

CANCER ADVOCACY COALITION OF CANADA

REPORT CARD ON CANCER IN CANADA™

2011-2012

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REPORT CARD ON CANCER IN CANADA™

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James D. Gowing, Darwin Kealey and Colleen Savage

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Norm Archer PH.D., is a Professor Emeritus in the DeGroot School of Business at McMaster University, and Special Advisor to the McMaster eBusiness Research Centre (MeRC). His main research interests are in the adoption and use of electronic health records, including issues of interoperability, decision support, electronic medical record systems for physicians, and personal health record systems for consumers.

Larry Broadfield, BScPharm, MHSc, is Manager of the Systemic Therapy Program Cancer Care Nova Scotia, and a member of the Cancer Systemic Therapy Policy Committee, NS Department of Health. He is a Fellow of the Canadian Association of Hospital Pharmacists and a member of numerous professional associations. He has been a member of the Standards Working Group of the Canadian Partnership Against Cancer and has authored many publications on systemic therapy guidelines.

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

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

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

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

Kong Khoo (Vice Chair) MD, FRCPC, is a Medical Oncologist based in the Southern Interior of British Columbia in Kelowna.

Jackie Manthorne BA, BEd, is President and CEO of the Canadian Cancer Survivor Network (CCSN). She is the former CEO of the Canadian Breast Cancer Network (CBCN); Executive Director of the Canadian Centre of International PEN; and National Administrator of the Royal Canadian Academy of Arts. She is also the author of seven published books of fiction.

Joseph Ragaz MD, FRCPC, is a Medical Oncologist and a Senior Oncology Researcher, Professor of Medicine & Oncology, McGill University, Montreal, QC. Prior to this he spent 27 years as a senior Medical Oncologist and an internationally recognized breast cancer researcher at the BC Cancer Agency in Vancouver, BC.

David Saltman MD, PhD, FRCPC is the Chair and Professor of the Discipline of Oncology, Faculty of Medicine, Memorial University. His current interests include cancer advocacy, community oncology and telehealth.

Sandeep Sehdev MD, FRCPC, is a community focused Medical Oncologist at the William Osler Health Centre in Brampton, ON—one of Canada's largest community hospitals—where he has worked since 1992. He is past Chair (five years) of the Pharmacy and Therapeutics Committee.

Elizabeth (Liz) Whamond has a long and distinguished history in the Canadian cancer community. In 2001, Ms. Whamond was one of the founding members of the Canadian Cancer Action Network and currently serves as Chair as well as the CCAN representative on the Cancer Journey Advisory Group of the Canadian Partnership Against Cancer.

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

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Daniel Gillespie BSc, is a Toronto consultant providing research, coordination and administrative support to the Board

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

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Cancer Advocacy Coalition of Canada

Suite 204 – 60 St. Clair Avenue East

Toronto, Ontario M4T 1N5

E-mail cacc@canceradvocacy.ca

Phone toll free 1-877-472-3436

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About the Cancer Advocacy Coalition of Canada

The CACC is a full-time, registered, non-profit cancer group dedicated to advocacy, public education, policy analysis and evaluation of health system performance. 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 health professionals, business 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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A Tribute to Carolyn Henry

Carolyn Henry's passing last October marked a tremendous loss for the Canadian myeloma community. A woman of courage and compassion, she was a pioneer who fearlessly ventured forth to make a difference.

Carolyn was a true inspiration, fighting tirelessly to make a difference for so many, both those who knew her and the many others who were not aware of the impact she had on their lives. Her passion, dedication and indefatigable spirit inspired many to join her in her ongoing campaigns to improve the lives of myeloma patients and their families.

I first met Carolyn eight years ago and was immediately struck by her tenacity and unrelenting desire to make the world a better place for myeloma patients. Carolyn's passion was advocating for patients to ensure access to new, life-saving treatments and optimal care. From advocating for funding for drugs in Ontario to spearheading funding efforts for myeloma research, Carolyn was always there for us, shining the light on the path forward.

I last saw Carolyn last summer when I visited her at Princess Margaret Hospital while she was undergoing treatments for AML. I was struck by Carolyn's radiance and optimism that belied the seriousness of the situation. We parted with an embrace, promising each other to have a glass of wine together when she got better. Alas, that was not to be, but the memory of our last encounter will continue to inspire me as I continue along on my own personal journey. It is very difficult to accept that Carolyn has left us, but her legacy will live on.

Aldo Del Col
Co-founder & Executive Director
Myeloma Canada

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EDITORIAL

Health ministers in Canada have a growing appetite for innovation, provoked by financial pressures and the escalating needs of an aging population. Change is unavoidable; will it be crushing or inspiring?

Opportunities to improve cancer outcomes through innovation are found throughout the patient journey and in the surrounding infrastructure. In the controversial arena of screening for breast and prostate cancers, innovative discoveries have the potential to resolve the disputes, in favour of patient outcomes. Dr. Yaffe's review of screening mammography for women 40-49 years of age concludes the shift would save lives and is more feasible now than in the past, when technology was inadequate for the task. Drs. Thoms and Sathya write that expanded PSA testing for prostate cancer might prove less useful than biomarkers capable of denoting aggressive or non-aggressive disease.

In lung cancer, molecular testing for targeted therapies would save money and speed many patients on to other, more appropriate treatment choices. Targeted therapies are the trend, not the exception, in a new wave of cancer drugs for many cancers. Dr. Ellis calls for a pan-Canadian strategy for the adoption of molecular testing, to optimize the use of expensive treatments for the target patient group and protect other patients from added risks. Canadian jurisdictions should provide simultaneous funding of the patient selection test when these targeted therapies are funded.

Lung cancer incidence and mortality rates overshadow all other cancers, yet the success of anti-tobacco messages installed an identical stigma for the cancer and its victims. The intensity of stigma crushes research funding and charitable donations, impedes family/caregiver empathy and extends to health professionals offering subtle messages of blame. Nobody deserves to die from lung cancer. Dr. Lobchuk's research finds that lay caregivers – the family and friends of a lung cancer patient – can harbour negative attitudes that impact their support for the patient.

Dr. Schultz explores the role of hospitals and health professionals in treating tobacco dependence during hospitalization, an option not consistently offered. Inpatients are forced to leave the hospital grounds to alleviate their withdrawal symptoms while clinical relief is at hand. There is an organizational responsibility to adopt a system-wide approach for treating tobacco dependence among hospital patients, which could include a role for Accreditation Canada.

Kevin Coady and Dr. Saltman offer survey results and implementation advice for smoke-free public and private multiunit housing. Smoke-free housing appeals to the majority of Canadians, protects residents from environmental tobacco smoke and reduces property owners' costs. Public housing lags behind the private sector in providing this alternative, although the residents are more vulnerable and have few housing choices. Most provinces have both public and private examples of smoke-free multiunit hous-

ing; only Saskatchewan, Quebec, Northwest Territories and Nunavut do not. The authors call on provincial and municipal governments to do more to educate both tenants and landlords about how to implement and maintain smoke-free policies.

Dr. Brydon offers context for emerging information on the human papilloma virus, which causes disease and death from cancer in both men and women. HPV vaccine programs targeting only girls, in a small window of opportunity, cannot overcome the risk. Rising incidences of anal cancer, head and neck cancer and oral cavity cancers in both sexes are increasingly attributed to the virus. Dr. Gowing challenges the provinces to learn from each other and heed the advice of experts for a cost-efficient, gender neutral HPV vaccine program.

Complementary medicine is a burgeoning field of significant interest to patients who may or may not discuss their self-administered therapies with treating physicians. The merits of pursuing improved health independently must be balanced with the impact on cancer treatments. Dr. Balneaves concludes that cancer patients deserve treatment and care that encompasses the most effective therapy options available, including complementary medicine.

Cancer patients express their hopes and frustrations in the annual section Living With Cancer, describing delayed diagnosis, scarce research funding, limited information for patients, barriers to treatment options, and a lack of public and medical awareness about their lesser-known disease. Fighting for care, fighting for attention, fighting the cancer - the burden can be overwhelming. Innovation focused on the needs of patients will invite and hear the patient voice, responding to gaps and disparities or modifying programs in need of a tweak. Deb Maskens describes the first experience with pCODR, finding optimism for its process and collaborative operating style.

Dr. Gowing closes this issue of the Report Card highlighting key disparities in research funding, access to PET scans and provincial adoption of drug review recommendations.

It may appear that the only innovation still required is from policy-makers but this is not accurate. Solutions to the unsettling issues in cancer care are not entirely on the shoulders of health ministers, although most would see a government role in the implementation of new directions for patient care. Prevention, screening, access to diagnostics and treatments, and the pursuit of national standards are certainly in the realm of ministerial responsibility.

On other fronts the innovators are health professionals, arm's length agencies and institutes, networks of organizations, federal/provincial/municipal regulatory bodies and the private sector. Collaboration, knowledge-sharing, education and adaptation belong with all those who have a role in sustaining health.

—Dauna Crooks, Chair and Colleen Savage, CEO

HPV in Men

By LIZABETH BRYDON, MD

The Human Papilloma Virus (HPV) causes disease and death from cancer in human beings, both men and women. We now have two commercially available vaccines that prevent a large proportion of these diseases. These vaccines are effective and safe. The universal use of these vaccines would lead to a significant decrease in disease and death from HPV.

There are many questions. What is the incidence of these diseases in our population? How many are HPV-related? How many are related to the subtypes for which we have an immunization? What is the burden of these diseases both in men and in women. Do we have effective screening for these diseases? Do we have effective treatment? The vaccine is costly. Will it do all it promises?

HPV—the Science

HPV, is a small, stable virus that exists in over 100 different subtypes. While the majority of HPV infections are transient and have little clinical significance, some are associated with the development of different diseases. These diseases range from the annoying, embarrassing and occasionally disabling warts to invasive cancer. Tremendous work over the past three decades by researchers like Drs. Harald Zur Hausen and Ian Frazer, has added considerable knowledge about this small virus and how it causes disease.

HPV is a DNA virus composed of nine genes, seven of which—the “E” genes—encode for active biologic processes. This in turn enables the virus to exist in the host cell nucleus and replicate there awaiting the natural death of the cell, which then allows infection of other epithelial cells. Within the genome, there is the ability to infiltrate into the host DNA and begin to alter the normal cellular control mechanisms that balance growth with natural destruction. In this way, the cell can become so deregulated and immortalized that uncontrolled growth occurs, resulting in the development of cancer. Not all HPV subtypes have this capability. This oncogenic, or cancer-causing capability is recognised as the cause of cervical cancer. We now know that many other cancers may be associated with oncogenic HPV.

The remaining two genes, the “L” genes, encode for the formation of capsid proteins, which form the overcoat of the virus. One of these genes, L1, has been manipulated to form vast quantities of capsid-like proteins. These then are used to induce antibodies to each specific subtype of HPV from which that L1 gene is derived. These inert antibodies have been developed into remarkably safe and effective vaccines against HPV.^{1,2,3,4} To date, there are two commercial products available. One is a quadrivalent vaccine against the subtypes 6, 11, 16, and 18; the other is a bivalent vaccine against the subtypes 16, and 18. Both vaccines have been tested extensively in randomized clinical studies on large numbers of

women around the world. These specific subtypes were chosen because they are known to be the cause of 70 per cent of cervical cancers worldwide. The remaining 13 or so subtypes that are considered oncogenic account for the remaining 30 per cent of cervical cancers.

Currently, there continues to be considerable interest in HPV. A nonavalent vaccine, which targets nine HPV subtypes, is undergoing testing at this time. Work on the development of a vaccine against the L2 gene may give us an opportunity to immunize against all HPV, as the L2 gene is not unique to each subtype, but is universal to all. However, this research and development is still in the early stages.

We continue monitoring the long-term efficacy of the two vaccines in use, concentrating on how long immunity remains present. Currently, there has been no sign of failure after nine years of use. We do not know if this immunity will persist in the older adult, as we know the immune response to immunization wanes with age. We do not yet know how effective it is to immunize the adult over 45, the immunocompromised host, those who are on immunosuppressive drugs, or those who are immunocompromised secondary to diseases such as HIV.

The present technology creates safe and effective antibodies to specific subtypes of the virus. The vaccines to date have been expensive. The present vaccines are preventive, not therapeutic, for the subtypes in the vaccine and are best given prior to sexual debut. There has been some cross-protection to two related oncogenic subtypes demonstrated. We are faced with the dilemma of deciding who should be vaccinated, when and with which vaccine.

The Impact of HPV Diseases

The HPV virus is being investigated as the associated cause of different diseases in different populations. The presence of the HPV virus is necessary to begin the process that leads to disease, but there are host factors as well that are not yet clarified. Of the more than 100 subtypes of HPV, some 40 subtypes—referred to as anogenital—cause disease in the anogenital areas of men and women: the cervix, vulva and vagina of women; the penis, scrotum of men; and the perianal and anal area of both men and women. As well, these anogenital subtypes are associated with disease in the upper airway: the larynx, tonsils, pharynx, vocal cords, trachea, bronchi and lungs of both men and women.

Although HPV is found in lesions and cancers of the susceptible host, the ability of some human hosts to ward off these infections, while others cannot, remains under investigation.

The anogenital HPV subtypes are transmitted by skin-to-skin contact. This usually occurs during sexual contact. However it rarely occurs during childbirth through contact of the infant's airway with the vaginal/cervical HPV of the

mother. The HPV virus appears to be opportunistic as it infects the basement membrane of the epithelium of the host when there are minute breaks in this epithelium. The host may mount an immune response to an HPV infection, resulting in no ongoing infection. Researchers believe that 60 to 80 per cent of women will develop a transient HPV infection of the cervix within the 24 months following their first ever episode of intercourse. Ninety percent of these infections are merely transient, and the remaining ten percent develop persistent disease. Some of this persistent disease may progress to cervical cancer. Virtually all cervical cancers harbour oncogenic HPV. The role of HPV as the underlying cause of all cervical cancer was the initial drive for the tremendous amount of research in the science of HPV. Although cervical cancer screening programs have succeeded in significantly decreasing the incidence of cervical cancer, the past decade or more has shown few ongoing signs of improvement from screening. The incidence and mortality from this disease have reached a plateau despite our best efforts at screening.

HPV in men permits transmission of the virus to women through various sexual behaviours, not merely sexual intercourse, and may also cause the transmission of virus to other men. The incidence of anal cancer is rising in both men and women in the general population.⁵ The population most at risk are HIV positive men who have sex with men (MSM). Others are also at risk. We currently estimate 90 per cent of anal cancers are associated with HPV and of these, 90 per cent are associated with HPV16 or 18.³ HPV 6 and 11 cause more than 90 per cent of genital warts in men and women. Data in the U.S. show there are approximately three to four million cases of warts per year. The peak attack rate is in the 25 to 29 age cohort, where the estimated rate is 500 per 100,000.⁶

Detection of HPV DNA in studies on men's genitalia shows wide variation. This is due in part to diversity in techniques for testing. There is no standard testing protocol.⁷ There is no recognized screening for the HPV-related diseases apart from those of the cervix. There is work on screening for peri-anal and anal disease in high-risk populations, but this is not universally available. Many medical communities have no one with expertise in not only screening, but also in the treatment of these diseases.

Australian studies demonstrate that the quadrivalent vaccine has been effective in decreasing the incidence of genital warts in both women and men. Those people who received the vaccine experienced a relative reduction of 59 per cent in the incidence of genital warts, within two years. At the same time, the incidence of genital warts in heterosexual men, ages 12 to 26, declined by 39 per cent.⁸

In addition to the anogenital area, we now know that 25 per cent of cancers of the head and neck in both men and women are thought to be due to HPV.^{9,10} The incidence of these cancers has been increasing in the past decade.¹¹ Around 90 per cent of HPV linked to oropharyngeal squamous cell carcinomas (OSCCs) has been found to

be due to HPV16. The incidence of OSCCs is increasing and expected to surpass that of cervical cancer by 2020.¹² Other cancers occasionally associated with HPV include the base of the tongue, the tonsils, the vocal cords, the larynx, and even the bronchi and lungs. It must be emphasized that these are cancers that have no effective screening strategy. They will not likely be found in a premalignant state, and they do affect both men and women. Subtypes 16 and 18 are most commonly found in cervical cancers, and they are the subtypes for which we have effective vaccines. In an American national survey of healthy individuals aged 14-69 years, HPV of any kind was found in 6.9 per cent of the population; one per cent of the population overall had HPV16.¹³

Surprisingly, research shows that men do not seem to clear the HPV virus as effectively as women. Men have a higher prevalence of HPV than women. Prevalence of HPV in men was 10.1 per cent while, the prevalence in women is 3.6 per cent.¹³ The ongoing HPV in Men Study (HIMS) assesses HPV infection in men over the age of 18 who are sexually active. To date the prevalence in this population of HPV infections has been found to be 65.2 per cent. HPV16 is the commonest cancer causing subtype. The highest risk factor for acquisition of HPV infection among males is the lifetime number of sex partners.¹⁴

The burden of HPV-associated cancers among both genders is estimated at 5.2 per cent of all cancers worldwide. Eighty to 90 per cent of anal cancers, 40-50 per cent of penile cancers, 35 per cent oropharyngeal cancers and 25 per cent of oral cavity cancers are attributable to HPV types 16 and 18.¹⁴

Recently, the National Advisory Committee on Immunization (NACI) published its update on Human Papilloma Virus. Current knowledge indicates quadrivalent and bivalent vaccines prevent cervical adenocarcinoma in situ and cervical cancer from HPV16 and 18 for girls and women ages 10 to 25. In addition, the NACI recommends the quadrivalent vaccine for both genders from ages 9 to 26

AVERAGE ANNUAL NUMBER OF CASES AND INCIDENCE OF HPV-RELATED CANCERS IN CANADA, 1997-2006

	Anatomical site	Average annual incidence per 100,000	Average annual number of cases	Estimated % attributed to any HPV type
MALES	Penis	1	127	50
	Anus	1.6	208.2	90
	Oral cavity	6.5	853.1	25
	Oropharynx	0.64	84.3	35
FEMALES	Cervix	10.1	1,356.8	40
	Vagina and vulva	4.2	651.8	90
	Anus	1.7	267	25
	Oral cavity	3.3	501.2	35
	Oropharynx	0.18	27.2	

Age-standardized rates
 Population aged 15 years and older
 Source: National Advisory Committee on Immunization.
 Update on human papilloma vaccines.
 Public Health Agency of Canada, Jan 2012

for the prevention of anal pre-cancer and anal cancer caused by HPV 16 and 18.³

The American Committee for Immunization Practices gave a permissive recommendation for boys aged 11 to 12 years with a catch-up in the age group 13 to 26 years. Permissive recommendation allows for the use of the vaccine but stops short of placing it on the routine vaccination schedule. However, in the case of the quadrivalent vaccine, the American Committee for Immunization Practices also recommended that the cost of the vaccine be covered for boys eligible for the Vaccines for Children program.¹⁵

Cost

The issue of HPV disease and immunization is complex. HPV and certain HPV subtypes are creating a huge burden of disease. Initially, we studied cervical cancer, a cancer of women, however other HPV disease in both men and women is rising, and these other HPV diseases will soon out-number the cervical cancer cases.¹⁶ These other cancers and HPV diseases do not yet have—and may never have—effective screening strategies.

