject require confirmation. The only way to do it is by accessing tumour samples of patients who participated in all five randomized Herceptin trials.

However, the pathology specimens in most of these trials are not easily available. They are consumed either by the primary research or by required centralized retesting to confirm the status of Her2/Neu or ER and PgR biomarkers.

These steps are important, but they all require the extra specimens. As a result, very often the only effective way to confirm a preliminary biomarker observation appears to be to launch yet another full-fledged randomized trial, with assessment of biomarkers as the main objective. Yet the idea of launching another Herceptin vs. placebo randomized trial is clearly not feasible. Aside from the logistical and financial barriers, there are ethical and potentially legal issues in withholding a curative therapy from the placebo arm of the trial.
When is a Biomarker Ready for Prime Time?
This brings up the important question: when should researchers and oncologists consider altering guidelines? Which is the greater mistake: to act prematurely on newly identified biomarkers or to fail to save lives and dollars by not acting until overwhelming evidence offers absolute certainty?

For instance, the data are now mature associating chemotherapy resistance with the absence of Her2/Neu expression, particularly if linked with a positive ER expression. However, no major change has yet been made in clinical practice guidelines. A great majority of node positive patients are still receiving dose intensive CEF in Canada—and/or taxol added to AC in the US. Yet chemotherapy intensifications (with anthracyclines or taxanes) have produced minimal benefit for the 70–75 per cent of breast cancer patients with Her2/neu negative tumours and/or with a positive expression of estrogen receptor biomarkers.

The reluctance to act more assertively on biomarker data probably reflects ongoing generalized concern that acting prematurely could disqualify patients from a potentially curative therapy—with obvious serious consequences.

False positive results are not infrequent—the very reason why most oncology representatives and journal editors are cautious in accepting results based on smaller patient samples, even with statistical significance. However, a refined balance exists between these legitimate worries and not acting at all, even once the evidence is available. In both instances patient interests are not well served.

Cancer patients and their physicians increasingly feel a compelling need for full information about the most recent research, even if the data are not completely mature. In the absence of new, prospectively randomized biomarker studies confirming important preliminary results, clinicians and patients may have to resort to tailor-made individual decisions. While the obvious choice is participation in a clinical trial that could produce new evidence or confirm a preliminary observation, many patients will not fit trial criteria and therefore have fewer options. Thus, patients and their physicians try to balance need and hope with uncertainty, and make therapeutic decisions in a grey zone.

Quality Control
Essential aspects of biomarker development include the reliability, quality and reproducibility of techniques identifying individual biomarkers. If these are faulty, negative consequences occur both in giving and not giving a certain treatment. Good candidates would not receive a curative therapy; and patients who would not benefit may receive the drug, perhaps for a long time, deriving little benefit but more toxicity, at times considerable.

Poor quality control has been evidenced in North America and Europe, e.g., falsely negative estrogen receptor tests disqualifying thousands from curative hormonal therapies; or clinical errors occur due to inaccurate immunohistochemistry tests for Her2/Neu.

Once a biomarker is of proven value, conducting the tests for patients requires uniformity and quality control, particularly if done by multiple laboratories. This is a priority and should be enforced not only by independent research groups but also by provincial and national bodies regulating cancer developments.

Funding
Ultimately, the successful entry of biomarkers into clinical practice guidelines will be determined by the funding available for both the research and the cost of routine use.

In this process, conclusions based on strong evidence should stimulate social interest—and eventually financial support. As molecules such as the recently identified biomarker K-RAS gene have shown a clear cost-benefit, public funding for their use should be expedited.

On the other hand, if the evidence is weak then funding is clearly less warranted. Patients and clinicians need to see a direct interaction between the strength of research results and their adoption in publicly funded health care.

In summary, ongoing challenges occur at two levels.
• Research of biomarkers is often slow, with industry or granting bodies not always prospectively allocating funds for biomarker research.
• Once a biomarker is proven to contribute—even with a high level of evidence, such as the Oncotype Dx 21 gene assay—Canadian health ministries, cancer agencies and institutions refuse funding, arguing that its routine use may not contribute significantly over established practice.

Conclusion
Considering the magnitude of the side effects and the expense of most cancer therapeutics, restricting therapies to those patients most likely to benefit will substantially improve their cost-benefit and serve the best interests of patients. Biomarkers are essential to making these decisions.

Recommendations
Provincial health ministries should set aside a fixed percentage (two to four per cent) of their drug budget to finance:
• the research of biomarkers,
• routine use of biomarkers already established as useful in individual patient management.

Joseph Ragaz is a Medical Oncologist and a Senior Oncology Researcher, Professor of Medicine and Oncology, McGill University, Montreal, QC and a Director of the CACC.
In a Rowboat of My Own
A SURVIVOR’S STORY

DEBORAH MASKENS

At the age of 14, my outlook on life was forever warped by a diagnosis of cancer, not a usual cancer, but a cancer typical of older, heavier men with a history of smoking. From that moment, I have been in uncharted waters in what seems to have been a rowboat of my own. Through some 34 years of cancer survivorship, I have learned a lot—much of it by sheer accident.

Lifelong Follow up is Essential
I have learned most importantly that the smiling surgeon who says “I got it all” really means to say “I got everything that I could see, but that you will still need to be followed up for the rest of your life.” Five years after my initial treatment (a radical nephrectomy, or removal of the kidney), I was discharged from my urologist’s office and told to “go and live your life. You’re cured.”

From that point, while I mentioned often enough “I had kidney cancer you know,” I was never scanned for recurrence—not every year, every five years—never. Of course, 22 years later when the silent recurrence finally made itself known, it was huge and life-threatening. A tumour in the renal bed was so large that it had abscessed, necrotized, and required extensive emergency surgery and a week in the ICU.

Since then, I have heard of other kidney cancer patients whose cancer has metastasized after 14, 17, 19 years. Some of these patients are lucky enough to have a scan for some other reason. Others are as blissfully unaware (as I was) of their life-long risks or the signs of recurrence.

Delayed Complications of Successful Treatment
Patients know well enough that treatments have side effects and long term consequences. In my case, I would like to have known how to protect my now solo kidney from damage, I have since learned that smoking, diabetes, hypertension, and some NSAIDs are all damaging to kidney function. At the time of initial treatment, the only advice I was given as a teenager was not to play touch football. I had no idea whether I could have children (I have), live a normal life (I have) or how the cancer diagnosis would affect the rest of my life.

You Might Get Another Cancer
At a routine physical, my family physician casually mentioned that I have a higher risk of getting another cancer. This was news. What should I do to reduce the risk of acquiring a second cancer? How much screening is too much screening? How much radiation from CT scans can I be exposed to? Since 1996, I have already had more than 45 CT scans. Who is counting? Who is looking at the long-term picture of those of us living today with cancer as a chronic disease?

You Can Improve Your Odds of Recurrence
Again by accident, I have come across research that points to the favourable effects of diet and exercise in reducing the risk of recurrence. There is convincing research about the role of diet,
about lifestyle, about vitamin supplements, but none of this comes to me from my cancer centre. We discuss the latest CT scan and schedule the next one, but in the meantime, what should I do? “Live your life. Follow Canada’s Healthy Eating Guide. All things in moderation.” I would stand on my head if it would reduce the risk of recurrence.

**There are Resources Out There**

In my 34 years of cancer survivorship, I have never once met with a dietician, a social worker, or a psychologist as part of my care plan. I have since learned that these specialists are tucked away in the corners of my cancer centre, but I have never known they were there or how they might be able to help. In 10 years of being treated at a large cancer centre, I have never known a primary care nurse. I come in for an eight-minute clinic appointment and I leave. Sometimes I have news to celebrate. Sometimes I cry in the parking lot.

**Patients Need to Connect With One Another**

For over 30 years, I was the only person I had ever known with kidney cancer. Meeting (by accident) another patient with papillary renal cell carcinoma was a life-changing experience. Since then, we two patients have formed a national patient organization so that no one with this disease will ever feel so utterly alone. We’ve discovered first-hand how a survivor support system can make a profound difference for patients and caregivers. As fellow survivors, we educate, inform, and help to fill in the gaps between those eight-minute clinic appointments. We have built a national support system that informs and enriches our individual personal journeys of survivorship. Each story is unique, but none of us is alone.

Deborah Maskens is a cancer patient on the Board of CACC and Vice Chair, Kidney Cancer Canada. Deb is currently undergoing treatment in the United States for a rare form of kidney cancer that still has no publicly funded treatment options in Ontario. © 2009. Deborah Maskens. Used with the kind permission of the author.

### Navigating the Cancer System with a Rare Cancer

Patients who are diagnosed with rare cancers face additional challenges in finding the expertise, treatment options, and support systems that will help them navigate towards their goal of long-term survival. Patients often feel isolated and disadvantaged simply because they had the misfortune to be diagnosed with something not-so-common. In many cases, patients with rare diseases need to take their care plan into their own hands:

**Step 1: Seek an Expert Opinion**

Many kidney cancer patients are still uncomfortable asking their urologist or oncologist about getting a second opinion. Some are afraid of hurting their doctor’s feelings and damaging the local doctor-patient relationship for the long-term.

For kidney cancer patients, that second opinion should be with an expert who sees many cases of kidney cancer per year. Depending upon where patients live, they might expect to travel into a major cancer centre. In my experience speaking with hundreds of fellow patients across Canada, no patient has ever reported that they regretted seeking a referral — only that they wished they had done so sooner.

**Step 2: Build Your Own Multi-Disciplinary Healthcare Team**

Cancer centres are excellent places to treat tumours, but they often fall short of treating the patient as a whole human being. Back in the community setting, the patient’s family doctor can play a huge role as the gateway to a multi-disciplinary team of resources including pharmacists, physiotherapists, dieticians, and counselors.

**Step 3: Learn What You Can From Others in the Same Boat**

Patients with rare cancers often feel that they are entirely alone. Generalized cancer support groups often aren’t always helpful for someone with a non-traditional form of cancer. Specific cancer groups such as Kidney Cancer Canada play a huge role in helping patients navigate the cancer system and learn from one another through online discussions, patient education meetings, and peer support.

**Step 4: Help us Build a Bigger Boat**

Sadly, treatments for rare cancers are often overlooked in public funding decisions. The first two drugs to be approved by Health Canada in over a decade were denied by the Common Drug Review. More recently, the Joint Oncology Drug review recommended against funding a third drug. Patients and families need to raise their voices to help governments understand that it wasn’t our choice to have an unpopular cancer. The choice we make today is to advocate for our own survival.
The Many Surprises of Life and Cancer

ROMAN GAWUR

We all know and expect that life is full of surprises, unexpected twists turns, joys disappointment, ups and downs. We even say, “That’s Life!”

As a Canadian baby-boomer, I have grown up with an expectation and belief that if life zinged me or my family with a truly life threatening situation the “Social Safety Net” would be there to for us. After all, I have paid taxes for over 40 years as well as premiums for private supplementary health insurance. I was fortunate to never require any kind of help from any level of government and I never filed a major claim with the private health insurers. So in my mind I should be more than adequately covered for life's gotcha.

Surprise! I wasn’t.

At the age of 56, I was diagnosed with colon cancer in October 2006. Surprise!

A successful colon resection was performed in November 2006. In January of 2007 it was discovered that I had lesions on my liver that were considered inoperable.

Surprise!

Along with my chemotherapy the oncologist recommended a drug called Avastin to be injected at a private clinic, if I had the means to pay for it. Since Avastin was already approved by Health Canada and covered by British Columbia and several other provinces, I asked why I must pay for it.

I was told the Government of Ontario had decided not to cover Avastin. Surprise!

There appeared to be holes in the Safety Net. Ah, but all was not lost because I had supplementary health insurance which covers drugs. Because the Avastin was going to cost in excess of $30,000, I wrote the insurance company to inform them of the anticipated expense. The insurance company promptly informed me that Avastin was not covered because it's supposed to be a hospital administered drug. Surprise!

So, the provincial health plan will not pay for Avastin. The hospital would not administer cancer drugs that the province would not pay for, forcing the use of a private clinic. The supplementary health insurance company will not pay for the drug because it's supposed to be covered by the province. This is Alice In Wonderland!! From what I thought were two Safety Nets to no Safety Net. I was in free fall.

This was Canada after all, and I shouldn't be forced to sell the "family farm" to pay for life saving treatment. That's only supposed to happen in the big bad USA. Right? I started my chemo without the Avastin and looked for help in finding a private clinic and arranging for the Avastin. If the farm had to go it had to go! The hospital social worker pointed me in the direction of the Avastin Help Line. It turned out that the pharmaceutical company that provides Avastin was funding a compassionate program that not only helped defray part of the drug cost but also coordinated the private clinic where I could be treated. Surprise!

Baby-boomers just don’t know how to take NO for an answer. We have a long history of challenging authority going back to the 60’s. So it was natural for me to challenge the decisions of my supplementary health insurance company and the government.

I discovered that the insurance company had a process for appeals and exceptions. I filed the required documentation and promptly received approval for 75 per cent of the cost for a year of Avastin treatments. Surprise!

I had some great results with my chemo and Avastin. After five cycles the surgeon observed significant improvement and decided I was a candidate for surgery. Upon completing 13 cycles of chemo (nine with Avastin) I had a successful liver resection in August 2007.

Subsequent to the surgery, even though there was No Evidence of Disease, I had another eight cycles of chemo to eradicate any microscopic seeds. I am currently NED for CRC. Surprise!