The dollar cost of treating HPV disease is large. In British Columbia alone, in 2008, the cost of treatment per episode of anogenital warts alone was \$190 translating into estimated annual, direct medical costs of approximately \$1 million.¹⁷

There have been economic modeling of costs of introducing HPV vaccination to girls alone or to girls and boys. These models support a definite cost-benefit to immunizing girls. The immunization of boys as well is more controversial.^{8,19,20}

Our society mandates universal access to health care. We know that the cost of the vaccine will disallow easy access for a proportion of our socio-economically depressed parents of children who would benefit from the vaccine. Yet these children are in need of the protection as much as children of the more wealthy, who will be able to pay. This is discriminatory. In addition, the burden of disease for men is significant and is rising. Not only do men provide the means of transmission of the virus to women through intercourse, they also are infected through sexual activities whatever the gender of their partners. The science also suggests that men do not clear these infections as easily as women.

The exploration into better vaccines is ongoing. We may learn better strategies in the future. Should we wait?

Summary

HPV-related disease costs us more than we previously imagined. Health and well-being are not measurable in dollars, but the cost of treatment is measurable, despite the difficulty in estimating all the variables. The models of HPV vaccination of men and women are not in agreement about cost-benefit. It is becoming increasingly apparent that HPV-related disease is a growing economic and social stress and neglecting prevention is unconscionable. HPV disease and cancers take time to develop, but they are preventable. It is difficult to convince governments that vaccination is necessary, as the effects of the vaccine on prevention are not evident immediately. Nevertheless, now is the time for governments to apply universal vaccine coverage for our boys and our girls to protect them from disease in the future.

Lizabeth Brydon, MD, is a colposcopist in the Regina Qu'Appelle Health Region in Saskatchewan, and the president of the Society of Canadian Colposcopists. She is the Physician Consultant for the pre-clerkship undergraduate medical program for the University of Saskatchewan in Regina. She was the recent physician adviser to the Prevention Program for Cervical Cancer for the Saskatchewan Cancer Agency and has recently retired from practicing gynecological oncology in the health region.

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HPV—A Challenge to the Provinces

By JAMES D. GOWING, BA, MB, BS, FRCPC

Canada's first HPV vaccine programs started with federal grants to the provinces to immunize girls age 9–17.¹ Starting with this age group was not expected to reach all females who might be appropriate candidates (age 9–26), as the older age group was required to pay for the vaccine and the cost could diminish their interest or be prohibitive.

The provinces began free vaccine programs in 2007 and 2008 with one school grade. Quebec offered the most comprehensive coverage: a school-based program for girls in grade 4 and coverage through family physicians for all girls under the age of 18. Outside Quebec, the provinces were more restrictive although limited catch-up provisions were established to reach girls in grade 9 who were not previously immunized.² Most notably, Saskatchewan and Manitoba have extended coverage to any girls born after 1996 who missed the school-based program^{3,4} and Quebec's program now covers any females who initiated the vaccine before age 18 or October 1, 2010.⁵ The "once covered, always covered" approach is expected to increase the size of the immunized population.

The HPV vaccine program for girls met pockets of resistance from parents unwilling to give consent for their daughters to be immunized. (Table 1) The lowest rates of uptake, as a percentage of the target age group, were in Western Canada and Ontario, with the highest in Eastern Canada. School-based immunization for HPV falls far short of the rates achieved for other vaccine programs; in BC it is 30 per cent lower than the rates for other school-based vaccines.⁶

This situation gives rise to concerns about how to control HPV-related cancer. Immunizing girls does not protect the men having sex with men. Indeed, the disappointing uptake of the vaccine for girls in some provinces will mean that a considerable percentage of that entire generation will develop an avoidable risk of chronic disease and cancer.

Three pieces of advice are offered to the provinces.

1. Learn from Quebec, Manitoba and Saskatchewan and adjust existing programs to provide "once covered, always covered" HPV vaccines. This will increase the number of people who are protected from avoidable diseases and cancers.

2. Heed the advice of the National Advisory Committee on Immunization.⁷

"The public health and economic burden of anogenital warts in Canada is considerable, particularly among men whose incidence rates and incidence rate ratios compared to females have been increasing in recent years.

In addition, cost effectiveness needs consideration.

Provinces and territories will need to compare the impact of vaccinating males with that of vaccinating additional female cohorts.

While not directly comparable, lessons learned from gender-targeting of other vaccines should be considered. For example, like rubella, control of HPV among women may only be achievable through a gender-based (female only) vaccination policy if vaccine coverage among women is extremely high. Factors such as vaccine refusal, cost and weaknesses in vaccine delivery systems may support a gender-neutral (universal) policy to adequately control disease.

Furthermore, if herd immunity effects are significant, this may improve the impact of the program on health equity which is a significant factor in cervical cancer epidemiology."

3. Consider the merits of a gender-neutral approach to vaccination.⁸

- "Female-only vaccination will not protect men who have sex with men from HPV and HPV-related diseases;
- The fastest way to achieve the greatest protection for females from cervical cancer and its precursors is to vaccinate males as well as females;
- Vaccinating males is a more equitable public health policy and recognizes that both genders contribute to the transmission of HPV;
- Vaccination of males may be more acceptable to some cultural groups than vaccinating females;
- Genital warts and HPV-related cancers in males represent costly and emotionally burdensome conditions that can be prevented more expediently by vaccinating both males and females; and
- Historically, implementation of risk-based (or gender-based) vaccination policies have been less effective and more confusing to the public."

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Table 1

Province	Coverage reached (% of target)
BC	62
AB	50-60
SK	58-66
MB	52-61
ON	53
QC	81-86
NB	n/a
NS	85
PE	85
NL	85

The Pros and Cons of Screening Mammography

By MARTIN J. YAFFE, PhD

Screening mammography has been the most intensely studied imaging intervention and is certainly the most controversial. It is an issue where scientific considerations are frequently confounded by those of politics and health economics. In North America this is clearly illustrated by the recent recommendations on breast cancer screening of the United States Preventive Services Task Force (USPSTF) in 2009¹ and the Canadian Task Force on Preventive Health Care (CTFPHC) in 2011² and the response to these recommendations.

Here are the facts—Breast cancer is the most common cancer and the second largest cause of cancer death in North American women. Incidence rises continually with age beginning in the late thirties (Table 1, Column B)³. Note that about 19 per cent of the breast cancer deaths (Column C) and 30 per cent of the years of life lost to breast cancer (Column D) arise from cancers that are discovered in the 40-49 year age range. About 40 per cent of the deaths and 56 per cent of the years of women’s lives lost come from cancers that emerge between the years 40 and 59.

More facts—The causes of breast cancer are not well understood and no reliable method of prevention is currently available. The probability of successful treatment of the disease is greatest when it is found at an earlier stage, i.e., when the cancer is smaller and the lymph nodes are not occupied by tumour cells⁵. Screening (periodic examination of asymptomatic women) using mammography has been demonstrated to contribute to reduction in mortality from breast cancer in women between 40 and 69 years of age. A mortality benefit of at least 15 per cent is generally accepted, based on results of randomized controlled trials (RCTs)⁶. More modern studies point to a reduction of 24 per cent or higher^{7,8}.

Medical tests are not perfect and mammography is no

exception. To perform the examination it is necessary to compress the breast and this causes some discomfort. The breast is exposed to x-rays, which themselves have carcinogenic potential, however, for the dose levels used in modern mammography, the risk is considered to be far less than the benefit of the examination. High-quality mammography is capable of detecting 70 to 85 per cent of cancers depending respectively on whether the breast is highly fibroglandular (dense) or fatty in composition, i.e., 15-30 per cent of cancers can be missed^{9,10}. Furthermore, even if cancer is detected, screening will not be helpful for all cancers. Some will grow so quickly that they will not be found before they have metastasized to the lymph nodes or beyond and others will grow so slowly that they likely would not pose a threat of lethality. Despite these limitations, detection of a subset of “effectively treatable” cancers from the spectrum of all breast cancers contributes to the overall expected mortality benefit of screening of 24 per cent or higher. To address the limited sensitivity of film-based mammography in the dense breast digital mammography was developed. While its contribution to mortality reduction has not been directly tested, it has been demonstrated to provide a marked improvement in the detectability of cancers in women with dense breasts and those under 50¹¹.

In addition to the benefits of lives and years of life saved, earlier detection can allow reduction in the morbidity associated with treatment, by affording the possibility of surgery by lumpectomy rather than by a more extensive mastectomy or by being able to avoid chemotherapy. Most clinicians and patients consider this to be a major benefit.

The recommendations on screening for breast cancer detection released in 2011 by the CTFPHC closely followed those published two years earlier in the US in suggesting that less screening be done. Specifically, the CTFPHC recommended against: 1) routine screening by mammography for

Age	(B) Risk of Developing Breast Cancer in the Next 10 years	(C) % of Deaths From Breast Cancer Surfacing in This Decade	(D) % of Total Woman-Years of Life Lost From Cancer in (C)
40s	13 per 1000	18.7	30
50s	23	21.4	25.6
60s	29	19.3	15
70s	31	18.6	8

Source: (B) Public Health Agency of Canada, (C, D) SEER Data ⁴

About 40 per cent of the deaths and 56 per cent of the years of women's lives lost come from cancers that emerge between the years 40 and 59.

women in their 40s, 2) clinical breast examination (CBE), 3) MRI for screening women at average risk for breast cancer and 4) teaching breast self examination to women. It also suggested that, 5) screening of women over the age of 50 should take place at two to three year intervals, an increase from previous recommendations of one to two years and current practice of two years in most Canadian programs. This final guidance went beyond the American recommendations, which suggested extending the interval from one to two years.

It should be mentioned that both the Canadian and U.S. task forces support mammography screening of women over the age of 50 and that no randomized trial was performed to support the recommendations of increasing the screening interval (from one to two years in the U.S. and from typically two years to two-three years in Canada). This change was based primarily on computer modeling.

The recommendations were framed with the message that while "routine" screening was not recommended for women in their 40s or screening with CBE for any age group, women should make a decision to partake in one of those interventions or not based on consultation with their primary health care provider. It is suggested that if women decide to be screened with one of those interventions, this can be done "in the community". While superficially this approach is attractive it suffers from two major difficulties. The first is that it is assumed that the health care provider has been sufficiently and accurately informed to be able to provide appropriate advice to the woman. As discussed below, the CTFPHC itself doesn't appear to clearly understand all of the issues around screening and includes some erroneous information in its report. This suggests that there are likely to be major knowledge gaps among the health care providers, many of whom rely on Task Force guidelines for their information.

The second problem is that, particularly under the current tight economic conditions, screening programs are under pressure to cut costs. Those programs that currently do not provide the services that are not recommended by the CTFPHC are unlikely to start now. In fact, existing services provided by some provinces and territories may be threatened. At the same time, there are compelling arguments that if screening is to be done at all, it should be done under the framework of an organized program where an invitation and recall system and quality assurance is in place^{12,13}. Opportunistic screening within the community is not to be encouraged.

The CTFPHC approached the process of developing its recommendation as a balancing of benefits versus harms of

screening interventions. This is a reasonable approach. The process involved an initial systematic evidence review by a separate group responsible for grading and analyzing evidence¹⁴. This was followed by the synthesis of the recommendations by the CTFPHC. Unfortunately, both processes were carried out by individuals who did not have specific familiarity with the issues of breast cancer detection, diagnosis or treatment. This was justified through the principle of avoiding conflicts of interest, but in this case, at the price of serious scientific errors in evaluating the usefulness of the evidence and assigning values to benefits and harms.

For example, to estimate benefit, results from studies that used mammography from the 1960s, 70s and 80s were pooled by those who conducted the evidence review. The accuracy and ability to find early cancers from the mammography in use decades ago does not represent the performance level of modern film mammography, and certainly does not consider the impact of digital mammography.

A critical question for the CTFPHC is, what is the tradeoff between the value of a life saved through earlier detection of a cancer and the possible harms? As part of the value assessment for screening women in their 40s, the CTFPHC estimated that it would be necessary to screen 2,108 women for 10 years to save a life. This number is incorrect and actually refers to the number of women who would need to be invited to a randomized controlled trial per life saved; the number needed to screen is about 750, almost three times lower than the Task Force estimate.

One of the harms identified is what the CTFPHC refers to as a "false positive" result of screening. In reality, this is a request for a woman to return after an equivocal screening examination for further noninvasive imaging to increase the certainty that cancer is not present. On a woman's first screening exam this may occur in 10–15 per cent of examinations, but on subsequent screens is about five to seven per cent. This often induces stress, but this can be mitigated by timely and appropriate counseling. Some studies found that anxiety disappeared rapidly after the definitive imaging was performed, although the literature is somewhat inconsistent¹⁵.

Only about one per cent of women screened receive a needle biopsy, of whom 16–35 per cent will have breast cancer. It is extremely rare for breast cancer surgery to be performed on women who do not have breast cancer. Certainly, some of the cancers that are treated are not destined to be lethal, but currently it is not possible to reliably define that group. Once it is known how to do this, treatment can and will become considerably more selective.

So, here is a summary of the numbers. For every 750

In the U.S., the Secretary of Health and Human Services and Congress rejected the Task Force recommendations and asked insurance companies not to deny coverage of mammography screening for women in their 40s.

women in their 40s who are screened for 10 years we can avert a death due to breast cancer, saving, on average 30 years of life and possibly avoiding more difficult treatment. These are the benefits. Against this we must consider costs and harms. Over those 10 years about 150 women would be called back for noninvasive imaging, there would be about 75 biopsies and 20 cancers detected. So 75–20 = 55 biopsies (mostly needle biopsies) would be performed on women without cancer and this is the main harm of screening. To save a year of life, it would be necessary, over a 10-year period, to recall about 150 women for noninvasive imaging and two unnecessary biopsies would be performed.

Overall, each year, screening women in Canada in their 40s would prevent about 200 premature deaths due to breast cancer and save about 6,000 woman-years of life.

In developing its recommendations, the CTFPHC did not reveal the algorithm that it used to weight the negative of these recalls and biopsies against the saving of life. The benefits associated with screening have been supported by RCTs and backed up by data from observational studies. The data that were accepted on harms come only from observational studies and from anecdotal information. My impression is that in formulating its recommendations on screening the CTFPHC grossly overweighted the negatives and downplayed the saving of life.

In the U.S., the Secretary of Health and Human Services and Congress rejected the Task Force recommendations and asked insurance companies not to deny coverage of mammography screening for women in their 40s. To date, the Federal Government in Canada has not responded to the CTFPHC recommendations, but in my view they should request a re-evaluation of the data, carried out with the participation of clinicians and scientists knowledgeable in the areas of breast cancer detection, diagnosis and treatment. It is better to have the benefit of expert information than to reach scientifically unsupportable and dangerous conclusions because of the lack of relevant expertise. Methods of handling conflict of interest are widely and successfully used in society.

This article attempts to provide quantitative values reflective of the performance of organized screening as utilized in current breast cancer management. I hope that this information is useful to health care providers to be aware of the actual benefits, limitations and harms of mammography screening so that they can help their patients make truly informed decisions.

Martin J. Yaffe, PhD, is Senior Scientist, Sunnybrook Research Institute, Tory Family Chair in Cancer Research and Professor, Departments of Medical Biophysics and Medical Imaging at the University of Toronto. He served as Chair of the Scientific Advisory Committee for the Canadian Breast Cancer Foundation *It's About Time* Report on Mammography Screening.