As for the fight with the Ontario Government over Avastin funding, that is a whole other story. Suffice it to say that the Government of Ontario approved funding for Avastin as a first line cancer treatment drug in July of 2008. Not a surprise!

Roman Gawur is a business executive and colon cancer patient, currently with no evidence of disease, living in Toronto.

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Who is Bearing the Cost?

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

Introduction
Last year we reported on the cost of cancer drugs in Canada. We identified that a small number of new oral take home agents accounted for a large proportion of increasing expenditures which were being met by both public payers and private insurers. We noted that Western Canadian provinces had more comprehensive public funding for these drugs than provinces east of the Manitoba border. The latter were relying more heavily on a combination of private insurers and pharmaceutical company compassionate access/assistance programs. If you had cancer, where you lived in Canada determined if the drug was available to you, and whether you had to rely on private insurance or pay for it yourself.

In this follow-up study we investigate the expenditures in the years 2002 to 2007 in each province for a more comprehensive list of oral take home cancer drugs (THCD). We calculate the proportion of costs allocated to THCD in the cancer drug budget of British Columbia, the province providing the best access to new cancer drugs and with the most comprehensive provincial data for cancer drug utilization. Using this proportion, we estimate the total national expenditure which would be required for all (both intravenous and oral) cancer drugs by public payers and private insurance companies in 2007, to achieve the level of access and utilization in BC.

Again, this study was made possible by the generous provision of the Brogan Inc. claims databases by Brogan Inc. as well individual provincial data by the BC Cancer Agency, Alberta Health Services – Alberta Cancer Board, Saskatchewan Cancer Agency, Newfoundland Cancer Treatment and Research Foundation, and Newfoundland and Labrador Ministry of Health.

METHODOLOGY

The Brogan Inc. Claims Databases
The Brogan Inc. claims databases capture most of the THCD provided by private insurers and public plans (i.e., provincial pharmacare plans) in most provinces except public plan data for BC, Alberta, Saskatchewan and PEI. They did not include public expenditures in Newfoundland for the year 2007.

- The Brogan Inc. Private Drug Plan Database
  This database is comprised of pay direct drug benefit claims paid for the THCD by almost all private insurers in Canada, representing approximately 67 per cent of the total private drug plan business. The database in total collects information on more than 10 million (anonymized) claimants with 91 million prescriptions annually. The reported data were extrapolated to represent the complete private market in that province. Self payment by patients for THCD costs were not captured and neither were private insurance co-pays and deductibles born by the patient. These costs born by patients were not included in the present analysis.

- The Brogan Inc. Public Drug Plan Database
  This database captures take home drugs provided through provincial pharmacare plans including take home cancer drugs. Most intravenous cancer drugs (those given in hospitals and cancer clinics) are not captured, except for those given in private infusion clinics, representing a small but measurable proportion of cancer drugs. These intravenous, hospital and private infusion clinic administered cancer drugs were excluded from the analysis.

- Expenditures in the Brogan Inc. Databases
  The expenditures documented in the Brogan Inc. databases include drug cost plus markup costs which can be composed of a wholesaler markup and retail (pharmacy store) markup. On the private side the markup is unregulated and typically is 10–20 per cent, combined wholesale and retail. On the public side, the pharmacare plan in Ontario mandates the markup at eight per cent for combined wholesale and retail. Other provincial public plans have different markups, usually less than 10 per cent. The markup in Quebec was nine per cent until
June 2007, when it was lowered to seven per cent. Saskatchewan allows a gradual markup: 30 per cent for drug cost up to $6.30, 15 per cent for drug cost between $6.31 and $15.80 and 10 per cent for drug cost of $15.81 to $200.00, and a maximum markup of $20.00 for drug cost over $200.00.

Additional Data from Provincial Formularies
Data for publicly administered THCD for BC, Alberta, and Saskatchewan, which were not captured by the Brogan Inc. databases, and data for 2007 for Newfoundland, were kindly provided to us by the respective provincial cancer agency or cancer board, and the Newfoundland and Labrador Ministry of Health. Public data for PEI which has a small population (140,000) were not requested or obtained.

No public payer data were available for PEI. Public payer data for Saskatchewan, obtained from the Saskatchewan Cancer Agency were based on fiscal rather than calendar year but all other public and private data were reported by calendar year, including private payer data for Saskatchewan.

Establishment of THCD List for Analysis
Last year we looked at 24 newer cancer drugs (including both THCD and intravenous hospital administered drugs) for 42 specific cancer indications. This year we searched for all THCD, both old and new. Using several cancer drug formularies, a list was compiled of all approved antineoplastic drugs which have NOC (Notice of Compliance) and are thus commercially available in Canada. From this list the drugs indicated below were excluded, and any previously unidentified drug used for cancer added.

THCD Excluded in the Analysis
Some THCD are used significantly or predominantly for non-cancer indications, as detailed in Table 1. These drugs were excluded from the analysis. Examples included:

- Tyrosine kinase inhibitors (new “targeted therapies”)
- Supportive medications used primarily for cancer (antiemetics, bisphosphonates, hematopoietic stimulating factors)
- Miscellaneous drugs

Most THCD were oral formulations, but a small number are given by subcutaneous or intramuscular injection.

A final list of 43 THCD was derived, shown in Table 2 and by drug classification in Figure 1.

Final Calculation of Costs for THCD by Province
Expenditures for the final list of 43 THCD were extracted from the Brogan Inc. public and private payer databases as previously described (1). These claims were then merged with the expenditures made available to us by provincial pharmacare plans and provincial cancer agencies, and the Newfoundland and Labrador Ministry of Health to calculate the total cost of THCD by province.

Calculation of Costs Nationally
Total expenditure in all provinces for THCD was calculated for the most recent year studied (2007) for:

- All drug categories
- Only chemotherapy drugs
- Only hormonal agents
- Only tyrosine kinase inhibitors (the new targeted therapies)
- Only supportive medications
- Miscellaneous drugs
- The top ten THCD by cost

Calculation per Incident Cancer Case
In order to provide a perspective on the relative size of expenditures we related drug cost data to the burden of cancer in each province, by expressing the results as dollars per incident cancer case in each province for each year. The numbers of incident cancer cases were derived from the 2002-2007 issues of Canadian Cancer Statistics, Table 3, “Estimated New Cancer Cases by Major Cancer Site.”

Factors that Affect Summary Results of THCD
Several factors determining the total cost for THCD in each province were not adjusted for in this analysis, including:

- Inflation
- Cost-sharing programs with pharmaceutical manufacturers, e.g., compassionate access
- Pharmaceutical manufacturer drug assistance programs
- Manufacturer’s rebates (cash or free drug)
- British Columbia rebates were imbedded in the data provided
- Saskatchewan rebates were not imbedded in the data provided
### TABLE 1  Examples of cancer drugs excluded or removed from analysis for THCD
(significant non-cancer indications or reasons in brackets)

<table>
<thead>
<tr>
<th>Drug</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Azathioprine</td>
<td>(Organ transplant immunosuppression, connective tissue disease)</td>
</tr>
<tr>
<td>Bromocriptine</td>
<td>(Parkinson disease)</td>
</tr>
<tr>
<td>Cabergoline</td>
<td>(Parkinson disease)</td>
</tr>
<tr>
<td>Cyclophosphamide</td>
<td>(Connective tissue disorders, SLE, Wegener's, ITP, AIHA)</td>
</tr>
<tr>
<td>Cyproterone</td>
<td>(Andropause/ hot flushes)</td>
</tr>
<tr>
<td>Erythropoietin</td>
<td>(Anemia of chronic renal failure)</td>
</tr>
<tr>
<td>Interferon</td>
<td>(Hepatitis B and C)</td>
</tr>
<tr>
<td>Medroxyprogesterone</td>
<td>(Hormone replacement therapy, amenorrhea, irregular or abnormal menses)</td>
</tr>
<tr>
<td>Mercaptopurine</td>
<td>(Inflammatory bowel disease and psoriatic arthritis)</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>(Psoriasis, rheumatoid arthritis &amp; connective tissue diseases)</td>
</tr>
<tr>
<td>Short acting octreotide</td>
<td>(Post surgical/bowel obstruction, diarrhea)</td>
</tr>
<tr>
<td>Pamidronate</td>
<td>(Unable to discriminate how much is captured; included in many hospital IV cancer drug budgets)</td>
</tr>
<tr>
<td>Topical tretinoin</td>
<td>(Non-cancer skin indications)</td>
</tr>
<tr>
<td>Zoledronic acid</td>
<td>(Unable to discriminate how much is captured; included in many hospital IV cancer drug budgets)</td>
</tr>
</tbody>
</table>

### FIGURE 1  Take home cancer drugs studied, by category (n = 43)

- Supportive medications, n=7
- Tyrosine kinase inhibitors, n=6
- Miscellaneous drugs, n=5
- Chemotherapy agents, n=12
- Hormones, n=13

### TABLE 2  Final list of THCD (n=43)

<table>
<thead>
<tr>
<th>Drug</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anagrelide (Agrylin)</td>
</tr>
<tr>
<td>Anastrozole (Arimidex)</td>
</tr>
<tr>
<td>Aprepitant (Emend)</td>
</tr>
<tr>
<td>Bicalutamide (Casodex)</td>
</tr>
<tr>
<td>Buserelin (Suprefact)</td>
</tr>
<tr>
<td>Busulfan (Myleran)</td>
</tr>
<tr>
<td>Capecitabine (Xeloda)</td>
</tr>
<tr>
<td>Chlorambucil (Leukeran)</td>
</tr>
<tr>
<td>Clodronate (oral only) (Various/generic)</td>
</tr>
<tr>
<td>Dasatinib (Sprycel)</td>
</tr>
<tr>
<td>Dolasetron (Anzemet)</td>
</tr>
<tr>
<td>Erlotinib (Tarceva)</td>
</tr>
<tr>
<td>Estramustine (Emcyt)</td>
</tr>
<tr>
<td>Etoposide (oral only) (Vepesid)</td>
</tr>
<tr>
<td>Exemestane (Aromasin)</td>
</tr>
<tr>
<td>Filgrastim (Neupogen)</td>
</tr>
<tr>
<td>Fludarabine (oral only) (Fludara)</td>
</tr>
<tr>
<td>Flutamide (Various/generic)</td>
</tr>
<tr>
<td>Fulvestrant (Faslodex)</td>
</tr>
<tr>
<td>Gefitinib (Iressa)</td>
</tr>
<tr>
<td>Goserelin (Zoladex)</td>
</tr>
<tr>
<td>Granisetron (Kyliril)</td>
</tr>
<tr>
<td>Hydroxyurea (Various/generic)</td>
</tr>
<tr>
<td>Imatinib (Gleevec)</td>
</tr>
<tr>
<td>Letrozole (Femara)</td>
</tr>
<tr>
<td>Leuprolide (Lupron, Eligard)</td>
</tr>
<tr>
<td>Leucovorin (oral only)(Leucovorin)</td>
</tr>
<tr>
<td>Levamisole (Ergamisol)</td>
</tr>
<tr>
<td>Lomustine (Ceenu)</td>
</tr>
<tr>
<td>Megestrol acetate (Various/generic)</td>
</tr>
<tr>
<td>Melphalan (Alkeran)</td>
</tr>
<tr>
<td>Mitotane (Lysodren)</td>
</tr>
<tr>
<td>Nilutamide (Anandron)</td>
</tr>
<tr>
<td>Octreotide (long acting formulation only)</td>
</tr>
<tr>
<td>(Sandostatin LAR)</td>
</tr>
<tr>
<td>Ondansetron (Various/generic)</td>
</tr>
<tr>
<td>Procarbazine (Matulane)</td>
</tr>
<tr>
<td>Sorafenib (Nexavar)</td>
</tr>
<tr>
<td>Sunitinib (Sutent)</td>
</tr>
<tr>
<td>Tamoxifen (Various/generic)</td>
</tr>
<tr>
<td>Temozolomide (Temodal)</td>
</tr>
<tr>
<td>Thioguanine (Lanvis)</td>
</tr>
<tr>
<td>Thyrotropin (Thyrogen)</td>
</tr>
<tr>
<td>Tretinoin (oral only) (Vesanoid)</td>
</tr>
</tbody>
</table>
FIGURE 12  PUBLIC pay for take home cancer drugs in Canadian provinces, % increase 2002 to 2007

FIGURE 13  PRIVATE pay for take home cancer drugs in Canadian provinces, % increase 2002 to 2007

FIGURE 14  PRIVATE pay for take home cancer drugs in Canadian provinces, per incident cancer case in 2007
RESULTS

- Public and private payer expenditures for THCD by province, expressed per incident cancer case

Several points emerge as shown in Figures 2 to 11 and Figures 12 to 17.

In the western provinces the proportion paid for THCD by the public system is much higher than by the private insurers. This proportion decreases east of the Manitoba border and by the time the Atlantic Provinces are reached, the ratio of public to private pay is reversed (shown in Figures 2 to 11).

The heavy reliance on private pay for THCD in the Atlantic Provinces dates back to 2002 and in the following 5 years, private pay has been increasing at a faster rate than public pay in every case where data are available (Figures 8 to 11).

Comparing the per cent increases in pay for THCD from 2002 to 2007, in every province the private pay has increased more than public pay (Figures 12 and 13). However, private pay for THCD remains lowest in the western provinces (Figure 14).

The public pay in 2007 for THCD was remarkably constant at $2500 per estimated incident cancer case for all provinces up to and including Quebec then it dropped sharply to less than half of that in the Atlantic Provinces (Figure 15). Conversely, private pay in 2007 for THCD was generally higher among the Atlantic Provinces (Figure 16).