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Prostate Cancer

TO SCREEN OR NOT TO SCREEN

By JOHN THOMS, MSc, MD, FRCPC and
JINKA SATHYA, MB, BS, FRCR, FRCPC

More than 25,500 men in Canada were diagnosed with prostate cancer in 2011, and 4,100 men died from the disease.¹ The early 1990s saw a sharp rise in prostate cancer incidence. This correlates with the introduction of widespread prostate-specific antigen (PSA) testing in Canada in the late 1980s that led to increased detection of early stage disease.² While the incidence rate for prostate cancer in Canada has not changed significantly in the last 15 years, during this same period the mortality rate has decreased from 31 to 21 cases per 100,000.¹ This has been attributed to improvement in treatment and possibly to early detection by PSA screening.

The effectiveness of prostate specific antigen (PSA) to reduce prostate cancer mortality remains uncertain. Recently, published up-dated results of several trials evaluating PSA screening show conflicting results. The 2011 update of the U.S. Preventive Services Task Force now recommends against routine PSA screening for prostate cancer in asymptomatic men.² A similar position is shared by many health organizations including the Canadian Cancer Society and the Canadian Task Force on Preventive Health Care (2004) that recommends patients discuss the harms and consequences of PSA testing with their family doctors before testing.

The goal of screening in a population is to detect a disease in individuals without signs or symptoms of the disease, enabling early intervention in the hope of reducing mortality and suffering from the disease. For a screening program to be effective the benefits of screening need to be balanced against the disadvantages or risks of early detection. Recent updates of the two largest trials evaluating PSA screening: the Prostate, Lung, Colorectal and Ovarian screening trial (PLCO) and the European Randomized Screening Trial of Prostate Cancer (ERSPC) following longer term follow-up were published in March 2012.^{3,4}

PLCO PSA Screening Study

The PLCO screening study randomized 76,685 men, aged 55–74 years at 10 screening centres in the United States to organized annual PSA screening and digital rectal examination (DRE) or to the control arm of usual care which did include opportunistic screening.³ It is important to note that 52 percent of men in the control arm did undergo PSA screening during the study, leading to potential significant

degree of contamination, which may have contributed to the difference observed between the two trials. Following 13 years of follow-up, there was no difference in all-cause mortality or in prostate cancer mortality. The cumulative mortality rates from prostate cancer were 3.7 and 3.4 deaths per 10,000 person-years, in the intervention and control arms respectively.³ The PLCO trial did, however, show a non-statistical significant decrease in the incidence of high-grade prostate cancers in the intervention arm (RR = 0.89, 95% CI = 0.77 to 1.01).³

ERSPC PSA Screening Study

The larger ERSPC trial randomized 182,160 men from eight European countries, between the ages of 50–74 years, to the intervention arm of PSA screening (PSA screening interval was two or four years) or to the control arm of no screening.⁴ It is estimated that 20 per cent of men per year underwent PSA screening. The degree of contamination in the ERSPC is likely less than the PLCO trial however, complete details regarding the degree of contamination is unknown. After 11 years of follow-up there was no difference in all-cause mortality. There was however, a reduction in the risk of death from prostate cancer in the screening group. The relative risk reduction was 21 per cent. The absolute reduction in mortality in the screening arm was 1.07 deaths per 1,000 men.⁴

Viewed another way, to prevent one death from prostate cancer 1,055 men would need to be invited for screening and 37 cancers would need to be detected and treated. This was similar to the ERSPC 2009 report. In the recent meta-analysis of randomized prostate cancer screening trials by Djulbegovic et al., which included the PLCO and ERSPC 2009 reports, there was no statistically significant effect of screening on prostate cancer mortality or on overall mortality.⁵

Harms of PSA Screening

The disadvantages of prostate cancer screening using PSA and DRE, may appear minimal. Physical harms of screening are minimal and included bleeding or pain from DRE; bruising or fainting due to venipuncture, both occurring at low rates. However, prostate biopsy complications include infection, bleeding and urinary problems.^{6–8} A false positive PSA test can have adverse psychological effects (i.e., anxiety) and prolonged knowledge of a diagnosis of prostate cancer can cause unnecessary stress and anxiety, but it is difficult to estimate their magnitude from the current literature.⁷ None of

the randomized clinical trials of PSA screening reported results on the potential of psychological harms or on quality of life.

The risk for false-positive results was 12 per cent from the Finnish centre in the ERSPC trial after three rounds of PSA testing and 13 per cent in the PLCO trial after four PSA tests.^{6,9} A false negative PSA test can lead to a false sense of security and delay in final diagnosis. The positive predictive value of PSA is estimated at 37 per cent; the rate of having a positive biopsy with a “normal” PSA of < 4.0 g/ml can be as high as 15-20 per cent.¹⁰ In addition, the cost-effectiveness of PSA screening and use of medical resources is not well known, the annual cost of PSA screening in the U.S. is estimated at \$3 billion.¹¹

Importantly, PSA screening can lead to overdiagnosis and unnecessary treatment. The rate of overdiagnosis with PSA screening is estimated to be as much as 50 per cent.¹² The harms associated with radical treatment of prostate cancer are well documented in the literature. Both radical prostatectomy and radiation therapy, when compared to watchful waiting, are associated with an increased risk of urinary incontinence and erectile dysfunction. (USPSTF)² The median increase in absolute risk of erectile dysfunction was 14–26 percentage points. Radical prostatectomy does carry a low risk of perioperative mortality; a low risk for serious rectal or ureteral injury ranged from 0.3 to 0.6 per cent.^{13,14} Radiation therapy is associated with increased chronic rectal symptoms.¹⁵

At the present time, the evidence is lacking to support expanded PSA screening beyond current practices of ad hoc or opportunistic testing in asymptomatic men who do not have a strong family history. If PSA screening is found to be clearly effective in the future, the optimal screening interval and clear guidelines remain to be determined. A conservative approach towards PSA testing and treatment (i.e., active surveillance) in appropriate low risk candidates may be a reasonable way forward, until further evidence is available.

The long held dogma that many men will develop prostate cancer, but few men will die from the disease needs to be balanced against the fact that 25 per cent of men with prostate cancer will present with locally advanced disease and a large percentage of these men will experience the adverse symptoms of their disease. Furthermore, once prostate cancer is detected in an individual, deciding if treatment is necessary and deciding on the magnitude and treatment type frequently presents a challenge in clinical decision-making.

Currently, the ability to predict an individual prostate cancer patient’s response to treatment is limited and based primarily on pre-treatment PSA, tumour stage, and Gleason score.¹⁶ Additional biomarkers that could be used with PSA for screening and to denote non-aggressive from aggressive disease are clearly needed. These biomarkers could effectively triage patients to more individualized prostate cancer management. Accurate and individualized risk stratification may have more profound implications for the individual (lower recurrence rates, better quality of life) and society (lower cost, better use of health resources) than early detection of the disease.

John Thoms, MSc, MD, FRCPC is a Radiation Oncologist at the Dr. H. Bliss Murphy Cancer Centre and Assistant Professor within the Discipline of Oncology at Memorial University. His primary research interests pertain to novel biomarkers of radiotherapy response and prostate cancer and novel clinical trials for prostate cancer.

Jinka Sathya, MB, BS, FRCR, FRCPC is Associate Professor, Memorial University (Previously at McMaster University and University of Manitoba). His primary research interests are in the field of genitourinary and head and neck cancers.

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Patient Organizations Cautiously Optimistic with New pCODR Process

By DEB MASKENS

The pCODR (pan-Canadian Oncology Drug Review) process was long anticipated by patient groups as an opportunity to provide early and meaningful input into a more open, transparent review process for cancer drugs.

December 2011 marked a first for pCODR, with the completion of its first drug review—pazopanib (Votrient)—for advanced kidney cancer. While other oncology drugs are currently under review, we believe that patient groups and the public have every reason to be encouraged.

Where the former process (the Joint Oncology Drug Review—JODR) was perceived as a black-box closed process, pCODR has openly invited and clearly incorporated patient input and feedback. The first patient group to experience the full process, Kidney Cancer Canada, strongly supports the new process. Through the Canadian Cancer Action Network (CCAN) Drug Review Working Group (DRWG), patient advocates are committed to working to strengthen and improve the patient voice in the pCODR process. We remain hopeful that a pan-Canadian drug review with strong support from the provinces will contribute to greater consistency in coverage between provinces and reduce unnecessary duplication of effort across our provincial health systems.

The Evolution of pCODR

pCODR is the review body established through interprovincial collaboration to conduct clinical and economic reviews of cancer drugs and to provide recommendations about funding to the participating provinces (all provinces except Quebec). pCODR has gathered the best talent in Canada to establish a high quality review process, including experts in the clinical and economic aspects of cancer drugs. Patient input is also an important component of pCODR.

pCODR was launched in July 2011. Its structure was based on experiences gained from the interim JODR process, which had been in place since 2007. Throughout the development of the new pCODR, patient organizations including CCAN provided substantial input into how the pCODR process should be structured and how it should function in terms of transparency and communication with patient organizations.

Many cancer advocacy groups identified the need for the patient and caregiver experience of the disease and drug treatments to be directly presented and equally considered early in the review process.

The architects of pCODR welcomed many of these suggestions. Three patient representatives now sit on the

pCODR Expert Review Committee, which is responsible for reviewing drug submissions.

Patient groups are invited to make two formal submissions for specific drugs under review. These submissions include a qualitative and quantitative summary of the patient experience with the drug, including side effects, quality of life, treatment alternatives, and views on the specific disease and treatment options. A second submission gives patient groups an important opportunity to provide feedback on pCODR's initial recommendation. Patient groups must pre-register with pCODR and must meet certain funding requirements that work to ensure a balanced and objective submission.

CCAN and pCODR Working Together

On behalf of its member organizations, including national cancer patient organizations, provincial and population groups, CCAN created the DRWG to promote the interests of cancer patients with pCODR. The DRWG represented a major strategic area of focus for CCAN in 2011 and also in 2012.

The Drug Review Working Group identified that one of the main barriers to patient groups being perceived as credible contributors to the process is the perception by some reviewers of influence by pharmaceutical sponsors, through the grants given to groups. Indeed, many patient organizations reach out to corporate sponsors, including pharmaceutical companies, for unrestricted education grants to fund patient meetings, conferences, materials and core operating costs. The truth is that with no public healthcare funding available to support patient advocacy organizations in Canada, these valuable organizations simply could not exist without private donations and corporate support. Independent patient advocacy organizations are especially important in light of the fact that many organizations or agencies that receive federal government funding are strictly prohibited from advocating at the federal level (e.g., for a national catastrophic drug plan).

To address the issues of any real or perceived biases, the CCAN DRWG created and implemented a standardized Code of Conduct Governing Corporate Funding for CCAN member organizations. The Code was based upon international standards for patient organizations including the European Cancer Patient Coalition and the International Association of Patient Organizations. The Code launched in January 2012 to clearly delineate the boundaries and conditions of financial relationships between patient organizations and their commercial sponsors. Organizations displaying the



Deb Maskens

Code graphic seal agree to comply with strict annual guidelines governing the percentage of funding, recognition of sponsors, and patient group control of projects undertaken.

pCODR signalled that the Code of Conduct and associated Seal of Compliance are an important step forward to help to build the credibility of patient organizations that participate in their process.

What Issues Remain?

1. Promoting Involvement in the Process

Ensuring that patient organizations understand the value of participating in the drug review process. Without a patient group submission, decisions will be made based upon clinical and economic evidence without the patient or caregiver perspective. Cancer patients should know which patient organizations will be representing their voices in this new pan-Canadian process.

2. Helping Smaller Patient Organizations with Submissions

Helping patient organizations manage the additional work required to build a quality patient evidence submission. CCAN has created an online survey that patient organizations can use to poll their membership about direct experiences with the therapy under review. A quality submission requires extensive effort, within a very limited timeframe, often on the part of volunteers or very limited staff resources.

The pCODR template *Patient Advocacy Group Input on a Drug Review* and accompanying *Conflict of Interest Declaration* request very specific information. Answers require outreach to patients and caregivers who have had direct experience with the new therapy to address such questions as: "Is the drug easier to use?", "Which symptoms does the drug manage better than the existing therapy and which does it manage less effectively?"

To answer these questions, patient organizations must first find the patients who have had early access to the new drug (most often through a clinical trial). Due to privacy issues, patient organizations cannot simply obtain a list of patients who participated in trials. Recruitment for the patient survey may be unrealistic unless a) trials have been conducted in Canada and b) oncologists encourage their patients to contribute to the drug review process by offering their personal experiences.

3. Broadening the Conflict of Interest Disclosures to Promote Fairness

The Drug Review Working Group strongly believes that a singular focus on pharmaceutical funding as the only source for bias in the process is not sufficiently comprehensive and misses other significant potential conflicts of interest. Patient organizations have other sources of funding and other sources of potential biases. In addition, other stakeholders in the process have significant biases that are neither declared nor itemized to the same degree of detail. Our recommendation is for all groups to openly disclose all potential sources of support (in-kind, charitable donations, and grassroots effort) in addition to the singular dimension of industry funding.

4. Monitoring Provincial Reimbursement Decisions

Whether pCODR is successful in reducing provincial disparities remains to be seen. We will be watching carefully for provincial decisions to adopt the pCODR recommendation for each drug reviewed. Given the stated commitment from the provinces to support pCODR, we expect shorter decision cycles that will allow cancer patients access to the therapies they need.

DRWG will continue to work on forging a strong relationship with pCODR and to mutually find ways to strengthen the patient voice in the drug review process. We welcome your comments.

Through pCODR, we have a unique window of opportunity for Canadians to work together to develop a world-leading cancer drug review process. Our experience has been that pCODR is open to input and recognizes the unique value of the patient perspective. We will continue to work with pCODR to maximize opportunities for the patient voice to be heard.

Deb Maskens is Chair of the CCAN Drug Review Working Group www.ccanceraction.ca and Chair and Co-Founder of Kidney Cancer Canada www.kidneycancer.ca.

Members of the CCAN DRWG include: Marjorie Morrison, Vice Chair (Canadian Cancer Action Network); Tanny Nadon (Canadian Skin Patient Alliance); Sue Robson (Lymphoma Foundation Canada); Aldo Del Col (Myeloma Canada); Colleen Savage (Cancer Advocacy Coalition of Canada); Lauren Dobson Hughes, (Canadian Cancer Society); and Susan Turner (Facilitator).

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Lung Cancer and Stigma

FROM THE LAY CAREGIVER PERSPECTIVE

By MICHELLE LOBCHUK, RN, PhD

Most studies on lung cancer stigma have tended to focus on public and patient views without examining the impact on lay caregivers as vicarious and/or direct recipients of expressions of stigma. Furthermore, family and friends can also harbour negative attitudes toward patients with lung cancer that impact their helping behaviours.^{1,2}

Lung cancer stigma is a complex social phenomenon that is associated with labeling the suffering individual as tainted or less desirable.³ Of all cancers, lung cancer is viewed the most as a “matter of personal responsibility”.^{4, p.1799} Besides the well-known linkage of the disease with cigarette smoking (80 to 90 per cent of patients smoked), other characteristics prime us to mark the individual with lung cancer as deviant. Nicotine stained skin, fingers and teeth, the stained and bad smelling clothing, the bad breath, the smoker’s cough, and the look of premature aging all tend to motivate repulsion towards the guilty individual. Smokers are often individuals who live in low socioeconomic circumstances and may not be highly educated. These characteristics can reinforce stigma.

Smokers are sensitized to feel they are part of a special deviant class who must re-pay society for their bad choices through heavy government tax on cigarette purchases and enforced observance of public smoking bans. Boldly labeled cigarette packages show stark visuals of their diseased lungs and physically wasted individuals in death beds. These images perpetuate public beliefs that all lung cancers are linked to cigarette smoking. The reality is that 10 to 20 per cent of lung cancer patients never smoked. Street⁵ noted that “care of self” is now placed as a responsibility to the public and engagement in smoking signals p. 235 a weakness in self-control, a disease itself.

Regardless of current or past smoking behaviours, patients with lung cancer continue to bear ongoing moral responsibility when asked to confess their smoking history to health care providers. Despite advances in curative treatment for early stage lung cancers, the disease remains the number one cancer killer in Canada.⁶ Lung cancer carries a negative connotation of imminent death with subsequent fatalistic attitudes by, for example, practitioners in general practice.^{1,7}

Caregiving family and friends are not immune to strong societal responses to tobacco use and smoking-related disease. Not all family caregivers are compassionate, espe-

cially when patients continue to smoke. Studies show that 13 to 22 per cent of lung cancer patients continue to smoke after diagnosis.^{2,8} As a case in point, a wife recalled her “livid” reaction to her husband’s lung cancer and continued smoking:

“I remember going to the store one time and buying him a carton of cigarettes and saying, ‘Here. Fill your boots. Kill yourself if you want. That’s what you’re doing.’”⁹

In our study with 304 pairs of lung cancer patients and family caregivers, we discovered that when patients continued to smoke, caregivers attributed more judgment and anger toward the patient thus leading to less engagement in empathic helping behaviour.² Caregivers who blame, feel anger and have less empathy are at risk for providing less than optimal supportive, sensitive care that preserves the patient’s sense of dignity and quality of life. When caregivers blame patients, they experience greater levels of depression and even avoidance of the patient.¹⁰ Due to powerful societal messages about smoking, any one of us is at risk for responding with judgment and anger. Such negative responses can add to the suffering of patients who are made to feel guilty for having brought the disease upon themselves.