The total (public plus private) pay for THCD has increased from 2002 to 2007 in every province for which we have data, with the greatest pay-outs occurring in Ontario and Quebec (Figure 17).

- Total expenditures in 2007 by drug categories

The expenditures for THCD in 2007 by drug category are shown in Figure 18, and by drug subcategory as indicated in the headings to Figures 19–23.

The top 10 THCD by expenditure are shown in figure 24. This small number (10 of 43) accounts for over 80 per cent of total expenditures for all THCD studied. Only one drug of the top 10 THCD has a generic formulation.

- Calculation of the total expenditure for all THCD in Canada

The total burden of the cost of the 43 take home cancer drugs examined across the 10 provinces amounted to approximately $555.7 million dollars in 2007.

- The BC data

Cancer drugs in BC are provided primarily through the centralized BC Cancer Agency (BCCA) oncology drug budget, while most supportive drugs for cancer such as anti-emetics and filgrastim are provided through the BC Pharmacare plan. The total 2007 expenditure (merged public and private) for the 43 THCD was $65.4 million. This represented more than half (57 per cent) of the BCCA provincial oncology drug budget (which, in fiscal 2007-2008, was $114 million dollars) or 50 per cent of the

![Figure 17: TOTAL PAY for take home cancer drugs by province expressed per incident cancer case for 2002-2007](chart-image-url)

- Reported analyzable differences

*Not available for certain provinces for certain years.*

- Financial analyses

*Some calculations may be affected by data limitations.*

- Data limitations

*Some data may be subject to rounding or other inaccuracies.*

- Reference sources

*Includes various government and private sector entities.*

- Summary of findings

*Includes a brief overview of the report’s key findings.*

- Conclusion

*Outlines the report’s main conclusions.*
total of all cancer drug expenditures in BC (BCCA oncology drug budget + BC Pharmacare plan claims + private payer claims = $130 million dollars).

- Extrapolating from the BC data
  Using the above estimate of the proportion of THCD for BC, we extrapolated the total 2007 THCD drug expenditure of $555.7 million to all 10 provinces. The extrapolated cost of all cancer drugs (both intravenous and THCD) for the whole country to the level of access and utilization in BC, would have been $1.1 billion.

DISCUSSION
The results of this study corroborate the findings of the last year’s analysis of a limited number of newer intravenous and oral cancer drugs1. That study was conducted because of the increasing emergence of expensive oral anti-cancer “blockbuster” agents.

In the present study western provinces’ public payer systems have again been shown to provide more complete coverage for a more comprehensive list of take home cancer drugs (THCD). As one goes further east, the proportion paid by private payers increases to the point where it becomes preponderant in the Atlantic Provinces. This pattern has been consistent for the six years analyzed 2002–2007. In addition, as indicated in last year’s report, the total payout for THCD in the western provinces is consistently higher than in the Atlantic Provinces. The disparities in funding by governments in the eastern provinces will make it more difficult for the evolving Joint Oncology Drug Review to develop a more harmonized approach to address unmet needs for cancer patients.

What has also emerged from the current study is that both public and private payer expenditures are increasing and the increase in private payer expenditures is increasing at a faster rate. Even in BC, which has the best access to public payer funded cancer drugs, private payer expenditure is also increasing.

If this trend continues, it will likely exceed public payer expenditures on a national basis, as has already occurred in the Atlantic Provinces. This shift of funding to the private sector, intended or otherwise by the public health plans, is steadily increasing the burden on employers and individuals who are ill-prepared to deal with these additional costs. Given the cost of the new drugs, access to systemic treatment of cancer is becoming a challenge even when individuals have private health plans because of the co-pays, deductibles and limits to coverage characteristic of many private plans (see A Primer on Private Health Benefit Plans in this issue). Apart from Quebec, where supplementary drug insurance is mandatory, private and public insurers have yet to come to grips with what is happening and coordinate their drug coverage plans in the provinces of Canada.

The present study also indicates THCD represent not only an increasing proportion of costs for all cancer drugs, but a proportion that has reached the neighborhood of 50 per cent.

We have found that a small number of newer agents (10 of the 43 THCD examined) accounts for over 80 per cent of the total expenditure on all THCD. Among these is one of the most expensive drugs, Gleevec. This agent has the most dramatic effect, completely reversing the progress of almost all cases of chronic myelogenous leukemia, previously an inevitably fatal condition if bone marrow transplant could not be performed. It is one of the “magic bullets” for which we have all been waiting but has to be taken on an indefinite ongoing basis.

An interesting observation is that the total expenditure for THCD calculated per incident cancer case was lower in the western provinces (BC, Alberta, Saskatchewan, Manitoba), than in Ontario and Quebec (Figure 17). This was contrary to what was expected, as access to cancer drugs in western Canada was previously found to be better than in provinces east of the Manitoba border. Why provinces with more public access should spend less in total than provinces which have lower public access, is unclear. The gatekeeping role which may restrict access to expensive new drugs may be a primary reason. British Columbia controls access to many expensive new cancer drugs through a mandatory, online (web based) submission of the key clinical data required to support access to evidence-based treatments. In Alberta, many expensive new drugs are restricted to prescription by a specific Alberta Health Services – Alberta Cancer Board oncologist, based on tumour site. Some provinces may have restricted access to cancer drugs because of shortages of care providers and infrastructure for cancer drug delivery, particularly in more distant, smaller rural or small urban communities (See Community Oncology in this issue). An additional factor may be the extent to which markups are allowed to raise costs. The public systems in BC, Alberta and Saskatchewan purchase their THCDs through provincial hospital contracts, thus they leverage best prices, even on single source products, and avoid the markup of retail pharmacies. They dispense through hospital pharmacies, thus further reducing costs to the public purse and the patient.

The total expenditures of $555.7 million for THCD, seems a very modest sum for such a large group of life threatening diseases causing a significant public health burden in this country, and recognizing that in a few short years, mortality from cancer will exceed heart disease as the predominant cause of death in Canada. The estimated total amount of $1.1 billion for all drug costs which we have put forward should be compared to what the public systems currently pay for a large number of other drugs (see Sticker Shock, at the end of this article). Viewed from this perspective, optimal cancer treatment is affordable.

Gaps in the present data set, particularly in the form of
variations in rebates from pharmaceutical manufacturers and drug markups in each individual province, probably contribute to some of the differences in inter-provincial figures. However, we feel the data presented herein are a reasonable estimate of costs of the THCD studied. Also, the data within each province from year to year should not be much affected by these variables.

To corroborate our estimate of the total financial cost of cancer drug therapy, a study of the cost of hospital administered (i.e. intravenous) cancer drugs would be needed to supplement the analysis of THCD presented herein. A study of out-of-pocket self-pay (including co-pay) for cancer drugs, as well as pharmaceutical company assistance and compassionate access programs, would complete the picture of cancer drug costs in Canada.

**Summary**

1. Expenditures on take home cancer drugs (THCD) now represent approximately half of the total for all cancer drugs.
2. An uncoordinated shifting of costs is rapidly occurring from public funding of THCD to private insurers.
3. Employers and insurers should be made aware of the magnitude and pace of these shifts.
4. In western provinces with more comprehensive publicly funded cancer drug programs less is spent in total (public and private expenditures) for THCD than in some eastern provinces with more restricted access.
5. A small proportion of highly effective brand name cancer drugs accounts for the majority of the total expenditures for THCD.
6. Extrapolating from the calculated total THCD expenditure, we estimate the potential cost for all cancer drugs in 2007 to be $1.1 billion to reach the level of access and utilization in BC.

**Recommendations**

There is a pressing need for:

1. A national forum to be held of all stakeholders involved in cancer drug provision including public payers, private payers, patient groups, and drug manufacturers, to deal with rising costs of and variable methods of payment for emerging cancer drugs. Broader sharing of the risk pool is urgently required if individual cancer patients are to be shielded from catastrophic financial burdens just at the time they are literally fighting for their lives.
2. A program focused on improving cancer drug coverage in the Atlantic Provinces, where access is the lowest and cancer mortality the highest.
3. A systematic educational program aimed at employers to make them aware of the size of the cost burden for cancer drugs which they will soon be expected to carry.

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**Robert Kamino** is Vice-President, Consulting Services, with Brogan Inc. and his colleague **Tania Redina** is an economist. Brogan Inc. is a healthcare data, research, and consulting company, providing strategic advice, analysis, data and market intelligence to the pharmaceutical industry, insurers, government, and others involved in the delivery of health care.

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

**References**

All provinces have public drug plans to provide some level of protection for people who otherwise might not buy the prescriptions they need. The provinces concluded long ago there is wisdom in paying for some, or most, prescription drug costs to avert the higher costs of deteriorating health.

Cancer drugs, with their enormous global research efforts, come to market with price tags considerably higher than other drugs. The sticker shock causes provinces to forget what they already pay for everything else. Specifically, the low volume of cancer patients compared to the high volume of patients with other ailments means the total cost of cancer drugs is relatively modest.

To put these costs in context, CACC compiled this brief list of provincial drug plan expenditures in 2007 for the most commonly prescribed drugs in Canada.

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Brand name (if no generics) or chemical name for multiple manufacturers</th>
<th>2007 Provincial Drug Plan Expenditures (Millions)</th>
<th>Indications</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lipitor</td>
<td>$733.0</td>
<td>A statin; lowers bad cholesterol and raises good cholesterol; reduces risk of heart attack and stroke</td>
</tr>
<tr>
<td>2</td>
<td>levothyroxine</td>
<td>$19.6</td>
<td>Thyroid hormone supplement</td>
</tr>
<tr>
<td>3</td>
<td>Norvasc</td>
<td>$304.3</td>
<td>A calcium channel blocker; for high blood pressure and angina pain</td>
</tr>
<tr>
<td>4</td>
<td>acetylsalicylic acid</td>
<td>$10.2</td>
<td>ASA relieves pain, fever, and inflammation</td>
</tr>
<tr>
<td>5</td>
<td>pantoprazole</td>
<td>$107.8</td>
<td>A proton pump inhibitor; reduces stomach acid causing GERD; used with antibiotics to treat ulcers</td>
</tr>
<tr>
<td>6</td>
<td>Crestor</td>
<td>$154.3</td>
<td>A statin; lowers bad cholesterol and raises good cholesterol; reduces risk of heart attack and stroke</td>
</tr>
<tr>
<td>7</td>
<td>ramipril</td>
<td>$138.0</td>
<td>ACE inhibitors; for hypertension and congestive heart failure</td>
</tr>
<tr>
<td>8</td>
<td>Ratio-Salbutamol HFA</td>
<td>$19.9</td>
<td>A bronchodilator, CFC-free; for asthma, chronic bronchitis and other breathing disorders</td>
</tr>
<tr>
<td>9</td>
<td>furosemide</td>
<td>$5.6</td>
<td>Diuretics: for fluid retention</td>
</tr>
<tr>
<td>10</td>
<td>Pariet</td>
<td>$118.8</td>
<td>A proton pump inhibitor; to reduce stomach acid causing GERD; used with antibiotics to treat ulcers</td>
</tr>
</tbody>
</table>

To look at these costs from yet another perspective:
- In these eight provinces, drug plan expenditures for all proton pump inhibitors totaled $610.7 million.
- Ontario’s drug plan alone spent $0.6 million on Tylenol 2, including the generic versions and the eight provinces in this data set spent $8.5 million on all forms/dosages of acetaminophen/codeine/caffeine.
- The central provincial drug plans spent $102.4 million on antiretrovirals (including NRTI, NNRTI and HIV fusion inhibitors) and protease inhibitors for the treatment of HIV/AIDS. This figure excludes numerous separate, provincially funded drug programs for HIV/AIDS.

Prescription drugs are necessary to maintain and restore health. Drugs for life threatening diseases tend to be more costly per unit than other drugs, but the volume of units varies. The top 10 drugs in this table account for 209 million prescriptions dispensed in 2007; cancer drugs are a tiny fraction of the total prescriptions in this country.

References
1. IMS Health, Canada, Compuscript: Pharmaceutical Trends; Top 10 dispensed medications by physician specialty, Canada, 2007; General Practice list. www.imshealthcanada.com
2. Brogan Inc.: Public expenditures, selected drugs, 2007; data available for eight provinces, excluding PEI and NL
3. The requirement for asthma inhalers to be CFC-free had not yet come into effect, and a similar amount, $21.9 million, was spent in 2007 for salbutamol sulfate.
A NATIONAL FORUM
On Catastrophic Drug Costs
and the Insurability of Canadians

Multiple payers including provincial drug plans, employment-based insurance and compassionate programs of the pharmaceutical industry still leave wide gaps in prescription drug coverage. In the absence of reliable drug coverage, cancer patients must choose between financial solvency or the treatment recommended by their oncologists.

The shift from public to private payers, as amply put forth elsewhere in this publication, demonstrates the magnitude of the problem with oral, take home, cancer drugs. A further layer of tension exists for hospital based cancer drugs where provinces delay or deny funding for powerful new agents but “allow” patients to pay the hospitals directly.

Probing into the problems of un-and-underinsured cancer patients who cannot afford their cancer drugs exposes other complex issues under the surface. One of these is the battle between the federal and provincial governments over health care funding: the first one to blink has to pay. Another is the reluctance of most private insurers to assume responsibility for hospital-based drug costs, which they regard as the responsibility of governments. A third example would be the split opinions on whether a new type of coverage should be formulary based or available for any catastrophic drug cost.