As a nurse I am concerned about the absence of practice guidelines that focus on supportive care for patients and families who must deal with complex psychosocial issues like lung cancer stigma. Best practice guidelines are built on evidence derived from research that is not well supported in lung cancer. In 2011 Charity Intelligence Canada (Ci) reported that, although lung cancer causes 27 per cent of cancer-related deaths, it gets only seven per cent of cancer-specific research funding, and 0.1 per cent of cancer donations.¹¹ On the other hand, despite representing fewer than 10 per cent of cancer deaths, breast cancer is the most funded cancer (45 breast cancer charities) and it receives 28 per cent of all Canadian cancer research funding.¹¹ The high survival rate for breast cancer is clearly related to well-funded research. Ci¹¹ pointed out that lung cancer has a very high opportunity for donor impact in the area of “care”: that is, donor dollars can assist caregivers who care for the 84 per cent of lung cancer patients who do not survive. Speculation remains that blame associated with the disease curtails investments by donors toward much needed lung cancer research.



Michelle Lobchuk

A lay caregiver had emailed me in support of my study on lung cancer stigma. She spoke of the lack of compassion and unwarranted stigma associated with her mother's lung cancer.

"I just wanted to express my appreciation for the research you will be conducting with respect to the effects of stigma, including blame and anger, on the care that lung cancer patients receive from informal caregivers. My mother died last year of lung cancer as a result of a lifetime of smoking and I often wonder what role the feeling of having imposed this illness on herself played throughout her illness. It pained me to have to watch her go through the agony of being diagnosed with the illness, receiving chemotherapy and radiation while also having to bear the weight of this uncompassionate/unwarranted stigma. This research is incredibly important and will undoubtedly help families and caregivers understand how better to deal with lung cancer patients. Thank you for recognizing this issue as a critical component of cancer research."

Hopefully Canadians will be sensitized to the unique suffering of individuals and families dealing with lung cancer stigma that is fueled by society's "just world mentality": people deserve what they get. Although exciting advances are being made in curative treatments for early stage lung cancer, more research is needed for caregivers (e.g., how to offer non-judgmental care that counteracts the negative effects of stigmatized disease). Widespread societal messages tend to favour judgment, even by health care providers¹ toward individuals with smoking-related disease. Guided by attributional theory, research efforts continue to advance our understanding of how to alter the harmful impact of blaming on empathy and helping behaviour toward patients with lung cancer who still smoke.^{2,4,12,13} Tobacco cessation literature indicates that social support is vital to offset any feelings of guilt for failure in attempts to quit smoking.¹⁴

Ongoing intervention work in this area will likely continue to be challenged, as long as caregivers feel pressured—or feel free—to conform to society's expectations to judge the individual with lung cancer as being socially irresponsible with one's health. Also, as long as society and the government view lung cancer research as a low priority, the needs of patients and caregivers who must deal with this "uncompassionate/unwarranted stigma" will remain invisible. Caregivers will not know how to overcome judgmental attributions and emotional distress that adds to the suffering of patients.

One thing that we can do now to de-stigmatize the lung cancer experience is to ask yourself: Why do I need to know whether the patient with lung cancer smoked? If it comes from a desire to blame, you may be doing more harm than good.

Michelle Lobchuk, RN, PhD is Associate Professor and Manitoba Research Chair in Caregiver Communication, Faculty of Nursing, University of Manitoba.

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Implementing Molecularly Targeted Treatments for Canadian Patients With Non Small Cell Lung Cancer

By Peter Ellis, MBBS, MMed, PhD, FRACP, FRCPC

Lung cancer represents a major burden of disease for the Canadian population. In 2011, 25,500 people were diagnosed with lung cancer and 20,600 died from the disease.¹ While the long term survival for patients with lung cancer remains poor, there have been improvements in treatment options over the last decade translating into modest improvements in survival and quality of life for patients living with the disease.

Some of these changes have been rapidly incorporated into clinical practice. Multiple trials published since 2004 demonstrated improved survival for patients with non small cell lung cancer (NSCLC) receiving post operative adjuvant chemotherapy.²⁻⁴ Analysis of Ontario population databases would suggest that widespread adoption of adjuvant chemotherapy has resulted in improvements in population-based survival for NSCLC.⁵

Gains have also been made for patients with advanced stage lung cancer. We have moved from a situation where chemotherapy was thought to have limited value in patients with NSCLC, to one in which available evidence supports multiple lines of therapy.⁶⁻⁹

However, significant changes have occurred over the last five years. Recent data support the importance of histologic subtype in the selection of treatment. Increased understanding of the molecular abnormalities associated with cell growth and proliferation of NSCLC has led to development of therapies targeting specific molecular pathways such as the epidermal growth factor receptor (EGFR)⁹ and Anaplastic Lymphoma Kinase (ALK) gene.^{10,11}

As a result of these changes, there has been a shift from a treatment algorithm applicable to the majority of patients, to a more complicated situation in which treatment decisions are influenced by a variety of factors including histologic subtype and molecular phenotype. It is not clear though, whether there is adequate infrastructure in place to facilitate rapid adoption of these changes.

The Importance of Histology

Historically, all subtypes of NSCLC were treated the same. More recently, the importance of accurate histological classification has been recognized. Data from several randomized trials demonstrate improved survival for patients with non-squamous histologies treated with pemetrexed.¹²⁻¹⁴ Additionally, patients with squamous histology are generally

considered ineligible for therapy with bevacizumab because of an increased risk of fatal hemoptysis.¹⁵ Distinguishing squamous from non squamous subtypes has become an important distinction.

However, the diagnosis of NSCLC is often made on small biopsies or cytology specimens that make accurate histologic classification difficult. Recommendations from the International Association for the Study of Lung Cancer,¹⁶ as well as Canadian consensus guidelines¹⁷ recommend the routine use of immunohistochemical testing to favour adenocarcinoma or squamous carcinoma, whenever such distinction cannot be made based on tumour morphology alone.

Implementing these recommendations poses challenges. There is often minimal diagnostic material available on which to perform additional testing. Additionally, there is a need for education of pathologists on the importance of accurate classification in order to facilitate appropriate treatment selection.

The Emergence of Molecular Testing in Treatment Selection

The presence of activating mutations of the EGFR gene were first described in 2004.^{18,19} Deletions of exon 19 and L858R point mutations of exon 21 were reported to be associated with a high likelihood of response to therapy with an EGFR tyrosine kinase inhibitor (EGFR TKI). Available data suggest that the incidence of such mutations is greatest amongst people of Asian ethnicity, adenocarcinoma, females and never smokers. Approximately 10–15 per cent of Canadian patients with NSCLC would be expected to have such a mutation.

During 2008, initial data from the IPASS trial were presented.²⁰ This was the first of six trials comparing first-line therapy with an oral EGFR TKI to a platinum-based chemotherapy doublet (Table 1). Patients were selected based on a high likelihood of having an EGFR mutation (Asian population, adenocarcinoma, light or never smokers). There was improvement in the objective response rate and progression free survival for patients receiving gefitinib.

The IPASS trial clearly demonstrated the importance of knowing a patient's EGFR mutation status. Patients who were known to be EGFR mutation positive had a significantly improved progression free survival if they received gefitinib versus chemotherapy (HR 0.48 95% CI 0.36-0.64, P<0.001). However, patients who were EGFR wild type appeared to be harmed if they received first-line therapy with gefitinib (HR 2.85 95% CI 2.05–3.98, P<0.001).



Peter Ellis

Patients receiving gefitinib had less toxicity from treatment and improved quality of life.

Similar findings were seen in the First-Signal trial which compared gefitinib to cisplatin and gemcitabine. Knowledge of EGFR mutation status appeared crucial in determining which patients should receive first-line therapy with gefitinib.

Four additional trials have compared an EGFR TKI to chemotherapy in patients known to have an EGFR mutation. Three of these trials were conducted in Asian populations and one in Europe. There is great consistency in the data,

with large improvements in progression free survival in all trials (range HR 0.16—0.49).

Both gefitinib and erlotinib have less toxicity than standard chemotherapy treatments. These agents have become the preferred initial treatment for patients with advanced NSCLC whose tumours are known to have an EGFR mutation.

The discovery of translocations of the echinoderm microtubule-associated protein-like 4 (EML4) and the anaplastic lymphoma kinase (ALK) genes has defined an additional molecular subset of NSCLC with particular clinico-pathologic features.¹¹ This translocation occurs in approximately four to seven per cent of lung adenocarcinomas and its presence appears to predict a high likelihood of response to crizotinib, a specific inhibitor of the ALK fusion protein.¹⁰ Crizotinib received FDA accelerated approval in August 2011, for NSCLC that is ALK positive using an approved test (ALK break-apart FISH probe). It is currently under review by Health Canada, with a decision expected in the coming months. There are ongoing randomized trials comparing crizotinib to chemotherapy to better determine where crizotinib fits in the NSCLC treatment algorithm. It appears to be an active drug for a small population of NSCLC patients.

Implementation in Canada

There was widespread acceptance of the data concerning first-line EGFR TKI therapy among oncologists. Canadian consensus recommendations¹⁷ and even an OHTAC technology report²¹ were published recommending EGFR testing in this population. In early 2010, gefitinib received a Health Canada indication for the first-line treatment of patients with advanced or metastatic NSCLC who have an activating mutation of the EGFR. This created a number of challenges. Firstly, this required additional diagnostic material in order to be able to do testing, which is not always available. More importantly though, it required accredited molecular testing

TABLE 1

SUMMARY OF FIRST-LINE TRIALS OF EGFR TKI VERSUS CHEMOTHERAPY

Trial	Treatment	Population Positive or Negative for EGFR mutation	Response Rate	Months of Progression Free Survival (median)	Progression Free Survival (Hazard Ratio)	Quality of Life
IPASS ²⁰	Gef v Cb/Pac	Positive Negative	71% v 47% 1% v 23%		0.48 2.85	↑
First Signal ²³	Gef v Cis/Gem	Positive Negative	85% v 37% 26% v 52%		0.61 1.52	↑
NEJ002 ²⁴	Gef v Cb/pac	Positive	74% v 31%	10.8 v 5.4	0.30	
WJTOG 3405 ²⁵	Gef v Cb/Doc	Positive	62% v 32%	9.2 v 6.3	0.49	
Optimal ²⁶	Erl v Cb/Gem	Positive	83% v 36%	13.1 v 4.6	0.16	
EURTAC ²⁷	Erl v plat doub	Positive	58% v 15%	9.7 v 5.2	0.37	Not reported

↑ – QoL better for gefitinib
 Gef – gefitinib
 Erl – erlotinib
 Cb – carboplatin
 Cis – cisplatin
 Pac – paclitaxel
 Gem – gemcitabine
 Doc – docetaxel
 plat doub – platinum doublet

To approve a drug for public funding and not fund a mechanism to identify which patients might benefit from that drug is short sighted.

laboratories in which to perform the EGFR testing. However, no mechanism for funding was in place for this to happen.

There was not a reliable and valid system in place to perform EGFR mutation testing. A national testing program was set up with support from AstraZeneca Canada to facilitate the implementation of EGFR TKI therapy for EGFR mutation positive patients.²² Five laboratories across the country undertook validation and quality control processes to establish a network for EGFR mutation testing using RT-PCR. They are: British Columbia Cancer Agency, Alberta Cancer Agency, University Health Network (ON), Centre de Lutte Contre le Cancer du CHUM and Jewish General Hospital, QC.

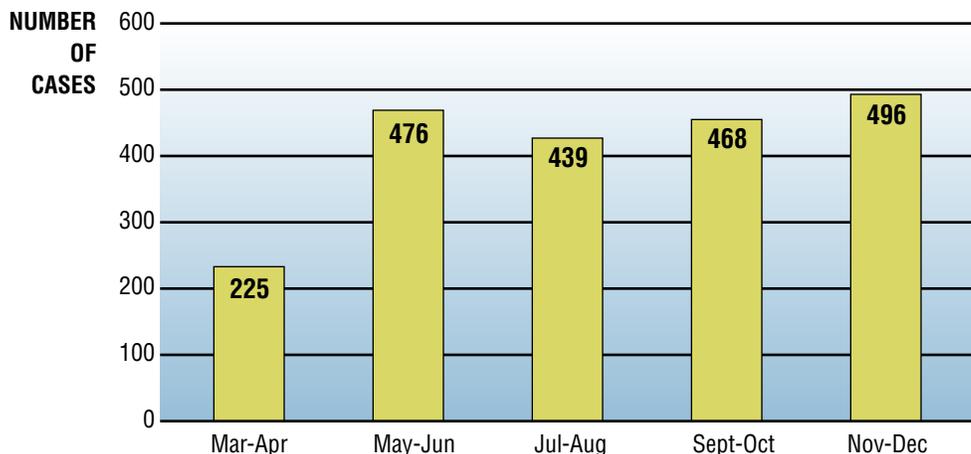
The one year program for EGFR mutation testing commenced mid-March 2011 and there was rapid uptake from oncologists across the country (Figure 1). Approximately 200–250 tests were ordered per month after the initial two months. Approximately 17 per cent of tests were positive for an EGFR mutation. At the end of the 12 month period government funding was still not in place to provide access to testing. Patients with private health insurance, or those willing to pay for gefitinib could still access testing. At this

time though, testing rates dropped to between 50–100 tests per month. To date, only four provinces (Ontario, Quebec, British Columbia and Alberta) are funding therapy with gefitinib for patients with EGFR mutation positive NSCLC. In at least two of these provinces, gefitinib was funded without incremental funding for EGFR testing. It is clear though, that a mechanism for molecular testing needs to be in place to allow appropriate patient selection and access to treatment.

Implications for Future treatment of NSCLC

We appear to have reached a therapeutic plateau with conventional chemotherapeutic drugs in the treatment of NSCLC. Molecularly targeted agents are now the major focus of clinical trials research in NSCLC. It is clear from emerging research that many molecular targets occur in only a small percentage of patients. As such, molecularly targeted agents are likely to be used in subsets of NSCLC patients who express a specific target. Such a situation is likely to exist in the near future for NSCLC patients with an EML4/ALK translocation. Specific inhibitors for this target, such as crizo-

FIGURE 1
UPTAKE OF EGFR MUTATION TESTING ACROSS CANADA DURING 2010



tinib, appear highly active in patients. Crizotinib is likely to be available to Canadian lung cancer patients in the near future and yet there is no mechanism in place within our healthcare system to provide testing to identify which patients might benefit from this treatment.

There is a need to develop a strategy across the country to provide access to molecular testing to identify appropriate sub populations of patients who are candidates for newer molecularly directed therapies. This situation exists not only for patients with NSCLC, but for patients with many different types of cancers. The strategy needs to be linked to drug approval processes. To approve a drug for public funding and not fund a mechanism to identify which patients might benefit from that drug is short sighted. The strategy also needs to be responsive to emerging data.

Lastly, the changing paradigm of treatment for NSCLC requires a change in the paradigm of diagnosis. Previously, pathologists were only called upon to distinguish small cell lung cancer from non small cell lung cancer. New algorithms for treatment separate patients according to squamous versus non squamous tumours, as well as the presence or absence of specific molecular markers. Therefore, additional information is required in lung cancer pathology reports. This can only be achieved through collection of larger tumour samples during diagnostic procedures. These steps will require education and knowledge transfer strategies to implement effective change in practice.

Peter Ellis, MBBS, MMed, PhD, FRACP, FRCPC is Associate Professor, Department of Oncology, McMaster University and Staff Medical Oncologist, Juravinski Cancer Centre, Hamilton ON.

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Exploring Possibilities for Treating Tobacco Dependence

EXPANDING THE HEALTH CARE CONTEXT OF PEOPLE LIVING WITH LUNG CANCER

By ANNETTE SH SCHULTZ, PhD, RN

The adverse health effects of tobacco use and the deleterious consequences of second hand exposure to tobacco smoke are undisputable. Tobacco use and smoke exposure are the single most preventable cause of disease, disability and death.¹⁻⁶ This evidence has supported the adoption of smoke-free space policies, along with a diverse array of other tobacco control strategies, which have collectively transformed how tobacco use is tolerated within our society. In particular, hospitals have increasingly restricted where smoking is allowed and tobacco products are no longer available for purchase in hospitals.^{7,8} Over the last five years, Canadian hospitals have adopted smoke-free grounds policies;⁹⁻¹¹ smoking is now prohibited on all hospital property.

Health professionals have played a key role in transforming opinion about tobacco use. Long gone are the days when health professionals posed for tobacco industry advertisements or suggested that cigarettes be used as a therapeutic means to alleviate anxiety or improve sleep. In more recent times, a common slogan offered to health providers has been: "Hospitalization is an opportune time to stop smoking!" When patients are faced with a health crisis, their regular smoking patterns are disrupted during hospitalization; health providers ought to capitalize on this change in routine and support smoking cessation.^{12,13} Alternatively, some smokers argue that, due to the stress associated with facing a health crisis, this is not the best time to make an unplanned attempt at quitting.¹¹ In addition, smokers' stress can be compounded by experiences of shame and blame when an illness is related to their use of tobacco.^{14,15} Given the tension between these two positions, one might wonder what role health professionals ought to adopt in treating patients' tobacco dependence during their hospitalization. In particular, when smoke-free grounds policies now require patients to leave hospital property if they wish to smoke, what are health professionals' responsibilities with regards to these patients?