Solutions require, at the outset, acknowledgement that a problem exists, recognition that it should be solved, and agreement that failure to solve it is unacceptable. On these points cancer patients are far ahead of their governments.

In some respects, payers, patients and planners simply did not foresee the evolution of the dilemma, arising from a patchwork of policies developed over time, finally converging on the shoulders of patients. The time for denial is past.

The national forum proposed by CACC is intended to engage public and private payers in acknowledgement of the new trend, i.e., retreat from public coverage of cancer drugs that leaves Canadians unaware of their vulnerability and unprepared for catastrophic costs.

When that reality is explored in a collaborative setting, the determination to find new solutions will not be far behind. Employers, insurers, government payers, patient groups and researchers need a voice in this discussion. Each brings information, ideas and useful perspective on the workability of various scenarios.

The forum can be an opportunity to discover new funding partnerships, effectively closing the gap in coverage that poses such a threat to cancer patients. Depending on age, health status and even employment status the 11 per cent of Canadians who are un-or-underinsured have little other opportunity to find protection from unaffordable drug costs. The result should be the introduction of integrated and universal, public-private drug insurance.
A Primer on Private Health Benefit Plans

CHRIS BONNETT

Introduction
This is not about two-tier medicine. It is about the invaluable role played by private health benefit plans, funding that ensures access to medically necessary treatments and services.

While the notion of private healthcare has been widely vilified, it is clear private insurance is essential. Governments could not afford to replace this critical, 20 billion dollar contribution to our national health. Nor can they afford to marginalize this community.

Today, private drug plans account for about $9 billion, or 36 per cent of Canada’s total expenditures on prescription drugs, and cover an estimated 20 million Canadians.

Private drug plans were conceived almost forty years ago when the average prescription drug cost just a few dollars. No one thought these plans would ever cover truly high-cost medications, or provide catastrophic protection. With each passing year, employers and insurers have seen claim costs rise rapidly, but have continued to invest without recognition by governments and their agencies and institutions. Today, private drug plans account for about $9 billion, or 36 per cent of Canada’s total expenditures on prescription drugs, and cover an estimated 20 million Canadians. As a nation, we pay almost $5 billion more out-of-pocket, making a total private contribution of almost $14 billion, or 55 per cent of total prescription drug costs. The private side is no small matter, but so far a largely silent partner at the health policy table.

For many years, the private payer community of employers, their advisors (meaning fee-based consultants and commissioned brokers), insurers, and pharmacy benefit managers have offered very high quality plans, and talked about cost-shifting and cost containment. Built on the skills of actuaries and underwriters, it is the financial dimension that generally dominates, sometimes at the expense of the patients. This does not augur well for benefit plan members (employees and their families) facing catastrophic health costs due to advancing medical technology without the benefit of either a public or private safety net.

Benefit Plan Design
Health benefit plans that supplement Medicare and reimburse dental costs are essentially unchanged since the 1970s. The maximum for some benefits, such as vision care, have increased, some benefits have been added, like acupuncture. Others, seen as less essential or abused, have been controlled.

The core of the plan is prescription drug coverage, and generally, this has remained very generous. There are still some plans with deductibles of $0.35 per drug, dating from when the average price of a drug was about $3.50. The average cost per prescription was approaching $60 in 2007.

There are differences in plan design by region, by industry, by employer size, and by insurer. Regional Blue Cross organizations and some specialty companies tend to have more restrictive plan designs, and more drugs reimbursed only with prior authorization – case-specific review against criteria of varying quality, fairness, and transparency. There are no industry standards for these reviews.

In contrast, the national insurers, such as Great-West Life, Manulife and Sun Life, tend to have plans with broader lists of eligible drugs. The top three insurers control over 60 per cent of the employee benefit marketplace. Each contracts with specialty companies, called pharmacy benefit managers (PBMs), that electronically adjudicate drug, dental, and other health claims on-line and in real time. Paper-based reimburse-
in a recent national survey, 54 per cent of Canadian employees believed their employer-sponsored health benefits continued after retirement. Industry estimates put this figure at closer to 15–20 per cent⁸.

Benefit plans are slowly disappearing, since they lack convenience and the breadth of plan design and cost control tools available to plans managed by PBMs. Most plans have patient cost sharing, typically of about 20 per cent, which for most employees makes the “average” drug reasonably affordable. Employees also typically pay a share of the monthly premiums through payroll deduction. The challenge comes with biologic drugs, and specifically oncology drugs, where the cost can be $10,000, $25,000 or even more per course of treatment. Twenty percent of $25,000 means $5,000, if a full course of therapy is required. Few employer plans outside Quebec have caps on the out-of-pocket expenditures, so most Canadians face serious financial hardship for any such drug not provided by the province or hospital formulary. This is exactly why there is a need for a truly national—and not just public—pooling mechanism to protect patients. For many of the sickest among us, serious or prolonged illness presents a significant, and sometimes catastrophic, financial hardship.

And this is Canada, 40 years after the introduction of Medicare.

Benefit Plan Quality
The good news is that employers know benefit plans are highly valued by plan members, and beneficiaries are highly satisfied with their plans. In the 2008 sanofi-aventis Healthcare Survey, 57 per cent of 1,500 respondents said their benefit plan was excellent or very good. Though they obviously cover different things, by comparison, just 35 per cent described Canada’s public healthcare system as excellent or very good.⁴ A year earlier, the same survey indicated a majority of plan members believed all Canadians should have access to benefits similar to those they had through their employers.⁵ Access to both public and private health plans is the true standard of care, protection, and security.

Benefit plans are important as a recruitment and retention tool for scarce skilled labour. Good quality benefits are linked to job satisfaction, loyalty, and employer image.⁶ While our current economic woes will undoubtedly affect hiring plans, the longer-term trend suggests benefit plans will remain high quality and comprehensive.

The Demographics of Cancer
Cancer is justifiably associated with aging; in fact, about 70 per cent of all cancers are diagnosed after age 60. That leaves about 30 per cent occurring in the working age population, those ages 18-60.⁷ There are two implications from these statistics. First, in a recent national survey, 54 per cent of Canadian employees believed their employer-sponsored health benefits continued after retirement. Industry estimates put this figure at closer to 15–20 per cent⁸, although those employed in the public sector, in large companies, or with collective bargaining agreements are more likely to retain their benefits, at least in part. As more of the working population nears retirement, there will be some rude awakenings.

Second, with almost one-third of cancers diagnosed among the working age population, many employers are likely to be surprised to learn they have a significant, devastating, and emotionally-charged disease to integrate into their health strategies. One large insurer reports cancers are the third largest cause of long-term disability.⁹

Benefit Plan Funding
The largest cost of these plans is borne by the “plan sponsor”, typically an employer, but sometimes a union, or a joint management-labour trust. The employer pays the insurer a monthly premium depending on the plan design, the spread of risk (i.e., the number of people covered and the cost of claims), and the administrative cost. Provinces also charge taxes on insured premiums for life and health benefits.

Larger employers, those with at least 100 employees, may choose to self-insure their drug plans, and retain an insurer to provide administrative services only (ASO). The employer does this believing the year-to-year costs are relatively predictable, to pay lower administrative fees and to gain more control over the plan design.
A major irritant for the private payer community has been a sense that governments are constantly off-loading costs from health ministry budgets without regard to who will ultimately pay.

Since most small employers, those with 50 or fewer employees, cannot handle the cost of anything other than routine claims, they typically get a standard plan that is entirely the risk of (“fully insured” by) the insurance company. They pay a monthly rate based mostly on the claims experience of a group of similar employers (the “pool”), plus an administration fee that often includes a commission for the broker or agent, as well as taxes. One widely held perception is that those “rich insurance companies” absorb all the claim costs, not the employer. People therefore might think they can claim with impunity. However, this is not true except for the smallest companies. Sooner or later, your employer will pay, so sustaining these plans becomes a shared responsibility of plan sponsor and member alike.

**Benefits by the Numbers**

Benefit plans, like their public Medicare and Pharmacare counterparts, are under serious financial strain; annual costs escalated at 400 per cent of the Consumer Price Index between 1985 and 2007. Private drug plan costs doubled between 2000 and 2007. Like government plans, this is not sustainable. Unlike public plans, private health benefit plans are not mandatory, and changes can be made except where governed by collective bargaining and for people already retired.

Employers face huge pressure to maintain the status quo, and there is evidence that significant attempts to weaken health benefit plans may be met with serious resistance by beneficiaries. The 2005 sanofi-aventis Healthcare Survey reported that 71 per cent of private plan members agreed that government regulation and minimum standards were needed for health benefit plans. Two years later, the same question garnered 78 per cent agreement. We can safely conclude that companies cannot act in a vacuum, and most will not take a decision to curtail coverage lightly...unless and until they are desperate.

A major irritant for the private payer community has been a sense that governments are constantly off-loading costs from health ministry budgets without regard to who will ultimately pay. Too often it will be patients, patients, patients.

**Why does pooling matter?**

Imagine you’re the decision-maker at a small or mid-sized company. A cancer patient, or someone with rheumatoid arthritis (RA), could benefit from access to one or two biologic drugs. This class of drugs is often highly effective... and incredibly expensive. It would be easy to spend $25,000 annually for each course of therapy.

Even if you can afford it, you’re thinking of trade-offs. If $25,000 bought a biologic drug that would allow an employee disabled from RA to return to work, that could be a wise investment. What if that money bought a drug not provided by your provincial cancer agency that would extend the life of a terminal cancer patient by a few months? But is either better than spending $25,000 to vaccinate 50 young women against HPV, the cause of cervical cancer? Perhaps those funds could buy some new equipment that would improve your plant’s productivity and pay for itself in three years.

It can get more complicated. What if the cancer patient were the company owner; what if the drug was for a secretary who had worked for you for twenty years? A shipper with just three years’ experience? This is not a rare event for companies. There are no wrong choices, but there are winners and losers. This is the outcome of drug policy that is stuck in silos, started forty years ago, and that hasn’t kept up with drug costs, patient needs, or employer realities.
many with high cost drug regimens. Out-of-pocket expenditure on prescription drugs was estimated at nearly $4 billion in 2007; fortunately, individuals have faced the slowest growth in their costs, though still up 52 per cent between 2000 and 2007.11

**Government v. Employers?**

There is another factor that could affect costs and therefore access: a much more dynamic marketplace. Changes to Ontario’s public Drug Benefit programs, under the ironically-named Transparent Drug System for Patients Act, and British Columbia’s PharmaCare plan have introduced “competitive bidding” for certain drugs. In each case, the tendering process requires the drug manufacturer to pay a confidential rebate to the province in exchange for being granted a period of market exclusivity by the public plan.12 While this has affected only one drug in BC, olanzapine, competitive bidding has affected both brand-name and generic drugs in Ontario. In addition to reducing the price to the province, the Ontario deal has also reduced the mark-up and professional fees paid to pharmacies. The combined effect is a cost reduction of $260 million to the Ontario government in 2007-08.13

While this has successfully reduced the government’s cost, it has also left their “silent partner” private drug plans behind. Pharmacies and some drug manufacturers have been quick to hit private plans with higher costs to compensate for the margins they no longer receive from government plans.

In fact, the Competition Bureau estimated in 2008 that Canadians could save up to $800 million annually on generic drugs—20 per cent of the $4 billion Canadian generic market—with the largest part of that potential ($540 mm) resting in the private market.14 To the extent private plans do not demand their insurers, pharmacy benefit managers, and/or consultants negotiate similarly reduced drug prices—brand-name or generic—higher prices can only increase the pressure on employers to control costs and limit their exposure to a newly competitive marketplace.

One way this will play out is through increased scrutiny of medications that are expensive, that are commonly misprescribed by physicians or abused by patients, or deemed unsuitable for employer plans. On this last point, intravenous cancer drugs are ineligible under most employer plans because they are typically infused in-hospital and are therefore seen to be a publicly insured service.

**Everyone into the Pool**

Pooling is an important element of plan design and financing. Especially for the smallest group plans, risk is too volatile to be borne by one or a few employers, so it is shared among many.

Eventually, whether large or small, most plans will be hit with a large claim. To protect against this, insurers offer optional protection against high-cost claims, called stop-loss pooling. When an unexpectedly large claim occurs, e.g. over $10,000, the risk transfers from the employer to the insurer. This works well, until the second large claim hits, and then insurers tend to significantly increase the cost of the pooling protection. Sometimes, the employer can no longer afford it, so the plan terminates or transfers to another insurer. The second insurer, however, rarely takes on a risk without knowing as much as possible about it. Typically, claims experience is provided, and with a smaller group of insurers these days, there are few secrets. The employer will invariably end up paying more.

**The Better Way**

Quebec has had a province-wide, public-private drug regime since 1997. Employers there are required by law to offer a drug program with coverage at least as extensive as the government plan if they offer any other health benefits. The insurers active in that market support a high-cost (catastrophic) drug claim pool that spreads risk across all players and reduces pool charges in both cost and volatility.

Outside Quebec, neither private insurers nor governments have yet developed adequate, integrated protection from catastrophic drug costs. As a result, there are large and growing gaps in coverage, and cancer patients are among the most exposed.

It is time that void was filled.

**Healthy Workplaces**

Traditionally, employers, their consultants and insurers have focused on managing costs after illness and injury occur. Absence and disability are expensive; data from Statistics Canada indicates the wage-only cost of absence for illness and disability can be estimated at $13.8 billion in 2007.15 One insurer reports that each new long term disability claim requires a reserve of about $60,000.16 After seeing the incidence and duration of absence and disability climb relentlessly for many years, employers have begun to turn to the idea of prevention.