In this paper, treatment of tobacco dependence is considered in relation to a specific patient population; that is, patients who have received a cancer diagnosis, particularly lung cancer. Various tobacco-related trends are presented and followed by a summary of the "calls to action" that help define health professionals' roles. Findings from a recent ethnographic study inform a discussion of current practice norms within hospital settings¹¹. The final section critically reflects on health professionals' roles related to tobacco dependence.

Current Trends in Tobacco Use

The Canadian Tobacco Use Monitoring System (CTUMS) reported that, in 2010, 17 per cent of Canadians over the age of 15 years used tobacco products.¹⁶ While prevalence rates among the general population have continually declined, the same is not true for a variety of subpopulations.¹⁷ For example, individuals living with a diagnosis of lung cancer have reported rates at time of diagnosis between 24 and 60 per cent.¹⁸ Most people living with lung cancer, who smoke, have high levels of nicotine dependence and will continue to smoke after their initial diagnosis.¹⁸ Although smoking cessation can be an initial response, evidence suggests that relapse is common.^{18,19}



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In Canada, it is promising that the number of former smokers exceeds the number of current smokers.²⁰ However, for the nearly five million Canadians who currently use tobacco, support to address tobacco dependence is most likely rarely offered.^{16,21-23} This is unfortunate given the fact that over two million of these individuals will have made a quit attempt in the last year,¹⁶ meaning that they would benefit from receiving robust and ongoing tobacco dependence treatment. Moreover, research evidence suggests that, in general, most smokers think about quitting and anticipate that

It is particularly important that health providers address patients' tobacco use, as most patients would be reluctant to raise the topic themselves.

health providers will address their tobacco use.²⁴⁻²⁷ It is particularly important that health providers address patients' tobacco use, as most patients would be reluctant to raise the topic themselves.

Emerging evidence related to the effects of ongoing tobacco use after initial diagnosis of any cancer suggests poorer health outcomes, including earlier death, among these patients.^{15,18,19,28} In addition to their increased risk of developing heart or lung diseases and secondary tumours, these patients experience more treatment complications. Infection rates are higher among patients who continue to smoke and are compounded by poorer wound healing and treatment response. Ongoing tobacco use can compromise immune system function, which is likely one of the mechanisms underlying poorer healing trajectories. Alternatively, benefits have been reported among patients who stop using tobacco after their initial diagnosis. It is likely that improved oxygenation plays a central role in their overall health, ability to heal and sense of well-being. In addition, improvements have also been noted in appetite and fatigue levels among these patients; both of these benefits are related to greater energy and activity levels. Finally, these patients experience improvements in their mood, perceived psychological well-being, and self-esteem. Given these benefits, it may not be surprising that cognitive functioning is also enhanced.

Due to advancements in diagnostic tests and medical interventions, lung cancer is now being diagnosed in earlier stages.^{18,19} As a result, survival among stage 1 and 2 lung cancer patients is an emerging reality.^{18,19} One could argue that it is imperative to treat tobacco dependence among patients with lung cancer who use tobacco products. There are many reasons to offer tobacco dependence treatment as part of the full spectrum of health care services for lung cancer patients; at the very least, to enhance patients' response to cancer treatment regimes and improve their survivorship trajectory.

People who live with a diagnosis of lung cancer, yet remain dependent on tobacco products, tend to experience significant stigma. This stigma may be rooted in internalized blaming or shaming messages or be a response to external experiences;^{14,15,29} both sources reveal the highly effective social marketing strategies focused on educating the public about the link between tobacco and lung cancer. While this knowledge is intended to encourage people to quit or to never start smoking, it can also nurture stigmatization of those who start and continue to smoke. Stigmatized people are less likely to seek health care, which is linked to a sense of personal responsibility and unworthiness to receive health care services.^{14,15}

Emerging evidence suggests the decision making dynamic among family caregivers is problematic when the person they are caring for, who has lung cancer, does not stop smoking.²⁹ When a person living with lung cancer is stigmatized within the family, health care decisions are often less collaborative and tend not to reflect the patient's needs. Since health care unfolds within the home, perceptions and processes that caregivers use for making decisions are of interest, as both guide health care planning.²⁹ Engaging family members in a conversation about tobacco use and dependency, regardless of interest in smoking cessation, is essential to support open family dynamics and enhance health care planning. Talking about nicotine addiction, possibilities to address withdrawal symptoms, supporting reduced tobacco consumption and/or cessation will aid in alleviating stigma within the family related to shaming or blaming the person addicted to tobacco products.

Calling Health Professionals to Action

In 1995, the first clinical guidelines for health professionals were published by the U.S. Department of Health and Human Services.³⁰ These guidelines have been updated twice and adopted by diverse health professional groups around the world. Tobacco dependence clinical guidelines articulate a practice standard and the steps that health providers could take to address patients' tobacco use. The steps are known as the 5 As:

1. ask if the patient smokes,
2. assess the patient's readiness to quit,
3. advise the patient about quitting,
4. assist the patient to quit,
5. arrange a follow-up appointment.

Since inception, these steps have been shortened to provide a brief one-to-three minute intervention. The briefest intervention includes 3 As:

1. ask the patient about tobacco use,
2. advise the patient to quit
3. arrange for follow-up.

While more intensive interventions are more effective, consistent delivery of the brief intervention to all patients can influence quit attempts. Integration of this intervention into practice has been demonstrated to be cost effective and, more importantly, to confer multiple benefits to patients. Finally, the clinical guidelines suggest that health care institutions integrate a process into their organizational systems that supports the treatment of tobacco dependence as a

health provider practice norm.

In 2005, the World Health Organization (WHO) adopted the Framework Convention for Tobacco Control (FCTC).³¹ Since its inception, 174 parties, globally, have signed and ratified the FCTC; Canada is one of these parties. These governmental bodies were and continue to be legally required to integrate strategies that would facilitate the adoption of the 38 articles in the FCTC into their health and public policies. Specifically, article 14 identifies the importance of tobacco dependence treatment within health care services.

In the same year, the WHO published a document to assist health professionals in adopting their role to support smoking cessation among patients with tobacco dependence.³² Then, in 2008, the Union for International Cancer Control generated a World Cancer Declaration; one of the eleven targets identified is reducing global tobacco consumption.³³ Nurses are the largest health professional group working in direct patient care roles and in 2009 the International Society of Nurses in Cancer Care updated their position statement concerning tobacco dependence.³⁴ This document provides useful information about tobacco products and their use within our society, including the role of the tobacco industry. An unusual feature of this position statement is:

"...tobacco use assessment, documentation and dependence treatment is an expected part of care in all cancer treatment programs, including addressing the stigma faced by many patients affected by a tobacco-related cancer and specifically highlighting the benefits of smoking cessation in the context of a cancer diagnosis."

In this position statement, the role of the health professional extends beyond the importance of assisting patients in smoking cessation to also embrace the importance of addressing tobacco-related stigma.

Practice Trends Related to Patient Tobacco Use

Over the last decade, I have listened to the perceptions and experiences of several hundred health providers as part of three research studies,^{8,13,35-37} which collectively involved seven hospitals in four provinces. Twenty-two presentations have been made (regionally, nationally, and internationally) to diverse health provider groups; each provided an opportunity to dialogue with wider health provider audiences.

From these varied interactions, I have been able to identify some recurring comments concerning patients and their tobacco use. While there is a keen awareness among health providers that tobacco use affects health, it is unlikely that tobacco dependence will be addressed or treated during a patient's hospitalization. This practice norm may be rooted in a knowledge deficit and insufficient health provider self-efficacy to address tobacco dependence, which works synergistically with the belief that it is inappropriate to address tobacco dependence during hospitalization. The following quotes reflect these generalizations:

- *This is not a front-line issue...it is a secondary issue with long-term effects that people are not willing to talk about*
- *How can I get someone to quit during a 12 hour shift*

- *I do not have time...I offered the patch but it was declined*
- *Tobacco is a leading cause of cancer. We see people when they have received a recent diagnosis and it is a crying shame that we do nothing...what are we to do? This really needs to be addressed.*

An ethnographic study conducted in two western Canadian hospitals, both with implemented smoke-free hospital grounds policies, provides insight into the interface of tobacco use and dependence within health provider practice.¹³ As one of five data sources in the larger study, focus groups with health providers working on eight adult inpatient wards (four wards at each hospital site) sheds light on practice realities from the providers' own perspectives. A total of 54 registered nurses and 27 allied health providers participated in a focus group discussion. Participants were aged 22 to 65 years and were smokers (n=13), former smokers (n=14), or never smokers (n=53). Discussions focused on management of patient tobacco use as well as participants' perceptions of smoke-free hospital grounds policies. Highlights of the study findings are presented here using three themes:

- practice activities framed by the 4 As (assess tobacco use, advise to quit, assist with smoking cessation, and arrange follow-up post-discharge);
- alternate tobacco-related practice activities;
- patient safety concerns.

The intention is to shed light on current practice realities within hospitals, beyond the dictates of clinical guidelines.

The following illustrates the findings from the current study with respect to practice activities framed by the 4 As. Commonly, on admission, patients were asked if they smoke. Patients who indicated that they smoke were advised about the policy and made aware that smoking is not allowed on the ward or on hospital property. This initial conversation might have also included advice about the health risks associated with smoking as well as advice to quit smoking. It was found that assistance with smoking cessation was not consistently offered during hospitalization. Moreover, if a nicotine replacement medication was offered and a patient refused, assistance was often never discussed again. It was then up to the patient to find support in getting off the premises to smoke. The fourth 'A', arranging follow-up, was very rarely addressed and was done by making a fax referral to the smoker's helpline. Based on the 4 As framing of practice activities, one might conclude that health providers on the wards included in this study were not treating tobacco dependence. However, this conclusion is only accurate within the dictates of the 4 As framing.

There were at least four alternate practice activities related to managing a patient's tobacco use that required a health provider's time and attention. Each of these four practice activities not only required additional time and attention, they were sources of strain on health provider and patient relationships.

1. Health providers negotiated with patients when health care treatments were delivered. For example, one nurse stated that she would rather change a dressing on someone who had just had a cigarette than on someone who

wanted to go out for a cigarette. While this makes sense from a compassionate standpoint, it also demonstrates a practice reality whereby health providers with busy workloads are providing options to accommodate patients who need to leave the ward to smoke. These negotiations, and the associated workload re-organization, take extra time.

2. The smoking ban on the ward must be enforced by health providers and other staff. While most patients do not attempt to smoke on the ward, security officers must become involved, and cigarettes may be confiscated, if a patient violates the smoke-free hospital grounds policy. These patients must then request one cigarette at a time from their nurse for the remainder of their hospitalization.
3. Patients with mobility limitations, who are unable to ambulate off the ward independently, will most likely request assistance to leave the ward. These requests may occur very regularly. Since this situation can be frustrating for busy health providers, it can incite tensions on a ward. It is then the responsibility of ward staff to deescalate the situation and calm the patient.
4. Health providers must critically reflect on where liability and responsibility is situated when patients leave the ward to smoke. Nurses expressed moral duress over patients leaving the ward for a cigarette, while also feeling unable to force a smoker to quit.

Health providers discussed their concerns related to patients leaving the ward to smoke and identified several safety issues.

1. Patients may have a health crisis when they are outside and unsupervised.
2. Hospitals located in unsafe neighbourhoods brought additional issues, as patients were vulnerable to potential violence.
3. Hospital equipment, such as intravenous lines and machines, sometimes malfunctioned when the patient was outside (particularly in cold weather), leading to a disruption in health care.
4. If patients were inappropriately dressed, they were vulnerable to extreme weather conditions. While health providers expressed concern about these issues, they also critically reflected on the boundary between their own and their patients' responsibilities. These concerns raised the following question: What role are health providers and health care organizations to play in addressing tobacco dependence during hospitalization?

Treating Tobacco Dependence Beyond the 4 As and Cessation

Health providers working in cancer care settings will encounter people within their practice who use tobacco. While advising people to stop smoking is logical from a health risk perspective, given the evidence linking tobacco use to cancer, there are other reasons for treating tobacco dependence among this population. Other reasons to treat tobacco dependence include:

- to enhance patients' responses to oncology treatment regimens as well as their general well-being,
- to circumvent patients' exposure to safety issues associ-

ated with leaving the ward to smoke,

- to defuse the effects of stigma on patients and support healthy family dynamics,
- to enhance survivorship experiences.

While smoking cessation remains important as a long-term goal, it may be more appropriate to focus on supporting abstinence and/or reduction of tobacco use as interim goals. Treating tobacco dependence is an integral component of health care services for a person's journey through cancer treatment.

Clean air policies, that restrict the number and range of places where people can smoke, have significantly changed our society. For tobacco-free individuals, exposure to second-hand smoke over the last three decades has been reduced. In hospital settings, patients addicted to nicotine, as well as the hospital staff who care for these patients, now face considerable challenges. Smoke-free hospital grounds policies means patients with tobacco dependence will experience withdrawal symptoms during hospitalization. There are at least three options available for managing these symptoms:

- the patient receives ongoing effective medical treatment;
- the patient goes outside and off the hospital grounds to smoke; or
- the patient suffers with unmanaged withdrawal symptoms.

How might practice change if managing tobacco dependence withdrawal symptoms were integrated into health assessment? Might some of the burdens related to managing tobacco dependence be eased, if tobacco dependence were seen as an addiction and treated?

In this article, I highlight evidence that provides rationale for treating tobacco dependence along with current practice context. I now invite health providers to critically reflect on their own practice of managing patients' tobacco use. The following two sets of questions are offered as a way to assist a self-reflexive process:

- What is your current practice standard?
- Do you ask patients if they smoke?
- What is the advice you give to patients who smoke? Health risk related and/or to quit?
- How do you to explain smoking restrictions?
- What is your standard script for offering assistance to not smoke?

While the above questions reflect steps outlined in practice guidelines, there are two additional areas of reflective questions:

How do I tolerate patients who smoke and leave the ward to smoke?

- What are my experiences with patients leaving?
- When am I frustrated with patients who smoke, what underlies my frustration?
- How do I deal with my frustration?

When I think of patients who use tobacco, how do I frame their tobacco use?

- Do I perceive the patient as dependent or addicted to a substance rather than someone with a habit who is making bad choices or decisions?

While there is a keen awareness among health providers that tobacco use affects health, it is unlikely that tobacco dependence will be addressed or treated during a patient's hospitalization.

- Can you imagine how your practice would differ depending on whether you frame smoking as an addiction or a habit?
- Might your assessment of these patients change based on whether you frame their smoking as a habit or an addiction?
- How could treatment options along with perceived priority for addressing tobacco use be influenced by seeing smoking as an addiction or a habit?
- Might your relationship with these patients differ if you perceive them as addicted to a substance versus making unhealthy choices?

The advent of smoke-free grounds policies may be the catalyst for hospitals and health authorities to take the next step in transforming tobacco dependence treatment in hospitals; that is, the adoption of a systematic approach to tobacco dependence treatment. The U.S. tobacco dependence clinical guidelines acknowledge the importance of adopting an organizational approach to support practice changes.³⁰ Since patient safety concerns are an unintended consequence of clean air policies within hospitals, these policies may serve as an impetus for health care decision-makers to reconsider tobacco dependence as a health care priority in this setting and allocate resources necessary to adopt a systemic strategy. Reflexive questions for those influencing health care system changes are:

- Is there an organizational responsibility to adopt a system-wide approach for treating tobacco dependence given that smoking restrictions require patients to leave the property to smoke?
- Is there a role for Accreditation Canada to play in changing how tobacco dependence is treated within hospitals?

Our society has come a long way from the days when there were no smoking restrictions in any health care setting and tobacco products were sold within hospitals. Today young health professionals are shocked to hear about a time when health providers smoked on patient wards. How could health professionals be so remiss as to smoke around sick patients? It is time for us to herald in a new era, where treatment of tobacco dependence becomes commonplace and patients hear the following upon admission to a hospital:

I know you will experience withdrawal while in hospital. Treating these symptoms is a priority and we have a variety

of medications available to support you. Treating nicotine withdrawal is important, as it will support your body in healing, make your stay in hospital more tolerable, and keep you on the ward, where you are safe. To be successful in treating your symptoms, we need to work together to find the right medications for you. I will be assessing your symptoms regularly to ensure your withdrawal is managed effectively. Based on your current tobacco use, here is what I suggest as your first treatment option.

A new generation of novice health professionals will be shocked to hear of a time when tobacco dependence treatment was not a standard of health care. They will be equally dismayed that patients who are dependent on tobacco products had to leave the ward and the hospital grounds to alleviate their withdrawal symptoms, while clinical relief was within reach.

Annette SH Schultz, PhD, RN, is an Associate Professor in the Faculty of Nursing, University of Manitoba and a Principal Investigator, St. Boniface Hospital Research Centre. As a nationally recognized scientist, her research focuses on best health care policies and practices to address and manage tobacco use. Her vision is to enhance supports for tobacco dependence within diverse health care contexts.