The risk factors for many cancers are the same or similar as for most chronic diseases: poor diet, excess weight, too much alcohol, smoking, sedentary lifestyles, and chronic, high levels of stress. In fact, research indicates the last factor can quintuple the incidence of colorectal cancer.17 Almost any strategy or program that addresses these root cause issues will benefit cancer prevention efforts as well as heart disease, diabetes, obesity, osteoarthritis, hypertension, asthma, and other conditions.

At this point, a preliminary search of published studies and articles suggests that cancer is not a primary driver of these workplace health promotion programs. A
comprehensive approach does not appear to exist, though at least one approach is under development and should be launched in 2009. Some organizations, particularly hospitals, have organized screening programs for their staff, but results are not generally known, measured, or communicated externally.

Illness and injury manifest themselves not only through the habits of workers on and off the job, but also the way work is organized (control, demands, pace), and how people are selected and prepared for their jobs. So, health promotion programs are not enough. Much of the stress in today’s workplaces is actually controllable by management and leadership, through their policies and practices. Organizations that carefully select, train, and support workers in their jobs tend to mitigate stress and have healthier work environments. These considerations can propel a company from being an also-ran towards being an “employer of choice” in the race for scarce talent.

And this is what company sponsorship of employee benefit plans and health promotion programs is all about: high performing organizations are dependent on a healthy, productive, engaged, and loyal workforce. This motivation is entirely honourable and is the mark of good corporate citizenship, but it is very different that what compels governments to provide health services to a population. Disease management strategies and advocacy needs to be adjusted accordingly.

**What is Critical Illness coverage?**

A recent BMO Nesbitt Burns survey reported just 26 per cent of Canadians have a plan to deal with a future need for health-related assistance*. Plan members are beginning to see alternatives to employer-paid plans emerge. Individual plans for Medicare Supplement have been available for some time, traditionally through Blue Cross organizations across Canada.

But new types of voluntary coverage are needed, particularly for critical illness (CI). In the 2007 sanofi-aventis Healthcare Survey, 62 per cent of 1,700 benefit plan members said they were willing to pay personally for this kind of coverage. CI plans provide a lump-sum benefit upon diagnosis of a listed serious illness and after survival for a minimum period of time (e.g., 30 days). The most common diseases are cancer, heart attack, and stroke, but plans vary in their coverage. Primarily sold to individuals, group CI coverage is new and sales have been limited. Consequently, several conditions exist.

Basic plans have a minimum amount (e.g., $10,000 or $25,000 for larger groups) usually mandatory for all employees, but available without proof of good health in larger groups. More employer-funded coverage is usually offered after providing additional health information, up to $50,000 for smaller groups, and up to $100,000 for larger groups. There are often exclusions for pre-existing conditions. Voluntary plans, fully paid by the employees, may also be available; again, proof of good health is required.

* News release, March 29, 2007: Caring for Aging Relatives Taking Toll on Boomers According to BMO Study.

**Trends, Established and Emerging**

Benefits have been remarkably stable, and increasingly valued by those who have them. In 2007, a national survey reported that 61 per cent of 1,500 Canadian benefit plan members would rather have their health benefit plan than $20,000 in cash. By all measures, that is an irrational amount but shows the tremendous security and peace of mind these plans deliver. People know there are gaps in Medicare, and those gaps can be financially crippling. This incredible perceived value, added to 15 years of economic growth, plus demographic changes and a shrinking labour pool, has made Canadian executives loathe to cut these entitlements. Now that recession is upon us, is this likely to change?

For longer-term and strategic decision-makers, the economic malaise will pass, though the next year or two may be quite painful. However, the demographic pressures will remain for many years, particularly since the average age of retirement in Canada is now 62, and the oldest Boomers turned 62 in 2008. The younger generation, sometimes affectionately labelled Generation Y, has been reported as fickle about their jobs and very mobile given their relatively small numbers. Hence, employee loyalty and engagement are terms now very well known to every Canadian Chief Executive.

Managing benefits remains largely an administrative role, and the economy and global competition will ensure continuous pressure to trim costs. However, considering the larger demographic and workforce trends, access to good quality health benefits is unlikely to be seriously affected. That noted, smaller employers will be considerably more likely to make changes to protect their cash flow. Those approaching retirement are likely to see their entitlement to health benefits diminish or disappear. And, if the number of companies going into
Intravenous cancer drugs are ineligible under most employer plans because they are typically infused in-hospital and are therefore seen to be a publicly insured service.

receivership and bankruptcy significantly increases, then another segment of the labour force will lose access and be exposed to financially catastrophic health care costs.

In this newly tumultuous marketplace, ethics will probably emerge as an important factor. Patients who need cancer drugs and other services deserve fair and appropriate access. Right now, entitlements vary according to whether coverage is private, public, or both; employment status; employer plan design and eligibility, and what the patient can afford. Under most plans, treatment location matters (hospital or clinic), and so does the form of the medicine (oral pills versus infusion). To add more variability, personal awareness, assertiveness, and health literacy also factor in. The various combinations and permutations of these factors mean not all patients will get what they need when they need it.

The Outcome
For twenty years and more, there has been a continuous stream of issues and threats, but the result has been minimal change. The benefits community is very conservative, but its diversity and proprietary aspects mean major trends are hard to detect and study. It could be that talk of more restriction will remain just that.

Where to From Here?
Given the tremendous importance of health care among Canadians, and our innate sense of fairness, the status quo is unlikely to be acceptable for much longer. Drug budgets will ultimately have to be restructured and resources reallocated to those most in need at the expense of others. We need to bring governments and the private payer community together, and the Cancer Advocacy Coalition of Canada (among others) has suggested that just such a forum be convened.

The goal of this dialogue cannot be more study. Beyond building trust, dialogue, and mutual respect between employers and government, the goal must be comprehensive, cross-Canada action to create standards and sustainable solutions. The beneficiaries are the parties themselves—payers who might generate significant public goodwill and finally play on the same field with clear, consistent rules, and the patients who may finally receive the protection they need from unaffordable drug costs.

Chris Bonnett, MHSc, is President of H3 Consulting, and co-founder and Editor of businesshealth, a periodical that addresses employer issues and opportunities in health benefits and healthier workplaces. He also serves as Vice President, Workplace Strategies for Canada’s Corporate Roundtable on Cancer Control. Prior to establishing H3 in 1999, Chris had an 18-year career underwriting, reinsuring, selling, and marketing employee benefits.

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The 6th Vital Sign in Cancer Care

WHY SCREENING FOR DISTRESS IS CHANGING PRACTICE

BARRY D. BULTZ

While the discipline of psychosocial oncology is relatively new in the field of cancer care, many if not most health care providers, would say that it is a vital component of clinical care and its application is necessary to improve the patient experience along the cancer care continuum from diagnosis, treatment, recurrent disease, palliative care and survivorship. Historically, this acknowledgement has been the politically correct response. Unfortunately, however, institutional funding for psychosocial care has been quite limited and services across Canada vary with less than two per cent of cancer programs’ operating dollars directed to the emotional care of the cancer patient.¹

As a society, when we talk about cancer, despite all the biomedical success and advances, we are all fully aware of the life-threatening issues associated with this illness. Susan Sontag, after being diagnosed with breast cancer, wrote *Illness as a Metaphor* and articulated her distress with cancer by saying she saw cancer as being synonymous with death, pain and suffering.²

Traditionally, cancer care has focused on the tumor and the biomedical aspect of treatments with survival being the sole endpoint. This is quite understandable given the focus on acute and inpatient care. However, care of the cancer patient has been changing. Today, cancer is being treated as a chronic disease with the focus much more outpatient oriented. In 1992, at the first National Forum on Breast Cancer, a panel of experts was asked where they thought the most significant changes in cancer care had taken place. David Beatty, then President of the National Cancer Institute of Canada, stated that he believed the greatest changes were occurring with the inclusion of formalized emotional care programs for the cancer patient.³

That was over 15 years ago. What was driving this change? I believe it came from two sources: i) the patient advocacy networks, and ii) ethical issues surrounding “informed consent”—the patient’s right to know the full extent and impact of cancer and the complex side effects of treatment. No longer was it possible

Institutional funding for psychosocial care has been quite limited and services across Canada vary.
There appears to be a groundswell of interest and commitment to the recognition of distress as the 6th vital sign.

In routine medical practice, vital signs are recorded by health professionals in order to assess basic bodily functions and area considered an essential part of a patient’s case presentation. The four vital signs which are standard in most medical settings: body temperature, pulse (or heart rate), blood pressure and, respiratory rate.

In 1999, the National Pharmaceutical Council and the Joint Commission for the Accreditation of Healthcare Organizations in the United States endorsed Pain as the 5th Vital Sign. In June 2004, given the prevalence of distress and benefits of psychosocial care to the cancer patient, the Canadian Strategy for Cancer Control took the bold step of endorsing emotional distress as the 6th vital sign in cancer control.

To get buy-in, after several publications and presentations directed to the professional community, there appears to be a groundswell of interest and commitment to the recognition of distress as the 6th vital sign. For example, in the Canadian Partnership Against Cancer (CPAC) 2007–08 Annual Report, screening for distress and recognition of distress as the 6th vital sign was designated as one of CPAC’s priorities for the next five years. As well, and most significant, the Canadian Council of Health Services Accreditation (Accreditation Canada) will include screening for distress as the 6th vital sign as a new accreditation standard commencing in 2009.

While many new initiatives have recently surfaced to support the cancer patient, including the Institute of Medicine’s report on Cancer Care for the Whole Patient, the challenge will be implementing the changes by adding the necessary resources to assure that patients’ concerns are being adequately addressed in a timely way by properly trained professionals. With persistence, effective use of research, education and evidence-based practice the culture of oncology care is showing signs of change. The timing seems ripe and the opportunities within our grasp to change practice.

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Supportive Care of Cancer Survivors

DAUNA CROOKS, ROSEMARY COLUCCI, MARGARET FITCH, DANIEL GILLESPIE, LYNN HRYNIUK AND WILLIAM HRYNIUK

Introduction
There is no agreement on exactly who is a cancer survivor; definitions range from anyone with a diagnosis of cancer\(^1\) to only those reaching landmarks such as five year survival.\(^2,3\) With the advent of newer and more effective treatments and screening, three per cent of Canadians (one million) are now cancer survivors, and cancer is considered a chronic disease. Attention has been recently focused on the range of psychological and physical problems cancer survivors face, that can be incapacitating or even life threatening.

Early literature discussed survivorship as dealing with negative psychological aspects of the cancer experience. Thus, survivorship was known to carry a price in terms of these sequelae, with issues related to psychological, social and spiritual aspects of well-being.\(^4\)

Clarity around survivorship is beginning to unfold. In a concept analysis of survivorship, Peck\(^5\) identified the following characteristics:

- confronting mortality and trust in life;
- dealing with alienation and isolation;
- searching for meaning and growth;
- needing to reprioritize life; and
- coming to terms and moving on within a continuing identity as a cancer patient.\(^3\)

In order to address these needs a variety of supports are needed for survivors to accept past life altering events, assimilate an altered self image and adapt to a modified (uncertain) future.

In addition to constant anxiety of disease recurrence, more recent studies have recognized a plethora of physical problems in survivors, especially those who received more intensive treatment. Among these are prolonged or delayed side effects in specific organ systems, altered physiology resulting in increased risk for obesity, and some combination of heart disease, diabetes, hypertension, or osteoarthritis (collectively known as the metabolic syndrome), and debilitating fatigue.\(^7\) Sexual dysfunction can also be particularly troublesome and is frequently overlooked or inadequately treated. As a result of all of these residua, survivors have a higher than normal death rate from non-malignant disease, and are among the most frequent claimants for long term disability insurance based on physical causes.\(^8\)

Common to all of these problems is some degree of distress, extending along a continuum ranging from feelings of vulnerability to disabling problems such as depression, and spiritual crises. Distress (or suffering) may interfere with the ability to cope effectively with the long term issues related to cancer survivorship.\(^9\)

Failure to achieve healthy resolution of distress may result in unhealthy behavior and many of the complications faced by survivors.\(^10\)

Recognition and successful management of distress by psychosocial and other supports can have substantial benefits. There is now considerable evidence that diet changes and increased exercise can not only prevent cancer but can also prevent cancer recurrence.\(^11,12\) Combinations of exercise and counseling can combat cancer-related fatigue,\(^13,15\) and exercise can reduce depression.\(^14,16\)

Interventions can enhance the quality of life and improve caregiver-patient communication resulting in better adherence to survivor recommendations geared to active treatment.

Given the threats to survivors’ mental and physical well-being, the impact of survivors’ disability on the workplace and society, and the effectiveness of interventions to circumvent a downward spiral to disability, clearly, more attention must be paid to supportive care for cancer survivors. This would encompass the range of activities that help survivors and families cope with the burden of illness, namely assistance with:

- adjustment to the physiological and psychosocial effects of having gone through treatment for cancer,
- alleviation or avoidance of the prolonged or delayed side effects of treatment, and
- education regarding the lifestyle changes required to reduce risk of recurrence of cancer and other chronic diseases sharing risk.
The Role of Nurses in Managing Survivorship Issues

Oncology physicians are increasingly preoccupied with efficient and effective application of newer technologies, are not trained in the techniques required for supportive care interventions, and do not have the time or education to provide the support survivors require. Given the predominant style of practice of cancer medicine in Canada (in institutionally-based nurse-doctor teams treating cancer patients in government-supported cancer centres and clinics), oncology nurses are strategically placed at the front line to deal with many of the issues facing cancer survivors. Secondly, their education amply qualifies them to take a leading role in both supportive care and screening, as well as successful delivery of the interventions listed earlier.

In an earlier survey conducted by CACC, oncology nurses across Canada were interviewed to determine the extent to which they were providing supportive care to cancer patients receiving active systemic (drug) treatment. The results of the survey indicated nurses were providing a level of support that could be considerably enhanced through administrative and attitudinal change. From that survey, improvements were recommended in physician control of clinics, attitudes of physicians and others in the instrumental role of nurses in supporting physician work and lack of understanding regarding the legislated scope of nursing practice. As a sequel, the present survey was conducted to determine in more detail the level of supportive care provided to survivors who had completed treatment for their cancer.

Methods

Staff nurses and nursing supervisors in medical oncology clinics across the country were interviewed or re-interviewed (90 per cent). Staff nurses were asked whether they personally provided supportive care to cancer survivors. Nursing supervisors were asked about both their clinic nursing policy with respect to support for survivors, and the extent to which they perceived staff were delivering such care. As part of the interview, both staff and supervisors were encouraged to voice their personal opinions regarding issues related to providing care for cancer survivors.

Emphasis was placed on interviewing nurses and supervisors in larger centres only to gauge the priority placed on supportive care within the formal cancer treatment system. The number interviewed is smaller than in the 2007 survey.

A standard set of questions was designed to probe the characteristics of the respondents’ practice, details of what they provided to survivors attending follow-up clinics, and the degree of responsibility they had in doing so.

They were also asked if patients completing treatment were being provided with a written survivorship care plan detailing: 1) the treatments they had received; 2) the toxicity they had experienced from those treatments; 3) schedules and tests for follow-up; 4) which caregiver would be responsible for what aspects of continuing care; and 5) advice on how to reduce risks of: (i) recurrence of the original cancer; (ii) occurrence of another cancer; (iii) development of delayed treatment complications; and (iv) development of chronic diseases (metabolic syndrome) sharing risk factors with cancer.

They were questioned whether patients and survivors were being screened for distress. A positive reply required that the screen used was a comprehensive standardized instrument eliciting details of the type and extent of distress such as the Basic Symptom Inventory (BSI) or the Centre for Epidemiologic Studies Depression Scale (CES-D) questionnaires. A simple question asking if the survivor felt distressed was not deemed sufficient to qualify as a screen.

The survey questions can be accessed on-line in the appendix to this paper at www.canceradvocacy.ca.

Telephone Interviews were conducted by an oncology research nurse with extensive administrative and personal experience delivering supportive care and primary nursing during and after a patient’s active treatment.

Respondents were assured their identity and the identity of their clinic would be kept confidential.

No statistical tests were conducted; the results are presented in descriptive form.

No attempt was made to determine the extent to which supportive care services were being provided to survivors by other categories of health care personnel in each centre.

RESULTS

Characteristics of the Nurses Interviewed

Twenty-two nurses (12 nursing supervisors and 10 staff nurses) were interviewed from 20 clinics across Canada. With two exceptions, the staff nurses interviewed were from different clinics than the nursing supervisors. Twenty of the nurses were practicing in multidisciplinary centres that also provided radiotherapy, and two were in clinics where radiotherapy was not provided.

Primary nursing was the predominant practice model (68 per cent), where nurses were partnered with a doctor or team and the team provided care to a particular group of patients on a continuing basis.

Staff nurses stated they spent on average 80 per cent of their time performing nursing duties; for administrators it was 25 per cent or less of their time in direct care.

All were full-time with one exception, and all were involved in the care of patients receiving systemic treatment, predominantly drug therapy (data not shown).
Screening for Distress
Only 59 per cent of nurses indicated their practice was to screen for distress all patients about to undergo treatment. Even fewer (18 per cent) reported routinely screening survivors for distress.

Nursing Time Spent Providing Supportive Care to Survivors
Table 2 shows the percentage of survivors reported as receiving supportive care from nurses and the associated time involved, with a further breakdown of those survivors who received care from the same nurse during active treatment. In each case the staff nurses estimated a lesser degree of coverage and a relatively smaller fraction of their time on these aspects than did the supervisors: 15-41 per cent vs. 33 to 47 per cent respectively. However, it must be pointed out that the supervisors interviewed were from different centres than the staff nurses in all but two instances.

Per Cent of Centres in Which Nurses Reported Providing Supportive Care to Survivors
Table 3 depicts the provision of a specified range of support and advice to survivors. In a large proportion of centres they reported activities focused on alleviating the persistent symptoms from side effects of treatment, although they did not develop a planned approach in most instances. A lower proportion said they directed their attention to reducing the risks of delayed side effects of treatment or risk of cancer recurrence in survivors. The least amount of attention seemed to be paid to reducing the risk of those chronic diseases that share risk factors with cancer. In 70 per cent of centres, nurses reported they provide sexual counseling to survivors attending their clinics.

In 85 per cent of centres, responding nurses reported that survivors were able to contact clinic nurses by telephone for advice after treatment was completed. Survivors usually received this form of support from triage nurses tending the phones on a rotating basis, rather than the particular nurse who had cared for them during active treatment.

Provision of a Survivorship Care Plan
Only one centre (five per cent of the total) reported that a survivorship care plan was provided to patients after treatment was completed.

Ongoing Developments
Positive trends were reported in some centres where a team worked together for patient care. Pilot projects were occurring to navigate newly diagnosed patients and survivors through their cancer journey. New and continuing linkages with community nurses and other services, including existing support groups, were mentioned as important to survivorship experiences. Some centres were working on the creation of survivorship plans, case summaries and psycho-educational interventions. There was considerable heterogeneity in the extent to which these new initiatives were being pursued in each centre.

| TABLE 1 Characteristics of the Nurses Interviewed |
|---------------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Prov. | Supervisors | Nursing Model | Time spent in patient care |
| | | Primary Care | Other | 0–25% | 26–50% | 51–75% | 76–100% |
| A | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 2 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| B | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 2 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| C | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| D | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| E | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 2 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 3 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 4 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 5 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 6 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Staff | | | | | | | |
| A | 3 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 4 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 5 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| D | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| E | 2 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 7 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 8 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 9 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| F | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| G | 1 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

✓ = Yes
Blank = A response of “No”
Dash = No response

Average 80%

Barriers to full scope of nursing practice
Similar to the last survey in 2007, barriers were identified that impede provision of the type of care nurses wished to provide for cancer survivors. For example, it was stated that no role was identified for nurses to provide supportive care in cancer centres where psychology or social work dominated. Some centres did not protect time for nurses to research and create formal plans for patients. Others did not allow overtime when nurses
TABLE 2  Survivors, Supportive Care and Nursing Time Spent

<table>
<thead>
<tr>
<th>Prov.</th>
<th>Centre</th>
<th>Survivors reported to be receiving supportive care</th>
<th>Survivors reported to be receiving supportive care from their original primary nurse</th>
<th>Nursing time reported to be spent on supportive care for survivors</th>
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<tr>
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<td>0–25% 26–50% 51–75% 76–100% 0–25% 26–50% 51–75% 76–100% 0–25% 26–50% 51–75% 76–100%</td>
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<td>Avg.</td>
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<td>47% 46% 33%</td>
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<td>Prov.</td>
<td>Staff</td>
<td>0–25% 26–50% 51–75% 76–100% 0–25% 26–50% 51–75% 76–100% 0–25% 26–50% 51–75% 76–100%</td>
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✓ = Yes  
Blank = A response of “No”

normally made end-of-shift follow-up calls to monitor patient or survivor adherence to plans. Limitations imposed on nurses’ scope of practice also prevented provision of supportive care, and resulted in lack of development or adoption of guidelines for survivorship care, assessments for risk or screening for distress. Nurses reported poor morale and feeling undervalued when their desire to provide comprehensive care was hampered by the roles assigned to them in their respective clinics by physicians, psychologists or administrators.

**Discussion**

The present survey was intended to provide a snapshot of supportive care being provided to cancer survivors by oncology nurses. Therefore, conclusions regarding the general applicability of the observations must be tempered by the limited sampling and small numbers. Nevertheless, several points did emerge.

Nurses are definitely engaged in supportive care of survivors, but the extent seems limited in the sample surveyed. First of all, in only 18 per cent of centres did
the nurses report that they routinely screened survivors for distress (according to criteria described in the Methods section). Secondly, staff nurses stated that only 28 per cent of survivors receive supportive care in their centres (supervisors put this number at 41 per cent) and that they spend only 10 per cent of their time providing supportive care to the survivors within their own practices (or 44 per cent according to the supervisors). Finally, in 22 per cent of the centres, nurses reported they are not engaged in providing any support to survivors in the form of advice on how to reduce the risk of cancer recurrence, risk of delayed side effects of treatment, or risk of other chronic diseases.

On the other hand, nurses in all centres and clinics are providing advice to survivors on how to deal with ongoing symptoms from side effects of treatment, and 85 per cent said they can be accessed by telephone when advice was needed. In addition, when nurses were involved in providing the breadth of services indicated in Table 3, their reach was comprehensive, as evidenced by the string of responses on each item shown in the Table. They evidently are responding to the needs of survivors and providing the full gamut of services when given the opportunity to do so.

An indication of how much improvement is still required was highlighted by the fact that, in only one of 18 centres is a written survivorship plan being provided to patients after they have completed treatment.

More needs to be done for survivors and it seems clear nurses are already engaged in the endeavor. The question is how to proceed. In regards to the psychosocial aspect, the strategies required for assisting someone to stop the spiral towards turmoil without resolve are known to nurses and could be readily incorporated in follow-up dialogue. As stated by Yu Ko and Degner, the uncertainty is modified by facilitative patient-provider communication, cognitive reframing and problem solving, resulting in achievement of a new and stable perspective. Rancour identifies a simple script for nurses to manage the existential crisis faced by survivors. Open communication is an essential element to adjustment and one that cancer nurses have identified as being practical, even if it has to be done on their own time. Moreover, nurses have the knowledge and opportunity to help individuals reduce the various life-style induced risks afflicting survivors.

This is not to say that other health care professionals should not be active participants in providing supportive care to cancer survivors. Indeed there must be assurance that interventions requiring expertise beyond the scope of nurses are readily available, such as from psychologists, psychiatrists, social workers, nutritionists, and exercise physiologists. However, nurses, as front line providers and points of contact, should and do play a central role in any multidisciplinary effort.

**Role of CPAC**

Fortunately, the Cancer Journey Action Group of the Canadian Partnership Against Cancer (CPAC) has recognized the deficits identified in this survey in supportive care for survivors and those on active treatment. The Action Group continues to provide leadership aimed toward changing the system of cancer care delivery so that patients’, survivors’, and family member needs are better served. Two strategic directions have been identified for its activity:

- One strategic direction is aimed toward achieving the vision of integrated person-centered cancer care. Two primary interventions will be mounted to accomplish this vision. Both are based on accepted standards and guidelines for supportive care of cancer patients and required additional education in person-centered care for all providers:
  1. Implementation of screening for distress (6th vital sign) programs in jurisdictions across the country
  2. Implementation of navigation (professional, peer, virtual) programs in jurisdictions across the country.
• The second strategic direction is survivorship. A Task Group is being organized to provide leadership in cancer survivorship based on the priorities agenda established at the Canadian Workshop for Cancer Survivorship held in March 2008.

Conclusions and Recommendations
Based on the survey evidence, the literature and work proposed by CPAC, CACC recommends the following:

Cancer survivors have a unique risk of recurrence, distress or sequelae therefore:
• All survivors should be screened for distress at appropriate intervals, and as clinically indicated especially with changes in disease status;
• Screening should identify the level, nature and causes of the distress;
• Distress identified through screening should be managed according to evidence-based clinical practice guidelines;
• Screening should also identify high risk survivors especially at risk because of the intensity of the treatment received or because of their past medical history.

Looking at scope of nursing practice/team practice:
• Adequately supported and educated nurses should play a critical and leading role in providing supportive care to survivors for health, screening, education and referral where needed
• Emphasize the role and scope of nursing;
• Screen for and manage first level distress and referral criteria for those requiring it.

National leadership:
• CPAC to develop national guidelines for survivorship addressing distress, treatment sequelae and criteria to be included in a screen at follow-up.

Local action:
• Multidisciplinary institutional committees should be formed to establish standards for distress management and guide the application of supportive measures in survivors.

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References
Medical Care if Necessary, But Not Necessarily Medical Care

MARTIN CAMPBELL

The purpose of this article is to show that current cancer care funding policy, particularly for some new and costly cancer drugs, fails to comply with a fundamental principle of the Canada Health Act, namely, that no one should suffer catastrophic financial loss as a result of a disease or a disability. The preamble to the Canada Health Act establishes the principle that the Parliament of Canada recognizes that “...continued access to quality health care without financial or other barriers will be critical to maintaining and improving the health and well-being of Canadians....” Accessibility and comprehensiveness are two of the five key principles set out in the Act.

This article also shows that where funding is not provided on the basis that the proposed drug or therapy is “not medically necessary”, the failure to fund not only creates financial hardship for patients, but the words that describe the rationale for non-funding, namely, that the drug or therapy is “not medically necessary”, also cause emotional hardship. Even more troubling, the use of the words “not medically necessary” masks the failure of non-funding provinces to comply with the Canada Health Act.