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Smoking Cessation

By JAMES D. GOWING, BA, MB, BS, FRCPC

Front line health workers giving nonjudgmental advice to patients to quit smoking is often the first step in smoking cessation. Numerous reports^{1,2} in the medical literature outline the evidence for combining counselling and medications to achieve better long term outcomes. Clinical guidelines exist which show that first line medications including nicotine replacement therapy, varenicline and bupropion along with appropriate counselling improves overall cessation. Many new medications are in the trials pipeline.³

Health ministries across Canada should support both counselling and pharmaceutical interventions for smoking cessation, which are among the most cost effective interventions in healthcare.⁴

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Smoke-Free Multiunit Housing in Canada

By DAVID SALTMAN, MD, PhD and KEVIN COADY, MEd

Exposure to environmental tobacco smoke (ETS) is an established health hazard.^{1,2} The adverse health effects associated with ETS include cancer, acute and chronic respiratory disorders, middle ear infections, cardiovascular disease and sudden infant death syndrome (SIDS).^{3,4} There is no safe level of exposure to secondhand smoke (SHS), so exposure to even low levels could be deleterious to your health.³

Children may be even more susceptible to ETS toxins than adults because of their higher respiratory rate leading to more exposure to air pollutants, and differences in the ability to biotransform and eliminate chemicals.⁵ Small infants may be at even greater risk because they are unable to remove themselves from an environment that exposes them to ETS. Even low levels of tobacco smoke exposure have been associated with decreased lung function and poorer cognitive function in children.^{3,6} Neurobehavioral disorders, such as attention-deficit/hyperactivity disorder have also been associated with ETS exposure in homes.⁷

Although every province and territory in Canada has laws that protect people from workplace exposure to ETS, there are currently no laws in Canada that ban smoking in the residential setting. Many Canadians live in private or publicly owned multiunit housing, either attached houses, or more commonly, apartments and condominiums. It is estimated that 32 per cent of Ontario residents and 49 per cent of Torontonians live in rental units.⁸ Data from the 2005 Canadian Community Health Survey indicated that 64 per cent of the population of Canada resided in homes where smoking was completely restricted.⁹ The number of people living in smoke-free homes was highest in British Columbia (77 per cent) and lowest in Quebec (43 per cent).

Cigarette smoke coming from within a single unit of a multiunit housing complex exposes nonsmoking residents in other units to the risks of ETS. ETS has been shown to seep into housing units through air ducts, walls, floors, windows, elevator shafts and along plumbing and electrical lines to affect adjacent units and those on other floors.¹⁰ During our winter months, cold air enters multi-level buildings and rises as it warms carrying ETS that exits through the units on higher floors. Nonsmokers may also be exposed to ETS from individuals smoking outside housing units, on balconies, patios or in common areas. Another source of exposure is "thirdhand" smoke, or tobacco toxics absorbed from the indoor surfaces of units that were previously inhabited by smokers, which can re-emit into the air or be ingested by children.¹¹⁻¹³ People who live in public multiunit housing may be even more susceptible to the adverse effects of ETS because of the higher number of people who are poor, elder-

ly and disabled, and also due to smaller units and inadequate ventilation. The only effective way to completely eliminate ETS exposure in multiunit dwellings is to establish 100 per cent smoke-free buildings.¹⁴

This paper explores the current status of smoke-free housing in Canada and reviews attempts to quantify ETS exposure levels and attitudes of tenants and landlords of private and public multiunit housing. We will also make recommendations on how to establish smoke-free policies in multiunit dwellings and discuss the availability of public and private smoke-free multiunit housing in each province and territory.

Levels of ETS in Non-Smoking Housing Units

Since there is no safe level of ETS exposure, the detection of even low levels of biochemical markers of ETS in nonsmoking units of multiunit dwellings is of concern. In experiments in low-rise apartment buildings, 13 to 26 per cent of airflow into units came from other units.¹⁵ Tracer studies suggest that newer buildings with continuous ventilation systems have less ETS transfer.¹⁴ Unfortunately, many private and public multiunit apartment buildings have inadequate ventilation.

A study of indoor concentrations of nicotine in low-income, multiunit housing units in the Greater Boston Area reported increased levels of nicotine concentrations in non-smoking units.¹⁶ Nicotine was detected in 89 per cent of non-smoking units. The mean concentration of nicotine in nonsmoking units was equivalent to 0.25 cigarettes per day, with some units exposed to the equivalent of one cigarette smoked per day in that unit.

In another recent study of tobacco-smoke exposure in children who live in non-smoking homes in multiunit housing in the United States, 73 per cent were exposed to SHS.¹⁷ Children who lived in apartments had significantly greater levels of serum cotinine levels compared to those living in detached housing. The same study showed less of an association of living in an apartment and exposure to ETS for people of Hispanic ethnicity, despite the fact that Hispanics may live more often in high-density multiunit dwellings. One possible reason is the lower smoking rates in this group. The authors speculated that this may also be true for Asians who also have much lower smoking rates than whites and blacks. The Richmond and Fraser District of British Columbia have a large Asian population and the highest percentages of smoke-free homes in Canada.⁹

Results from a survey of multiunit housing in Kitchener, Ontario revealed that over 50 per cent of non-smoker responders indicated that they were exposed to ETS in their homes.¹⁸ These results were similar to another survey sponsored by The Ontario Tobacco-Free Network that showed 46

Studies have shown that providing educational information to landlords on how to implement smoking bans is an important first step toward smoke-free multiunit housing.

per cent have tobacco smoke enter their unit from elsewhere in the same building.¹⁹ In a large study from New York State conducted between 2007 and 2009, 46 per cent of tenants of multiunit dwellings claimed SHS entered their homes in the past year.²⁰

The Economic Arguments for Smoke-Free Housing

It is mostly the health concerns regarding ETS exposure that motivate tenants to fight for smoke-free housing. However, if smoke-free private multiunit housing is to become more prevalent in Canada, landlords must be convinced of the business benefits of a smoke-free policy, as many may still worry about the economic impact and the risk of litigation by tenants who smoke.

Surveys done in private multiunit dwellings without smoke-free policies indicate that the majority of tenants would prefer to live in a smoke-free building.²¹ Most tenants of subsidized housing support smoke-free policies but acceptance and adherence to existing policies by smokers remains an issue. In the multiunit housing study from New York State, 56 per cent of tenants supported the idea for a 100 per cent smoke-free policy.²⁰ The support was highest among minorities and those who lived with children. Another study from Kitchener, Ontario suggested that those who were most likely to support a smoke-free policy were younger tenants, non-smokers, those who spent less time in their units on weekends and those who perceived smoking indoors as a fire hazard.¹⁸

Surveys from Oregon performed in 2006 revealed that most renters would rather live in non-smoking buildings and half of those surveyed would pay extra rent to do so.²² However, when property managers were surveyed they expressed concerns about the legality of no-smoking policies and whether there was enough of a demand for smoke-free housing.²³ Concern about the health of their tenants was not a mitigating factor in making decisions about implementing smoke-free policies. The same survey revealed the need for information to help landlords implement no-smoking policies. Studies from Canada suggest that vacancy rates in multiunit housing complexes that have implemented smoke-free policies are not negatively impacted by smoke-free policies. Most Canadians are non-smokers and wish to live and work in smoke-free environments. Smoke seeping into multiunit dwelling is now one of the most frequent complaints heard by organizations dedicated to reducing ETS exposure. Newly opened private and public housing units in Canadian jurisdictions with smoke-free policies have low vacancy rates.

Maintaining smokers' units in multiunit housing is con-

siderably more expensive than the upkeep of non-smoking units. Data from the Non-Smokers' Rights Association obtained from landlords in Toronto and other parts of Southern Ontario demonstrate significantly higher costs for painting walls and ceilings and cleaning carpets and curtains in smoking units compared to non-smoking units.²⁴ Studies from the State of Maine estimate that the cost of renovating a smoker's unit ranged from \$1,070-1,670 versus \$550 for a non-smoker's unit.²⁵ To completely decontaminate an apartment previously occupied by smokers may cost as high as \$25,000.

Smoking is responsible for approximately 13 per cent of fires and is the number one cause of fatal residential fires in Canada.²⁶ Smoke-free policies in multiunit dwelling would reduce the risk of fires and fire related injuries resulting in less expenditure for building owners and lowering of insurance premiums. Apartments that are damaged by fire may remain empty for long periods of time due to damage and the need for repairs. Multiunit housing complexes that are smoke-free are often eligible for discounts on fire and property insurance rates.

Implementing Smoke-Free Policies in Multiunit Housing

All multiunit dwelling property owners in Canada are permitted by both federal and provincial law to adopt smoke-free policies. Creating smoke-free multiunit housing does not prevent smokers from owning or renting. The policies prevent smokers from exposing other tenants to the harmful effects of ETS. For existing multiunit dwellings where smoke-free policies are newly implemented, tenants often have the right to remain in their unit, but once that unit becomes vacant, then it becomes smoke-free.

Contrary to what some Canadians may think, there is no charter right to smoke. Non-smokers' rights are protected by a number of laws in Canada. The BC Tobacco Control ACT does not ban smoking in housing units but does prohibit smoking in public places within multiunit dwellings. These public places include common areas, such as lobbies and elevators, and within three metres of public entrances.

Tenants can take legal action against landlords who don't make adequate provisions to protect them from ETS. The experience from Canada and the United States suggests that compliance is usually high and evicting a tenant for violating smoke-free policies is rarely required. The City of Waterloo in Ontario implemented smoke-free policies at 2,700 of its units in April 2010. As of February 2011, there were only 21 complaints regarding the ban.

Studies have shown that providing educational information to landlords on how to implement smoking bans is an

important first step toward smoke-free multiunit housing. Tenants should be given at least three months notice before a no-smoking policy is enacted. For those tenants who currently smoke, they will usually be permitted to smoke in their units but once the lease is expired, they will have to abide by the smoke-free policies or leave the building. For new smoke-free buildings, the written tenancy agreement should have a very explicit clause outlining the non-smoking policy. Since there is no safe level of ETS, all areas of the building must be smoke-free. This includes all units, common areas, patios and balconies. Some policies may even ban smoking both indoors and outdoors.

The Provinces and Territories

The data from many Canadian communities suggest a large demand for 100 per cent smoke-free housing. Unfortunately, smoke-free public housing in Canada lags behind the private sector. However, more municipal and provincial/territorial authorities are considering the implementation of smoke-free policies in their public multiunit housing.

Table 1 lists the provinces and territories that currently have public or private multiunit dwellings with 100 per cent smoke-free policies with or without grandfather clauses for existing smokers. Data was obtained from telephone and e-mail correspondence, as well as internet searches of government and media websites. The information was collected between November 25, 2011 and January 31, 2012.

The Yukon Housing Corporation designated all social housing units smoke-free in 2011, with a grace period for current smokers who had to quit or vacate their units by January 1, 2012. Seniors housing in Edmonton is gradually becoming smoke-free. The Greater Edmonton Foundation is Alberta's largest provider of subsidized housing for low-income seniors. It is converting its multiunit building to 100 per cent smoke-free with a grandfather clause for existing tenants who smoke. Currently, neither the Regina nor the

Saskatoon Housing Authorities have 100 per cent smoke-free multiunit dwellings. The Winnipeg-based company, Global Agencies, which manages over 8,000 private rental units in Canada, has successfully implemented smoke-free policies in existing and new buildings, in Winnipeg, Saskatoon, Edmonton and Montreal.

Ontario has the largest number of communities with smoke-free public and private multiunit dwellings. The City of Waterloo was the first municipality in Ontario to implement a 100 per cent smoke free policy at its public housing units. The Haliburton Community Housing Corporation operates two non-profit multiunit buildings in communities north of Toronto. In 2009 the buildings became smoke-free with a grandfather clause for existing tenants. The impetus to go smoke-free was a renovation bill of over \$25,000 to decontaminate an apartment occupied by a smoker for ten years.²⁷ The Schlegel Seniors Villages are privately run multiunit senior's facilities throughout Southern Ontario. The company has enacted a smoke-free policy at all its complexes from the outset and feels strongly about providing a smoke-free environment for their many residents and employees.²⁸

Under Prince Edward Island (PE) law, landlords can evict tenants who violate nonsmoking clauses in their lease. There are a number of private smoke-free multiunit dwellings in PE. The provincial government of PE is the largest provider of seniors' public housing on the island. It is implementing a smoke-free policy using a grandfather clause. Once the last smoker vacates the building, then all units will be smoke-free. If more than one multiunit public building exists in a community, then the government identifies at least one building as 100 per cent smoke free.

The St. John's Housing Authority was one of the first municipalities in Canada to implement a 100 per cent smoke-free policy in subsidized public housing units. The provincial Newfoundland and Labrador Housing Corporation subsequently implemented smoke-free policies for some of its multiunit buildings in St. John's and Corner Brook. The Department of Community Services of Nova Scotia (NS) has recently adopted a smoke-free policy for all new public housing. Over 150 new multiunit dwellings have been created in three new public housing complexes in Halifax and Sydney. There are designated smoke-free units in some of the existing public housing in NS without a 100 per cent smoke-free policy for the entire building, with plans to increase the numbers of smoke-free units in the future as smokers' leases expire.

Conclusions

The number of Canadians who smoke continues to decrease. The enactment of workplace and public smoking bans in every provincial and territorial jurisdiction has allowed millions of people in this country to work and socialize in smoke-free environments. However, many Canadians still live in multiunit dwellings that are contaminated with harmful ETS emanating from outside their homes. Sealing units and improving ventilation are inadequate remedies for ETS exposure in nonsmoking units. The poor, elderly and others who are disadvantaged are more often exposed to ETS because they are more likely to live in subsidized housing without smoke-free policies.

**TABLE 1
SMOKE-FREE PUBLIC AND PRIVATE
MULTIUNIT HOUSING IN CANADA**

Jurisdictions	Public Multiunit Housing	Private Multiunit Housing
BC	√	√
AB	√	√
SK	None	√
MB	√	√
ON	√	√
QC	None	√
NB	None	√
NS	√	√
PE	√	√
NL	√	√
YK	√	None
NT	None	None
NU	None	None

All multiunit dwelling property owners in Canada are permitted by both federal and provincial law to adopt smoke-free policies.

The only effective solution is 100 per cent smoke-free buildings and properties. The number of privately owned and publicly funded smoke-free homes in multiunit buildings continues to increase significantly each year. Provincial and municipal governments need to do more to educate both tenants and landlords about how to implement and maintain smoke-free policies by focusing not only on the health benefits but also the potential positive economic outcomes.

Smoke-Free Housing Internet Resources

www.smokefreehousing.ca
www.nsra-adnf.ca/cms/file/pdf/Business_Case_S-F_MUDs.pdf
www.smokefreehousingbc.ca/index.html
www.cdc.gov/healthyhomes/Healthy_Homes_Manual_WEB.pdf

David Saltman, MD, PhD, is the Chair and Professor of the Discipline of Oncology, Faculty of Medicine, Memorial University, St. John's NL.

Kevin Coady, MEd, is the Executive Director of the Newfoundland and Labrador Alliance for the Control of Tobacco.

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LIVING WITH CANCER

Complementary and Integrative Medicine

ADDRESSING A GROWING REALITY IN
CANADIAN CANCER CARE

By LYNDA G. BALNEAVES, RN, PhD

The treatment choices faced by Canadians diagnosed with cancer are becoming increasingly complex, with patient and families not only making decisions about whether to use conventional cancer treatments but also about which complementary and alternative medicine (CAM) therapies could help them during their cancer journey. The growing interest in and use of CAM therapies has put oncology health professionals in the challenging position of having to make recommendations about therapies that fall outside of the allopathic paradigm and to which they may have had limited exposure to during their training. Cancer agencies must now also consider what policies and standards may be required to manage the potential risks posed by concurrent CAM use by patients seen in their facilities. And as the empirical support for CAM grows, decision-makers must contemplate whether therapies, for which there is evidence of benefit and cost-effectiveness, should be integrated and funded as part of the Canadian health care system.

The Statistics in Canadian Oncology Populations

Complementary and alternative medicine has been defined by the National Institutes of Health (NIH) to be “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.”¹ While this definition has been a moving target, with some CAM therapies now being integrated into select clinical institutions, the general rubric has included such therapies as natural health products (e.g., herbal therapies), mind-body therapies (e.g., meditation), energy therapies (e.g., acupuncture), and physical/movement therapies (e.g., yoga). This definition has also encompassed whole medical systems, including naturopathic and osteopathic medicine, and traditional healing systems, such as traditional Chinese medicine and First Nations healing.

Complementary therapies are more specifically described as being those therapies used alongside conventional medicine, while alternative therapies are used in place of conventional medicine. Research has estimated less than 10 per cent of Canadians living with cancer use alternative therapies²; instead, the majority uses these therapies as a complement to conventional cancer treatments. Although this statistic may alleviate some of the fears that have existed regarding the loss of patients from potentially curative treat-

ment, it does raise concerns about the potential risk of concurrent use of complementary therapies with conventional cancer treatments.

Despite research being hampered by methodological and definitional issues, a recent meta-analysis suggests that internationally, 40 per cent of individuals living with cancer use CAM therapies.³ In Canada, between 34-80 per cent of individuals report using CAM therapies after being diagnosed with cancer.^{3,4} There has been some suggestion that women are more likely to be consumers of CAM than men⁵, which may reflect the role women have traditionally played in making health care decisions within families. In addition, those who report a high socioeconomic status have been found to be more likely to use CAM^{4,6}—an association that is not surprising when one considers that very few CAM therapies are covered by provincial health insurance programs in Canada.

The most popular CAM therapies used by cancer patients in Canada include natural health products, mind-body therapies, and physical/movement therapies^{4,7}. The popularity of mind-body and physical/movement therapies may be a consequence of the growing interest in the potential benefits of these therapies. An increasing number of cancer agencies in Canada have begun to integrate programs, such as mindfulness-based stress reduction, art and music therapy, and yoga, as part of their supportive care services. In contrast, natural health products have remained largely on the edges of conventional cancer care and their use is often met with skepticism, and in some instances, outright antagonism, by oncology health professionals concerned about the potential risks.^{8,9} These reactions may be partly to blame for the approximately 40 per cent of cancer patients who decide not to disclose their CAM use to their oncology health professionals.^{9,10} Hidden from sight, the positive or negative implications of CAM use cannot be discussed, assessed, or managed, resulting in care that falls well short of being comprehensive and safe.

Significance of Complementary Therapies in Cancer Care

Having CAM acknowledged and addressed as part of conventional cancer care in Canada has been challenging. Foremost, there has been the perception by oncology health professionals that CAM is a specialty that is beyond their scopes of practice and one in which they have limited knowledge and skills.^{11,12} CAM therapies have also been dismissed because of



Lynda Balneaves

what has been perceived to be a lack of sufficient empirical evidence. Further, the serious implications of CAM therapies, such as natural health products, have been downplayed because of the perception that these therapies are “natural” and can be easily accessed without a prescription.

A growing body of research, however, is highlighting both the positive and the negative effects of CAM therapies in cancer populations. Turning first towards the potential benefits, there is increasing evidence that many of the mind-body and movement therapies have a significant impact on cancer patients’ emotional and physical well being,¹³ with beginning indication that these therapies’ effects reach all the way to the cellular level.¹⁴ Therapies such as acupuncture and ginger may also be cost-effective alternatives for patients struggling with symptoms arising from their conventional cancer treatments.^{15,16} And in the realm of cancer control, attention is now focused on how select biological therapies, such as vitamin D and soy, may contribute to the reduction in the incidence of primary and secondary cancers.^{17,18}

But like any type of conventional treatment, there can be potential risks associated with CAM therapies. Most troubling has been the discovery that some natural health products may pose serious, if not fatal, health risks when used inappropriately.¹⁹ This can include toxic side effects, potential interference with the anti-cancer activity of chemotherapy and radiation,²⁰ and negative interactions with pharmaceutical agents.²¹ For example, a brain tumour patient taking the herbal therapy, St. John’s wort for mild depression may be unaware that this product acts on the drug metabolism pathway that regulates how the chemotherapy agent, etoposide, is processed in the body. Concurrent use of these two therapies may decrease the effectiveness of chemotherapy.²² Concerns have also been raised about CAM therapies other than the biological. For example, massage and acupuncture can cause an exacerbation of cancer treatment-related symptoms, such as radiation dermatitis and lymphedema, if inappropriately applied to an affected area of the body.²³

The risks posed by CAM therapies can also exist at a financial and existential level. The majority of provincial health services plans do not provide coverage for CAM—only Canadians with third party insurance may receive partial compensation for some CAM consultations and services. With CAM protocols sometimes reaching into the hundreds, if not thousands of dollars, this can cause significant financial hardship and may cause distress and conflict within families. Existentially, CAM therapies may become the sole source of hope for many patients faced with a terminal prognosis, as well as their family members.²⁴ Disagreements over treatment preferences and goals may lead to heartrending tension and conflict in families at one of the most inopportune times in the cancer journey, at the end of life.

Given both the promise and the threat posed by the broad range of CAM therapies that are used, and in ever increasing numbers, by Canadian cancer patients, the question must be raised regarding what is the responsibility of oncology health professionals and decision-makers to ensure individuals are receiving the best possible care and are being protected from unnecessary risks?

The Evidence Base for CAM and Cancer

In the 1980’s, CAM therapies were commonly referred to as “unproven” therapies. The lack of scientific research prevented these therapies from being considered as credible treatment options that deserved the attention of conventional health professionals. Pressure from both patients and CAM advocates, however, led to the development of focused funding programs, such as the NIH’s National Centre for Complementary and Alternative Medicine, which have encouraged researchers to develop research programs on CAM. This has led to a burgeoning and interdisciplinary community of researchers that are evaluating the effects of CAM using standard research methods.

The potential role of CAM in cancer control, treatment, and care has been of particular interest to researchers because of the high prevalence of CAM use in cancer populations. Research has now progressed to the point that there is a sufficient evidence to warrant the integration of some CAM therapies into standard care. In addition, clinical guidelines are now available through the Society for Integrative Oncology, an interdisciplinary organization of health professionals dedicated to studying and facilitating the integration of complementary cancer treatment options.²³ Knowledge translation resources, such as the Norwegian CAM-Cancer website (www.cam-cancer.org), have also been developed that summarize the latest evidence in a form that can be readily accessed and used by both patients and health professionals. But much research remains to be done, particularly on the efficacy and safety of natural health products that are so popular among individuals living with cancer. In addition, cost-effectiveness research is essential to ensure CAM therapies will not pose an additional burden to the Canadian health care system.

In Canada, interest in CAM research has led to the formation of the Canadian Interdisciplinary Network of Complementary and Alternative Medicine Research (IN-CAM) (www.incamresearch.ca). With the mandate to foster excellence in CAM research in Canada, IN-CAM provides

It is not unreasonable to expect oncology health professionals to play an important role in assessing, documenting and making recommendations about CAM use in the context of cancer care.

both funding and networking opportunities that has contributed to the growth of CAM research in this country. A select group of IN-CAM members with an interest in oncology have formed the Integrative Canadian Oncology Research Initiative (ICON), which aims to develop evidence related to the integration of CAM into conventional cancer care, as well as facilitate knowledge synthesis and dissemination related to integrative oncology. Backed by a strong and growing body of evidence, these groups are challenging oncology health professionals and decision-makers to acknowledge the growing impact that CAM is having, and could potentially have, on the lives of cancer patients.

CAM as Part of Health Professionals' Clinical Practice

There has been a great deal of controversy regarding whether CAM therapies can, or should be, included as part of oncology health professionals' clinical practice. The lack of CAM education in the majority of professional programs has made many hesitant to discuss CAM treatment options and to provide recommendations. In addition, confusion about regulatory issues and whether CAM can be offered, let alone discussed, as part of one's scope of practice has prevented many health professionals from addressing CAM with cancer patients. It can be argued, however, that all conventional health professionals in Canada are charged with the duty to provide safe care and to ensure patients are making informed decisions about their health care choices. As the evidence base for CAM grows, it is not unreasonable to expect oncology health professionals to play an important role in assessing, documenting, and making recommendations about CAM use in the context of cancer care.

In Canada, efforts have been made to develop education programs that will bridge the gap in CAM knowledge within conventional health professions. For example, the CAM Undergraduate Medical Education (CAM in UME) project (www.caminume.ca), led by the Canadian Research Chair in Complementary Medicine, Dr. Marja Verhoef, has made a concerted effort to collaborate with undergraduate medical programs throughout Canada to offer CAM education to medical students. Specific to oncology, the collaborative University of British Columbia/BC Cancer Agency Complementary Education and Outcomes (CAMEO) research program (www.bccancer.bc.ca/comeo) has launched an on-line CAM education program for oncology health professionals located in both clinical and community settings. These programs are raising the clinical bar of practice for physicians, nurses, and other allied health professionals in

relation to CAM use in cancer care and the expectation that all patients will be assessed for CAM use and supported in making safe treatment decisions.

Cautious Steps Towards Integration

In response to the growing support for CAM therapies to be incorporated within conventional cancer care by both consumers and researchers, the field of integrative oncology has developed. Defined as an "interdisciplinary, non-hierarchical blending of both conventional medicine and complementary and alternative healthcare that provides a seamless continuum of decision-making and patient-centred care and support... [that] results in more effective and cost-effective care..."²⁵; p.55, integrative oncology ensures that cancer patients receive care that addresses the whole person and promotes health, wellness, as well as the prevention of disease.

Integrative oncology has become a reality within many conventional cancer centres in Europe and the US, with internationally recognized cancer care institutions, such as the Royal Marsden in the UK and the Memorial Sloan Kettering Cancer Centre and MD Anderson Cancer Centre in the US, offering cancer patients access to CAM therapies within their facilities and through community-based programs. In Canada, integrative oncology is just beginning to gain a foothold within conventional care, with the recent development of integrative oncology programs at the Juravinski Cancer Centre and Hospital in Hamilton, ON and the Jewish General Hospital in Montreal, QC. More common has been the establishment of private community clinics that offer access to CAM therapies and professionals, as well as consultations with conventional health professionals. For example, the Ottawa Integrative Cancer Centre has recently opened and offers cancer patients, survivors, and the general public access to a range of therapies, including nutrition and lifestyle counseling, naturopathic care, acupuncture and traditional Chinese medicine, psychiatry, family therapy, registered massage therapy and physiotherapy (www.oicc.ca). The challenge with these types of community-based programs, however, is that CAM therapies provided outside of hospital settings may continue to be perceived as beyond the purview of standard conventional cancer care, resulting in care that lacks continuity and may be accessible only to those who can afford it.

For integrative oncology to occur in Canada, and in a way that is respectful of not only the needs of patients, families, and larger society, but also the scopes of practice of both conventional and CAM health professionals, there must be careful consultation among all key stakeholders and decision-

makers. Issues that must be considered include:

- What are the best practice models of integrative oncology?
- Where should integrative oncology be located—within conventional care settings? In the community?
- How will the outcomes of integrative oncology be evaluated and monitored?
- What are the professional regulatory issues associated with integrative oncology?
- What are the policy, resource, and funding implications of integrative oncology?

At a minimum, the time has come for CAM therapies to be acknowledged as being a reality in the lives of the majority of Canadian cancer patients. In the interest of safety and comprehensive care, all patients should have their CAM use assessed, documented, and discussed in a manner that is respectful and non-judgmental. Patients' information needs related to CAM also need to be addressed, using the latest evidence, to ensure patients are making treatment decisions that are informed and safe. The CAMEO research program at the BC Cancer Agency has taken a step towards this goal through the development of patient and health professional education and decision support programs that have raised awareness regarding the significance of CAM in conventional cancer care and are supporting patient-professional communication about CAM in clinical and community settings.

Conclusion

With at least one in three cancer patients using CAM therapies in Canada, this is a phenomenon that can no longer be ignored within conventional cancer care settings. As the evidence base continues to expand that supports not only the efficacy and safety of many CAM therapies, but also their cost effectiveness, health professionals and decision-makers will be challenged to consider how these therapies can be meaningfully integrated into the Canadian cancer care system in a way that is safe, fiscally responsible and does not simply co-opt therapies from other paradigms of care. Careful consultation among consumers, conventional and CAM health professionals, and policy-makers will be required to create a climate in which CAM therapies will be welcomed as valid and beneficial treatment options. Canadian cancer patients deserve treatment and care that encompasses the most effective therapy options available, no matter from which paradigm they arise.

Lynda G. Balneaves, RN, PhD, is Associate Professor, School of Nursing, University of British Columbia and Canadian Institutes of Health Research New Investigator.

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LIVING WITH CANCER

Bladder Cancer

Commonly known as transitional cell carcinoma or urothelial cancer, bladder cancer afflicts about 7,200 people per year in Canada (Ontario alone does not report carcinoma in situ cases), 5,400 men and 1,800 women, according to 2011 Canadian Cancer Society statistics¹. Eighth in numbers of cancer deaths, an estimated 1,850 people succumb to it annually, more than kidney, liver, melanoma or cervical cancers². This is the sixth most common cancer in Canada (perhaps fifth when Ontario's in situ cases are included), ranking fourth among men and twelfth among women³. With a recurrence rate which approaches 80 per cent, a diagnosis of bladder cancer means a lifetime of urological examinations and possible treatment. Early symptoms include blood in the urine (not always associated with pain), urinary frequency and urgency.

Stages 0 and I, which form the majority of cases, are typically treated by transurethral resection of the tumour under general anesthetic, followed by immunotherapy or chemotherapy instilled into the bladder. Stages II and III are typically treated by radical cystectomy (bladder removal) which may be accompanied by neo-adjuvant chemotherapy to shrink tumours prior to surgery or adjuvant chemotherapy to eliminate cancer cells following surgery. During surgery, a new way of draining urine must be created: options include an ileal conduit, where a piece of bowel is fashioned into a conduit exiting from the abdomen (stoma) where urine is drained into an external pouch; a continent urinary reservoir, where a sec-

tion of colon is formed into a pouch inside the body and urine is drained by catheter through a stoma; an orthotopic neobladder, where a section of colon is fashioned into an internal pouch connected to the ureters and urethra to create more normal elimination. Stage IV tumours are often not curable; they may be treated with chemotherapy, radiation or a combination of both. Bladder cancer may spread into nearby organs and typically affects lungs, liver and bones when metastasized.

Until 2009, there was no patient organization in Canada to bring awareness of the disease and support to patients. Bladder Cancer Canada, formed by two bladder cancer patients, is a nationwide, charitable organization which has raised over \$100,000 in the past two years, primarily from two 5 K walks in cities across the country. With its directors, and a medical advisory board and research team of leading academic urologists, oncologists and pathologists within the bladder cancer community, Bladder Cancer Canada's purposes are: to raise awareness of bladder cancer; to provide support for the patients and caregivers devastated by its diagnosis, who crave answers to practical questions and who rely on moral support from those who have walked where they walk; and to advocate for funding.

Patients are adamant: Family doctors must recognize the potential for cancer and investigate when a patient presents with hematuria. Additional testing and referral to a urologist are essential! Women particularly are often diagnosed late with later stage cancer and may require more radical intervention.

There have been small incremental advances in treatment over the years, but no breakthroughs and no high value products to entice the pharmaceutical industry to provide major support⁴. From diagnosis to death, bladder cancer is the most expensive of all cancers to treat on a per patient basis⁵, yet receives a disproportionately low amount of funding. That must be urgently addressed in both public and private sectors.

Patients requiring a radical cystectomy may rely on a local urologist for surgery, regardless of the experience

that hospital and specialist have with this surgery and its recovery. With the potential for serious complications, outlying patients need encouragement to obtain a second opinion from a major cancer centre where radical cystectomies are routinely performed and specialized nursing care post surgery is provided.

Patients feel that doctors and cancer support groups must promote awareness of this disease and ensure information gets to the public. Many people ignore the symptoms, unaware



Greg Neely

of the existence of bladder cancer, when early detection is essential. Awareness is increasing as Bladder Cancer Canada, with its supporting medical teams, moves into high gear. That's good news!

Greg Neely is a bladder cancer survivor and Director of Bladder Cancer Canada. For more information visit our website at:

www.bladdercancercanada.org.

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Brain Tumours

MORE COMMON AND COMPLEX THAN YOU THINK

It is estimated that 27 people are diagnosed with a brain tumour every day in Canada. That means that every hour more than one family will start the complex journey of living with a brain tumour and the impact it may have on physical ability, mental capacity and an individual's personality.

There are 55,000 Canadians currently living with this life changing diagnosis. These survivors come from all backgrounds and are of any age, from children to seniors. In fact, for children (up to 19 years of age), brain tumours are the leading cause of cancer death, surpassing leukemia and bone cancer.

A brain tumour diagnosis means there is a growth of abnormal cells within or around the structure of the brain. These cells can originate in the brain or spread from elsewhere in the body. Because the brain is delicate and often considered the most important organ in the body, diagnosis and treatment are not straightforward. In fact, the brain is the centre for everything that makes us "human" and a brain tumour and resulting treatment (which may include surgery, radiation and chemotherapy) can have a dramatic impact on health and well-being.

To make matters more complicated, there are 120 different types of brain tumours classified on the World Health Organization (WHO) grading system. This scale, as well as where the tumour is located in the brain, determines the tumour's impact and an individual's treatment. As a result treatment, symptom management, care plans and long-term side effects are varied and complex.

The word "benign" is sometimes used to describe brain tumours considered, based on the WHO scale, to be non life-threatening or non-aggressive. But the sentiment this encourages, the sense that the tumour could be non-

harmful or not serious, is not entirely accurate—no matter the grade, a brain tumour can cause serious health complications.

One survivor from the East Coast articulates the impact of such misunderstanding well, "Some people, when they heard it was non-malignant, acted like we should be celebrating and told us we should be thankful. This was hurtful." Because of this, there is a considered shift towards using the term 'non-malignant' rather than 'benign' to define brain tumours that are not aggressive.

Learning to cope with change is important for all brain tumour survivors regardless of the stage of their treatment. This may mean re-learning to read or speak, or walk or drive. For some, interpreting emotional cues from family and friends can be their biggest challenge. "After my surgery, my behaviour changed and many friends and family members drifted away..." remembers one Ontario survivor.