The Canada Health Act establishes a legislative scheme whereby the federal government makes cash contributions to those provinces and territories which establish health care insurance plans which meet the criteria of public administration, comprehensiveness, universality, portability and accessibility. The federal government may withhold or reduce funding for those provinces whose plans fail to meet the criteria.

To be eligible for the cash contribution the provinces and territories must provide health care services including hospital services. Hospital services are defined in the Act as those services which are “...medically necessary for the purpose of maintaining health, preventing disease or diagnosing or treatment an injury, illness or disability, namely: ...

- laboratory and radiological and other diagnostic procedures; and
- drugs, biologicals and related preparations when administered in the hospital;....

but does not include services that are excluded by the regulations.”

There are no regulations under the Canada Health Act excluding services. There is a regulation requiring disclosure of information related to extra billing and user charges, SRO/86-259.

Many health care services are now available which are not within the definition of “insured health services”, in particular, some cancer drugs which are not provided in a hospital setting. There is no obligation under the Canada Health Act for provincial and territorial health insurance plans to fund these drugs or therapies.

But the critical question raised by the Canada Health Act definition of “insured health services” is what services are “medically necessary”? The Canada Health Act does not define the term “medically necessary” but Health Canada does discuss the term in its annual report on provincial compliance with the Act. Section 23 of the Act requires the provinces to report to Parliament each year on the extent to which each provincial health care insurance plan has satisfied the criteria under the Act. The glossary to the Canada Health Act annual reports prepared by Health Canada includes this definition of “medical necessity”:

“Under the Canada Health Act the provincial and territorial governments are required to provide medically necessary hospital and physician services to their residents on a prepaid basis, and on uniform terms and conditions. The Act does not define medical necessity. The provincial and territorial health insurance plans, in consultation with their respective physician colleges or groups, are responsible for determining which services are medically necessary for health insurance purposes. If it is determined that a service is medically necessary, the full cost of the service must be covered by the public insurance plan to be in compliance with the Act. If a service is not considered to be medically required, the province or territory need not cover it through its health insurance plan.”
The *Canada Health Act* requires provincial and territorial health insurance plans to consult with physicians. But the consultation process does not mean that the provincial and territorial health insurance plans are obliged to defer to physicians.

The *Canada Health Act* requires provincial and territorial health insurance plans to consult with physicians. But the consultation process does not mean that the provincial and territorial health insurance plans are obliged to defer to physicians. For example, Cancer Care Ontario’s Disease Site Groups make specific recommendations for CCO oncologists about which treatments to use based on an extensive review of clinical evidence, and CCO oncologists also participate on an oncology subcommittee of the Ministry’s Committee to Evaluate Drugs. There have been many examples of the Ontario Ministry of Health and Long-Term Care deciding not to fund treatments because of cost even as the provincial cancer system recommends those treatments as the standard of care.

Thus Health Canada’s definition gives the provincial and territorial health insurance plans broad discretion to determine which services are “medically necessary” for health insurance purposes. While the criterion for the exercise of this discretion appears to relate to medical or clinical issues, in reality the provinces have discretion to define “medically necessary” in the light of financial constraints, funding or cost effectiveness as determined by the province or territory as a matter of funding policy.

The form of words used to limit what is “medically necessary” are the words “prescribed as medically necessary” or “prescribed medically necessary service”.

For example section 12 of the *Ontario Health Insurance Act* describes “insured services” as “...every insured person is entitled to payment....for....insured services in the amounts and subject to such conditions and co-payments, if any, as are prescribed.”

The “prescribed” services are set out in Regulation 552 made under the *Health Insurance Act*. Other provinces have enacted similar legislation and regulations. In determining whether or not a service is to be or is not to be “prescribed”, the provinces, in practice, take into account funding and cost effectiveness in addition to the medical worth of the service. But the use of the nearly identical terms “medically necessary” and “prescribed medically necessary services” may easily create confusion.

Colleen M. Flood¹, notes that “provincial governments have availed themselves of the latitude provided by the failure to define “medically necessary” in the Act and engage in “explicit rationing” and adds that they have done this by delisting certain services, i.e., removed them from the list of services that are publicly funded. In the case of failure to fund new cancer drugs and therapies, the issue is not “delisting” but whether a new therapy will be listed at all.

The confusing use of the terms “medically necessary” and “prescribed medically necessary services”, particularly as a rationale for funding decisions, raises four critical issues:

First, the distinction between “prescribed medically necessary services” and “medically necessary services” is unnecessarily confusing and a cause of unnecessary emotional hardship for patients and families who have not had “medically necessary services” funded despite, in some cases, assurance from their medical team that the service is clinically effective.

Second, the confusion and hardship is inevitably worsened when patients become aware of differences in funding among the provinces. When a patient is advised by his or her medical team that a service is “medically necessary” (on medical grounds) but is unfunded in the patient’s home province, it can only be frustrating and bewildering for that same patient to learn that the same service is “medically necessary” (on medical grounds) and is funded in another province. Would it not be far better for a provincial or territorial health insurance plan to clearly state that while a service may be “medically necessary” on medical grounds the province or territory deems it a service too costly for the province to provide?

Indeed, a British Columbia Medical Association Policy Statement in June 2007 states “The BCMA advocates an abandonment of attempts to explicitly define the terms “medically necessary” or “medically required” as these relate to those services that are insured under the Medicare program”.

However, by declaring certain cancer drugs and therapies to not be “medically necessary” the way is open
for those patients who have appropriate private insurance to obtain drugs and therapies on their own. Alberta, British Columbia, Manitoba, Ontario, Quebec (until Chaoollii v. Quebec (AG), [2005] 1 S.C.R. 791) and PEI prohibit private insurance from covering “medically necessary” services. The other provinces do not.

Third, the absence of clear terminology in the Canada Health Act frustrates the requirements in section 23 of the Act that the provinces and territories report annually to Parliament on compliance with the Act. At a minimum, this reporting should include a requirement that the provinces identify, not only those services which are “medically necessary” on medical grounds, but also those services which are not “prescribed as medically necessary” on financial or other non-medical policy grounds. Disparities in funding among the provinces and territories would thus be highlighted.

The provinces and territories are limited in the amount of money and other resources which must be allocated among insured persons. Canadian courts have long recognized the ultimate authority of the provinces as funders to make decisions including the decision to not fund medical services or treatments even if the medical services or treatments are beneficial or in accordance with generally accepted medical practice.

But the last and most important problem is the failure of the Canadian health care system to honour the fundamental purpose which the Canada Health Act was intended to address, that no one should suffer catastrophic financial loss as a result of disease or disability. Where the health insurance plan of a province or territory fails to prescribe an otherwise medically valid service as “medically necessary” the province or territory may be in technical compliance with the Canada Health Act, but patients still suffer catastrophic loss.

Although the most pressing issue is to find better ways to more fairly allocate scarce resources so that catastrophic loss does not fall on particular patients, it is also essential to better define the terminology of the Canada Health Act and to expand the reporting requirements under section 23 of the Act so as to clearly define those circumstances where a provincial failure to fund a medically necessary service is made on economic grounds.

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The Romanow Commission on The Future of Health Care in Canada, an issue/survey paper entitled “Medically Necessary: What is it, and Who Decides? (July 2002), considered whether the term “medically necessary” in the Canada Health Act should be defined. There have been numerous papers on the pros and cons of defining medically necessary services.

In a clinical sense, the words “medically necessary” or “medical necessity” could mean health care services provided to a patient for diagnosis or treatment of an illness, injury or disease by a physician or other health care provider based on reasoned clinical judgment. The services would reflect generally accepted standards or medical practice, and be based on credible scientific evidence, subject to peer review and generally acknowledged by reasonable medical practitioners. In this definition of “medically necessary” cost or cost-effectiveness is not a primary consideration.

See also the comment of Glen Griener “Defining Medically Necessity: Challenges and Implications” in Health Law Review, Volume 10, Number 3 at pages 6 to 8.

Health Canada’s definition of “medical necessity” is not definitive. There have been no judicial decisions defining the words “medical necessity” or “medically necessary” in the context of the Canada Health Act. There have been a number of judicial comments and decisions on these words in the context of provincial legislation. See, for example, Cameron v. Nova Scotia 177 D.L.R. (4th) 611.
A Growing Problem
The number of cancer patients is expected to grow by 55 per cent by the year 2020, significantly outpacing the availability of oncologists. This could lead to a shortage of some 300 to 400 oncologists in Canada by 2020 if we extrapolate from US data.

PREVENTION OF CANCER OCCURRENCE

PRIMARY PREVENTION
The Pill Cuts Ovarian Cancer Risk
A review of data from 45 studies showed that for every five years they’re on the pill, women who take oral contraceptives cut their risk of ovarian cancer by 20 per cent. These drugs may have prevented some 200,000 cases of ovarian cancer and 100,000 deaths to date worldwide.

HPV Vaccine May Cut Oral Cancers
The incidence of oral cancers linked to human papillomavirus (HPV) is increasing, even though oral cancers not linked to HPV are decreasing. That might be because of an increase in oral sex. If so, the HPV vaccine now approved for prevention of cervical cancer might also have a role in preventing oral cancers.

SECONDARY PREVENTION
Screening
A research team in Germany claims they have developed a blood test that can not only identify lung cancer already established (prevalent) in smokers but it can also predict which asymptomatic smokers will get lung cancer (incident) in the next two years. They report identification of a lung cancer-specific gene expression profile in peripheral blood monocytes which predicts prevalent disease with an accuracy of 88 per cent and incident disease within two years with an accuracy of 80 per cent.

TERTIARY PREVENTION
Breast Cancer
Prolonged hormonal therapy indicated
Several studies show that reduction in the recurrence of early-stage breast cancer is improved with additional years of hormonal therapy (either aromatase inhibitors or tamoxifen) after the standard five years of tamoxifen.

Low levels of vitamin D are associated with a predisposition to breast cancer recurrence
In women with adequate levels of vitamin D at the time of surgery, 83 per cent remained breast cancer free after 10 years, compared to 74 per cent in women with low levels. It is too early to recommend that breast cancer survivors go on vitamin D supplements but more research is needed to explore its usefulness as an adjuvant treatment.

Bone loss drug reduces early-stage breast cancer recurrence risk
Zoledronic acid, a drug which reduces bone loss caused by some cancer treatments, was shown in a randomized trial to reduce the five-year relative risk of breast cancer recurrence by 35 per cent compared to the controls who received hormonal treatment (either tamoxifen or anastrozole) alone. The overall occurrence of side effects was low.

LUNG CANCER
Genetic analysis identifies who benefits from chemotherapy
A genetic analysis of surgically removed tumors revealed a pattern which identified a patient group at high risk of recurrence. This patient group derived benefit from adjuvant chemotherapy whereas patients whose tumors showed a low risk pattern did not benefit from the same treatment.

PANCREATIC CANCER
Effective adjuvant chemotherapy
After surgery for early stage pancreatic cancer, patients with no evidence of remaining cancer who received gemcitabine had a two-fold greater chance of survival at five years compared to those who received the standard treatment of no additional therapy (21 per cent compared to nine per cent). Side effects included slight decreases in blood counts which were transitory. The results have established a new standard of care for localized pancreatic cancer.

UTERINE CANCER
Brachytherapy prevents recurrence with fewer side effects
Vaginal brachytherapy (radiation therapy given internally, using implants) was compared with external beam therapy (radiation given from a machine outside the body) to treat uterine cancer that had a higher risk of recurrence after surgery. Brachytherapy was as effective as conventional external beam therapy, simpler to administer, and was attended by a lower incidence of side effects (diarrhea). It was claimed to be the new standard of care.

TESTICULAR CANCER
Single dose chemotherapy is effective treatment for early stage seminoma
A single injection of carboplatin after surgical removal of the affected testicle was found to be as effective in preventing recurrence as two to three weeks of radiation (five year recurrence rate five per cent vs. four per cent). After seven years, men who received carboplatin were 78 per cent less likely to develop a tumor in the other testicle. Fatigue after treatment was also less marked in the carboplatin group.

MELANOMA
Better adjuvant therapy
A European study showed that a year of treatment with pegylated interferon—a newer, more active form of interferon—cuts the risk of recurrent melanoma by 18 per cent in patients who had the deadly skin cancers surgically removed.
TREATMENT OF ADVANCED DISEASE

BREAST CANCER
Bevacizumab benefits women with advanced breast cancer
In women with newly diagnosed advanced breast cancer, the addition of bevacizumab (Avastin) to docetaxel chemotherapy increased the response rate to 63 per cent from 44 per cent and reduced by 28 per cent the likelihood of cancer progression at 11 months. Side effects were increased to 75 per cent from 67 per cent due largely to high blood pressure which was treatable.

COLON CANCER
PET scanning spares futile laparotomies prior to resection of liver metastases
Patients about to undergo surgery for resection of metastases from their liver were randomized to have preoperative PET scanning or not. Futile surgery (resection could not be performed) occurred in 28 per cent of the scanned group vs. 45 per cent in the group that did not have preoperative PET scanning.

KRAS status predicts response to cetuximab (Erbilux)
According to researchers from Belgium, cetuximab combined with conventional chemotherapy improved one year progression free survival from 25 per cent to 43 per cent in patients whose tumors showed a normal KRAS gene. Those with tumors carrying a mutant KRAS gene did not benefit from the added cetuximab.

LUNG CANCER
Additional treatment after initial chemotherapy can delay lung cancer growth
Maintenance pemetrexed, an antifolate chemotherapy drug, increased overall survival when given after standard chemotherapy for advanced non-small cell lung cancer. Overall survival was 13 months for those receiving pemetrexed compared to 10 months in the control group.

Erbilux effective in advanced lung cancer
Adding Erbilux to standard chemotherapy increased survival by up to 21 per cent in patients whose tumors carried a molecule called epidermal growth factor receptor or EGFR.

EWINGS SARCOMA
Increased dose intensity of chemotherapy improves survival
Patients were randomized to receive chemotherapy every three weeks or every two weeks. After three years 76 per cent of those in the two week group were alive compared with 65 per cent in the every three week group. The incidence and severity of side effects were the same in both groups. About five per cent in each group experienced infection.

KIDNEY CANCER
A fourth drug effective against kidney cancer
Treatment with the targeted therapy drug everolimus (Certican), can slow the growth and spread of renal cell carcinoma when other targeted therapies such as sunitinib and/or sorafenib stop working. After six months the cancer had not grown or spread in 26 per cent of patients receiving the drug compared to 2 per cent of the patients who received best supportive care. This brings to four the number of agents for treating a disease for which there was no effective drug treatment just a few years ago.

CHRONIC LYMPHOCYTIC LEUKEMIA
A new old drug
Bendamustine (Treanda) had already been used in Europe for 30 years, but a new international trial showed it produced a higher remission rate and a doubling of progression free survival compared to the standard therapy with chlorambucil.

SUPPORTIVE CARE
New drug reduces oral mucositis resulting from chemotherapy
Recombinant human intestinal trefoil factor (rHITF) showed striking benefit in patients with recurrent oral mucositis (ulceration of the lining of the oropharyngeal cavity) resulting from chemotherapy. Compared with placebo, the active agent reduced the incidence of mucositis from 50 per cent to nine per cent, and the severity of the mucositis was also milder when it did occur in the treated group.

Acupuncture reduces side effects of treatment of breast cancer
Treatments for breast cancer can induce early menopause and dampen the production of estrogen, leaving women with hot flashes, excessive sweating, and fatigue. Hormone replacement therapy cannot be given for fear of reactivating the breast cancer, so doctors often prescribe antidepressants which are effective but which have their own side effects. At Henry Ford Hospital in Detroit, women were randomly assigned to receive a 12-week course of the antidepressant Effexor or acupuncture. After the study intervention, both groups reported similar improvements in hot flashes and other menopausal symptoms. In addition, many of those receiving acupuncture reported having more energy, a greater sense of well-being, and an improved sex drive. The effect of acupuncture was also longer lasting. Moreover, there were no side effects reported in the acupuncture group, whereas some women in the antidepressant group had nausea, dry mouth, headache, trouble sleeping, constipation and other side effects. In Chinese medicine, it is believed that acupuncture works by unblocking the flow of energy along meridians. In Western medicine, the exact reason acupuncture might work is not clear, but some theorize that the placement of needles may release endorphins, a chemical that makes you feel good. The meridian lines from Chinese medicine closely correspond to the body’s network of nerves.
**SURVIVOR ISSUES**

*Childhood cancer survivors face increased risk of heart disease*

Childhood cancer survivors are five to 10 times more likely than their healthy siblings to develop cardiovascular disease in early adulthood. The diseases covered the full spectrum including hardening of the arteries, congestive heart failure, heart attack, pericardial disease, and valvular disease.

**ACROSS THE COUNTRY**

**HEALTH CANADA**

The Drug Safety and Effectiveness Network was announced in July 2008, with $1 million to link research centres of excellence and coordinate a common research agenda. The intent is to increase knowledge about the safety and effectiveness of drugs based on their use in the real world, outside the controlled experimental environments of clinical trials. A national oversight body (unnamed) will set the research agenda.

**CANADIAN PARTNERSHIP AGAINST CANCER**

The Canadian Partnership for Tomorrow Project is a study of 300,000 Canadians that explores how genetics, environment, lifestyle and behaviour contribute to the development of cancer. The study will track randomly selected Canadians (ages 35 to 69) for at least the next 20 to 30 years. The information will help researchers, policy-makers and others understand how different combinations of risk-factors lead to cancer.

CPAC and the Terry Fox Research Institute are jointly funding an early lung cancer detection study to include 2,500 participants from Vancouver, Calgary, Toronto, Hamilton, Ottawa, Quebec City and Halifax. The study will screen current and former smokers between the ages of 50 and 75; higher-risk individuals would be recommended for in-depth examinations using spiral CT or bronchoscopy.

CPAC will launch the first phase of its web portal, Cancer View, in the spring of 2009. The portal is intended to be a one-stop comprehensive source of information about cancer control in Canada with search tools for data, programs and services across the country. Cancer View will support collaboration and user communities by helping people collect and share information about cancer control.

**PROJECT FALSE HOPE**

The Competition Bureau of Canada unveiled a campaign to help protect Canadians from internet sites that use false or misleading promotions about cancer cures. The Bureau's web site has a health fraud awareness quiz and information on how to recognize an online health scam.

**CANADIAN MEDICAL ASSOCIATION**

CMA President Dr. Robert Ouellet initiated a European health care fact-finding mission in search of measures that could improve access to Canada's health system and address lengthy wait times. A series of regional and national consultations with the Canadian public will follow the first draft of the report; the final report is due in June 2009.

**PATHOLOGY**

The Canadian Association of Pathologists released new guidelines that could address the increasing number of problems with laboratory services, with a five point plan:

- To demand certification for each prognostic test and predictive test performed by a medical laboratory.
- To have pathology test results verified by an external, independent laboratory.
- To disseminate the Canadian National Checklist for diagnostic immunohistochemistry. The checklist includes test validation, staff training and competency assessment, standardization of operating procedures and equipment maintenance.
- To create a body separate from government that will accredit all labs in Canada.
- To receive immediate and ongoing support from all levels of government to address shortages of trained staff.

Class action suits are pending in both New Brunswick and Newfoundland and Labrador on behalf of patients whose cancer tests were botched. The Inquiry by Justice Margaret Cameron into breast cancer tests in the Eastern Health District of Newfoundland and Labrador has been underway since late 2007, hearing from hundreds of witnesses, and is expected to conclude early in 2009. The New Brunswick Inquiry, headed by Justice PaulCreagh, reported in December 2008, criticizing both the Miramichi Regional Health Authority and the Department of Health for failing to ensure quality control in the lab.

**CANADIAN HEALTH SERVICES RESEARCH FOUNDATION (CHSRF)**

CHSRF released “Defining the Medicare Basket”, a report that tackles the question of why some health services are funded while others are not. The authors recommend solutions to resolve the conflict between quality, access and sustainability:

- Improve decision-making about services to be included in the exclusively publicly funded core, at both macro- and micro-levels, based on transparent rationales which take into account scientific evidence, cost-effectiveness analysis, and public values.
- Ensure that certain goods and services currently included in the intermediate ring (with partial public subsidy limited by restricted eligibility and/or co-payments) are covered for all through a mix of public funding and regulated private insurance. The principal example here is out-of-hospital pharmaceuticals, based on the model of the Quebec plan.
- An additional category of coverage should be considered, on a limited and experimental basis, for enhanced alternatives to services within the public core, offered on a private basis within a closely regulated framework.
THE PROVINCES

Data Quality
The North American Association of Central Cancer Registries recognized four Canadian cancer registries for meeting the gold standard of excellence. Alberta, Manitoba, New Brunswick and Prince Edward Island met data quality criteria for timeliness, accuracy and completeness.

Drug Programs
The Provincial and Territorial Health Ministers met in September, 2008 and released a communiqué expressing disappointment with the Federal Government for lack of action on the National Pharmaceuticals Strategy. Ministers stated their intention to host a series of forums, beginning in 2009, with governments, experts and stakeholders to advance collaborative work towards a sustainable health system that delivers excellent care at affordable cost.

Evaluation of the interim Joint Oncology Drug Review was completed at the end of 2008, with unspecified recommendations forwarded to Provincial Health Ministers. No decisions are expected about the future of JODR until the spring of 2009.

Alberta announced a new pharmaceutical strategy to take effect on January 1, 2009. It will establish a single, government-sponsored drug program with a common drug list, invite public input through a new committee, introduce flexibility to meet the unique needs of some patients, and provide catastrophic coverage for certain rare diseases. Sixty per cent of Alberta seniors will see their drug costs reduced or eliminated. Premiums will increase for non-group coverage. Drug review guidelines and target timelines will be established. Later in 2009 announcements are planned for an expanded role for pharmacists and more cost-effective drug purchasing.

The Ontario Institute for Cancer Research announced the investment of $500,000 in DVS Sciences Inc., for novel technology to facilitate the identification of biomarkers to study and diagnose cancer. OICR will actively participate in efforts to commercialize the project by providing additional expertise and resources and working collaboratively with the company and its scientists.

Ombudsmen
The Alberta Ombudsman is investigating the out-of-country health services program delivered by Alberta Health and Wellness. He invites Albertans who have had experiences with the program to contact his office.

Early in 2009, the Ontario Ombudsman is due to release a report on access to PET scans, a service tightly controlled in the province, with lower access for fewer indications than Quebec or Alberta.

The health ministry is due to report on the impact of changes made to the out-of-country approval process, following the Ontario Ombudsman's 2007 study that led to the health ministry retroactively reimbursing Suzanne Aucoin for her US cancer treatments. An overhaul of the program has been underway ever since.

Patient Wait Time Guarantees
Manitoba implemented its patient wait times guarantee for radiation therapy (within four weeks), the first such guarantee and the shortest one expected. By 2010, BC, NB, NS and PEI will have guarantees in place for radiation therapy within eight weeks and the Yukon will have one for mammography. In 2007 the Federal Government offered special funding for the guarantee, for pilot projects and for Canada Health Infoway grants, if provinces agreed to automatically offer an alternative source for the treatment when the time frame is missed.

Patient Satisfaction
Once again, cancer patients in Nova Scotia reported a high degree of satisfaction with their care, higher than the Canadian average in all categories: overall impressions, emotional support, co ordination and continuity of care, respect for patient preferences, access to care (not related to waiting times) and information/communication/education.

Prevention and Screening
An Alberta cancer prevention study called BENEFIT will measure what affects people's participation in weight-management programs, why they enroll, why they quit or stay with the program and what effect the program has on their weight, diet, health and physical activity. Poor nutrition, physical inactivity, and obesity have been strongly linked to the incidence of certain types of cancer.

Ontario introduced legislation to ban smoking in cars if any passenger is under the age of 16. The law comes into effect in January 2009, with a fine of up to $250 for offenders.

Most provinces now have plans for colorectal screening targeting the 50-74 age group, with public education and awareness programs to encourage participation. Ontario is the only province to offer province-wide screening; announced in 2007, screening began in 2008. BC, Alberta, Saskatchewan, Manitoba, Nova Scotia and PEI are all starting their programs in selected communities first, then planning to expand over several years. BC, Saskatchewan, Nova Scotia and PEI will begin screening in 2009.

Alberta built a colon cancer screening centre in Calgary to cut wait times for colonoscopies. Saskatchewan has a two-year trial to determine whether a simple blood test can detect colorectal cancer risk.

Ontario will begin funding the PSA test for prostate cancer screening and monitoring on January 1, 2009. The test will be covered for men who have been diagnosed with cancer and for men whose physicians suspect prostate cancer because of history, race or the results of a physical examination.

The End
The Alberta Cancer Board was dismantled in July 2008, along with all the regional health authorities. The new Alberta Health Services Board replaces Alberta's nine regional health authority boards, the Alberta Cancer Board and other boards. The AHSB assumes responsibility for the delivery of health services, and its new advisory council on cancer takes over the research agenda.
Hippocrates Would Be Turning in His Grave

JAMES D. GOWING

In a recent survey, 70 per cent of Canadian medical oncologists admitted they were not giving ideal treatment to patients with advanced colorectal cancer due to lack of public funding or private insurance.

Sadly however, they are not standing up as a group and advocating publicly for access to the best treatment. This, in contrast to their gynecologic oncology colleagues (www.g-o-c.org), their radiation oncology colleagues, or their American counterparts.

It is in their best self interest to advocate publicly for greater access. By doing so they will produce improved treatment results and their perceived value as professionals will be enhanced.

Instead of advocating, their association surveyed them to see what value they place on human life vs. costs of new drugs. Hippocrates would be turning over in his grave if he saw the survey questions.

The physician’s first duty is to the patient. In the privacy of the examining room, a patient being advised of treatment options has every right to think that the doctor is giving the best treatment advice. The patient must be confident, in a time of such distress and suffering, that the sacred trust between patient and doctor is being honoured.

The law reinforces this 5,000 year old dictum. Physicians are obliged to describe to their patients ALL therapies from which they may benefit. By not doing so, oncologists expose themselves to lawsuits (failure to obtain fully informed consent prior to instituting treatment). The Royal College of Physicians and Surgeons of Canada training guidelines explicitly indicate they should have “knowledge of the law as it applies to ethical decision making in medicine particularly law on consent.” It seems that may not be happening.

But there is a second duty to the public. The document continues: “As health advocates, physicians [should] responsibly use their expertise and influence to advance the health and well-being of individuals, communities, and populations.”

Canadian medical oncologists, individually, are among the most compassionate of physicians, spending an inordinate amount of valuable time advocating for their individual patients. However, as a group, they have failed to advocate openly for equitable access to care for all their patients. Colleagues, speak out!


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