This range of impact extends to the signs and symptoms that lead to a brain tumour diagnosis. While severe headaches are commonly thought to be the typical symptom, there are a variety of other common warnings that everyone needs to be aware of. These include:

- personality changes,
- morning nausea or vomiting,
- visual disturbance such as double- or blurred vision,
- weakness or paralysis,
- dizziness or unsteadiness,
- hearing impairment.

Raising awareness among the public and health care community about these symptoms is needed to help patients reach a diagnosis. Too often we hear from families whose loved one's diagnosis could have been made sooner, if only signs had been recognized. As brain tumour symptoms can be indicators for many other conditions, we know early detection is difficult. Awareness helps everyone to act as their best health care advocate and to seek additional opinions when necessary.

Since Brain Tumour Foundation of Canada's establishment in 1982, we



Susan Marshall

have been dedicated to providing hope and support to anyone affected by a brain tumour. We work collaboratively to ensure that brain tumour patients are empowered and emotionally supported on their journey. Finding the cause of and cure for brain tumours while improving the quality of life for those affected is our vision. This important activity is funded solely through the generosity of individuals, corporations, organizations, employee groups and special events.

Thanks to these contributions we can work with and support coordinated approaches to address the multifaceted issues associated with a brain tumour diagnosis. This includes working towards equal access to the best evidence-based care for all Canadians living with a brain tumour. And just as treatment plans are individual, so are the many programs and services required for those impacted.

We look forward to the future: a Canada where anyone faced with a brain tumour diagnosis finds the support they need to proactively seek out their best care while gaining hope from accelerated brain tumour research.

Together, we can *Imagine a Cure*.

Susan Marshall is the Executive Director of the Brain Tumour Foundation of Canada. For more information visit our website at www.braintumour.ca.

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Lymphoma

Although it is one of the least known and least understood forms of cancer, one in 30 Canadians will develop a cancer in their lymphatic system in their lifetime. Lymphoma is:

- the fifth most common cancer in North America
- the most common blood cancer in Canada
- the sixth most common cause of cancer death
- the most common cancer for young people under 30 years of age
- the only common cancer with increasing incidence rates.

Lymphoma develops when an error occurs in the production of lymphocytes, a type of white blood cell found in the lymph nodes and results in abnormal cells that become cancerous. Lymphoma does not discriminate: it affects men, women and children. Approximately 8,600 people in Canada were diagnosed with lymphoma in 2011 and the numbers are growing each year. Another 3,310 died from the disease in 2010. These numbers are also growing.

Each case of lymphoma is unique and complex. Lymphoma is a very complicated cancer with two main types, Hodgkin's and Non-Hodgkin's, and over 50 different subtypes: slow-growing, aggressive, and highly aggressive. Whereas most cancers are treated with surgery, radiation or chemotherapy, there is no one "right" treatment course for all patients and each case and treatment plan is unique. Lymphoma Foundation Canada is trying to increase awareness of this disease to speed up diagnoses, advocate for better treatments and help find cures.

Lymphoma patients are researching what is happening in Canada, in the US and around the world and they want access to the latest treatments, diagnostics and clinical trials. There is increasing optimism about new treat-

ment options available now and in the near future. However, across Canada, care and treatment options vary between regions and provinces. Frequently the care and treatment you receive depends upon where you live, how informed your physician is about lymphoma options, and whether your institution in your province offers access to clinical trials or treatments. Patients are concerned that the number of Canadian clinical trials is decreasing and that they may have to incur great stress and expense to travel outside Canada for access. It can be overwhelming, challenging and frustrating for patients and their caregivers to get proper information and to access the most current treatment options.



Sue Robson

Many family doctors are not as knowledgeable about lymphoma and it is quite common for newly diagnosed patients to claim they waited well over six months being treated for flu-like symptoms before they were properly diagnosed and referred to a specialist. Lymphoma Foundation Canada (LFC) is working hard to increase awareness about the signs and symptoms of lymphoma so patients will know when to seek proper care and which questions to ask of their doctors. The goal is to decrease the waiting time between symptoms, accurate diagnosis and effective treatment.

Hearing that you have cancer is very distressing. Having to fight for

care is unfair and presents exhausting challenges that these patients and their families simply do not need. LFC is working closely with patients and their caregivers to aid in better and more involved decision making. LFC is advocating for:

- Equitable access to standardized treatment across all provinces
- Patients and their families involved in the government's decision making process
- More mandatory sharing and collection of data to be shared across provinces.
- A national strategy for access to funding for diagnosis, treatment and clinical trials.
- Better training of family physicians on the signs and symptoms of lymphoma, decreasing the time to diagnosis and decreasing misdiagnoses.

Just this year Ontario added the drug rituximab to the provincial drug formulary for patients that have relapsed with lymphoma, finally allowing Ontario patients the same access the rest of the country has received. This is a wonderful piece of news and reinforces the urgency and importance of continuing to advocate and work together to improve the outcomes for all Canadians living with lymphoma.

Lymphoma Foundation Canada is the number one Canadian resource for lymphoma patients and their families. We are the only Canadian organization focussing solely on lymphoma and supporting patients directly in their experience with Lymphoma. Our goal is to advocate, educate, fund research and provide direct patient and caregiver support for Canadians with lymphoma. Please visit our website for more information at: www.lymphoma.ca.

Sue Robson is Executive Director of Lymphoma Foundation Canada. She has been in this role for two years. Her background was in nursing for many years and more recently in the pharmaceutical industry working in Community Relations.

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Melanoma

Melanoma is a form of cancer that is characterized by the uncontrolled growth of pigment-producing cells (melanocytes) located in the skin. It may begin in a mole, but can also begin in other pigmented tissues, such as in the eye or in the intestines. Survival rates are high if it is detected early. Melanoma develops when a cell's DNA genes become damaged. Overexposure to ultraviolet (UV) radiation either from the sun or from tanning beds is the leading factor in the development of skin cancer and melanoma and is the most preventable cause of the disease.

Ranked by incidence, melanoma is one of the fastest growing cancers worldwide. In Canada, this form of skin cancer has more than tripled over the last 30 years and continues to increase. It is estimated that in 2011, there were over 5,600 cases of melanoma and over 75,000 cases of other skin cancers. The chance of developing melanoma increases with age, but this disease affects people of all ages. It is one of the few cancers to affect young adults and is the second

**Delayed diagnosis,
Scarce research
funding,
Limited information
for patients,
Barriers to treatment
options,
Lack of public and
medical awareness,
Fighting for care...**

Is anyone listening?

most common cancer among 15–34 year olds. Excessive sun exposure in children and adolescents is likely to contribute to skin cancer in later life.

Melanoma is a particularly difficult cancer to treat when it has metastasized or spread. A metastatic melanoma patient's average life expectancy is about three to eighteen months, depending on the extent and location of disease. It is resistant to most chemotherapies and has not responded well to radiation. Until recent approval by Health Canada, (February 2012), of two new drug therapies—ipilimumab and vemurafenib—advanced melanoma patients had very little hope for the future. While these drugs are not a solution for all patients, they offer promise for extended life for a group of patients.

Unlike traditional chemotherapy, which introduces toxins into the body to kill the cancer cells, ipilimumab works indirectly by stimulating the body's own immune system. This approach, called immunotherapy, stimulates the immune system to seek out and kill the cancer cells in the same way the body attacks invading viruses and bacteria.

A BRAF mutation is prevalent in 40 to 60 per cent of all melanoma patients. Vemurafenib, a monotherapy treatment for BRAF mutation-positive unresectable or metastatic melanoma, represents a form of personalized medicine that targets cancer cells with a specific genetic mutation (BRAF).

Metastatic patients are eager to be able to access these two new therapies, where appropriate. The drugs are currently in the pCODR process and, depending on the outcomes, will then be looked at by each province for coverage under the provincial drug formularies. We are hopeful that governments will make melanoma treatment a priority.

Aside from access to treatment choices, patients are facing real issues with timeliness of diagnosis and treatment. Skin cancer diagnosis often follows a longer process than other cancers to diagnose and treat, because of the intermediate step of seeing a dermatologist. Timely access to a dermatologist is becoming exceedingly difficult. With approximately 500 dermatologists in Canada, and an increasing

focus on cosmetic procedures which have a greater financial return, skin cancers are often going undiagnosed or may be found too late.

Patients need access to physicians who are knowledgeable and experienced in diagnosing skin cancers and melanoma. With our aging population and the coming wave of retirements in the dermatology field, we are worried about the future for timely diagnosis and treatment. While melanoma accounts for only four per cent of skin cancers, cost of treatment is over 80 per cent of total dollars spent. Our governments should be worried about this too, in light of the financial burden treatment will present in years to come.

Until the Melanoma Network of Canada was formed in 2009, there were no organizations in Canada focusing on melanoma patients and their needs. There was, and continues to be, a significant gap in access to information and treatment therapies in Canada. Since 2009, our organization has grown to become the largest representative patient group in the country. We provide support services, education and funding for research. We have helped hundreds of patients with timely information and an opportunity to speak with other patients through our on-line discussion forum and our teleconference system. We are grateful for the support our physicians have played in providing new access to patient education sessions across the country.

The Melanoma Network of Canada will continue to focus on prevention and awareness activities as well as providing connections for patients for treatment and information. We hope to work with provincial governments to impact standards of care and research for melanoma patients in Canada.



Annette Cyr is Chair of the Melanoma Network of Canada.

www.melanomanetwork.ca

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Pancreatic Cancer

People don't often think about pancreatic cancer until it happens to them, a loved one, a friend or to a celebrity but it is an insidious disease that can strike anyone, at anytime. It is the fourth leading cause of cancer death in Canada, behind lung, colorectal and breast cancers. Most people who develop pancreatic cancer do so without any predisposing risk factors. Perhaps the biggest risk factor is increasing age it typically affects individuals older than 50 and affects men and women equally. It can also appear in younger people, particularly individuals with a family history of the disease.

This coming year, it is estimated that there will be more than 250,000 new cases worldwide including 4,100 Canadians. In 2010, 4,000 Canadians were newly diagnosed and tragically 3,900 died. There is no known cause, no early detection, limited treatment options and no known cure. Seventy-five per cent of all patients die within the first year, most within the first three to six months. The five-year survival rate is still in the single digits at six per cent and has barely changed in over 40 years.

Despite significant advancements in the treatments of other cancers, pancreatic cancer remains largely incurable. The majority of cases aren't caught in the early stages when the tumour is

most treatable. The international standard for treatment of advanced pancreatic cancer for the past 10 years has been gemcitabine. While gemcitabine can be beneficial in treating some patients, it cannot eliminate the cancer and is not curative. It does increase the cure rate when given immediately after surgery (adjuvant therapy).

FOLFIRINOX was recently approved for treatment of metastatic pancreatic cancer. In a large randomized phase III study, it demonstrated a survival benefit over the standard treatment of up to 80 per cent. It is currently approved in British Columbia, Ontario and on a case by case basis in Alberta, Manitoba and Quebec. It is accessible to patients with metastatic pancreas cancer (Stage 4) who have not yet received any chemotherapy.

Early diagnosis and effective treatment options for patients are key to improving survival rates for this disease but ongoing research is needed to make advances in the fight against pancreatic cancer. A landmark report from the nonprofit institute, Charity Intelligence Canada, cited pancreatic cancer as the most seriously underfunded cancer, receiving less than one per cent of research and charitable funding.

Pancreatic Cancer Canada (PCC) believes that the primary reason pancreatic cancer isn't as well known as other types of cancers is because there are so few survivors to champion the cause. It strikes so quickly and is so lethal that there isn't a collective voice to advocate for it. In a recent Ipsos Reid Poll, thirty-seven per cent of Canadians said they're knowledgeable about the disease and only six per cent considered themselves very knowledgeable about the disease. "It's a real worry that it's a disease that

is so deadly, and arguably the deadliest of the cancers in terms of the survival rate," said Mike Colledge, president of Ipsos Reid public affairs. "People don't know about it, people aren't aware of it, and without that, there's not a lot of hope to make gains in terms of awareness and funding on the medical side."

PCC is proud to be the only national foundation dedicated to the fight against pancreatic cancer. We are committed to raising money and awareness and supporting patients and their families by providing resources to help them better understand their diagnoses and make informed decisions about their treatment. A resource pamphlet entitled "You've just been diagnosed with pancreatic cancer... what's next?" was recently launched and provides patients with questions, facts and a listing of the hospitals across Canada that specialize in treating pancreatic cancer.

Each year, individuals whose lives have been affected by pancreatic cancer connect with us some participate in our signature events others hold their own fundraisers, contributing thousands of dollars to support lifesaving research. Since our founding in 2006, we have raised more than one million dollars to support research that focuses on discovering new and better ways to diagnose and treat pancreatic cancer and improve the quality of life of people living with this disease.

Pancreatic Cancer Canada was founded by Betty Aldridge and Laurie Ellies to address the needs for a national organization dedicated to raising awareness of this very deadly disease and the necessary funds to support and sustain scientific research. "We don't have our loved ones to carry the torch, so we're here to continue their fight!"

Laurie Ellies, Dr. Malcolm Moore, Dr. Steven Gallinger, Libby Znaimer, Betty Aldridge



Laurie Ellies and Betty Aldridge are the Cofounders of Pancreatic Cancer Canada. For more information visit our website:

www.pancreaticcancercanada.ca.

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Sarcoma Cancer

Sarcoma cancer affects nerves, muscles, joints, bone, fat and blood vessels, or the body's "connective tissues". Often called the forgotten cancer, one of the key challenges facing sarcoma patients is a lack of awareness about sarcoma in both the public domain and within the medical community itself. There are over 50 types of sarcoma cancer and, largely due to the disease's complex diversity, much work must still be done to develop new treatment agents and to understand how to more effectively use existing treatments.

Each year, up to 1,200 Canadians are diagnosed with sarcoma cancer. Though many are not familiar with sarcoma, people around the world are certainly familiar with the heroic story of Terry Fox, who ran across Canada to raise money for cancer research in 1980. What few who know his story realize is that the disease that claimed Fox's leg, and later his life, was osteosarcoma, a form of sarcoma cancer of the bones.

Especially prevalent in children and young adults, sarcoma cancer strikes Canadians of all ages and can present in various parts of the body. Approximately 43 per cent of sarcoma cancers occur in the extremities (e.g., arms, legs); 34 per cent in and around the internal organs (e.g., uterus, heart); 10 per cent in the trunk (e.g., chest, back); and 13 per cent in other locations. Since tumours can occur in all connective tissues, sarcoma is a highly specialized cancer to diagnose and treat.

Sarcoma cancer receives an alarmingly low amount of funding for research, as well as in development of patient resources and networks. Unfortunately, this is not only a Canadian issue, but also prevalent in many centres across the global cancer community. In many cases, sarcoma

receives up to eighty percent less funding than other, better-known cancers. A lack of public and private funding, coupled with a lack of research and development of new treatments poses an ongoing challenge to sarcoma patients in Canada and around the world, as well as the specialists who treat them. There is great opportunity for Canada to provide much needed leadership in this disease area that could greatly impact the lives of sarcoma cancer patients not only here at home, but around the world.

In 2010, the Sarcoma Cancer Foundation of Canada (SCFC) was founded to address the lack of research funding, patient support and awareness in Canada. Currently the country's only national organization dedicated to providing patient support and education while working with



Diana Arajs

Canada's leading research institutions to eradicate sarcoma cancer, SCFC's first area of focus was research support. With the establishment of a clinical fellowship chair at Mt. Sinai hospital in Toronto, SCFC established crucial long-term support for the training of sarcoma sub-specialists who will be able to provide treatment to patients across the country. Ongoing fundraising efforts will continue to support research across Canada at the country's leading institutions. Our eventual goal is to have sarcoma centres of excellence established across Canada so that every patient can be treated close to home where they are

There is a great opportunity for Canada to provide much needed leadership.

most comfortable, and their support network is strongest. These new sarcoma experts will join a small but impressive team—in the global context, Canada's sarcoma specialists are on the cutting edge of sarcoma treatment, their knowledge and expertise in high demand around the world.

The second immediate challenge that SCFC identified was the profound lack of credible information available to sarcoma cancer patients and their families at a central source. To this end, we have embarked on the development of a multi-faceted online resource to be launched in 2013, which will provide those seeking information about sarcoma with current research and treatment data, a connection to other patients and survivors, contact with all available patient resources, online access to medical professionals, and other much needed tools.

Another key project is the ongoing development of a network of survivors and those passionate about advocating on behalf of sarcoma patients. The SCFC aims to fill a void in the Canadian cancer landscape by bringing together the sarcoma community to inform, empower and mobilize a national effort to eradicate sarcoma cancer.

With increased funding and a better understanding, we can beat this disease together. For more information or to get involved, please visit www.sarcomacancer.ca and join our team of donors and volunteers committed to making a difference for sarcoma cancer patients and their families across Canada.

Diana Arajs is the Founder and Chair of the Sarcoma Cancer Foundation of Canada. www.sarcomacancer.ca
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Great Innovations

Creative minds are at work across the country to find new solutions for cancer control. They bring passionate commitment to the challenges of the disease, the health system and the needs of patients. In some regions of Canada the challenges are more severe than others, but the effort and achievement of building core programs and providing services to patients are no less worthy of praise.

Here is a short summary of only a few recent achievements, with apologies to the many others not mentioned. Information was copied from websites, announcements and compiled from personal communication with government officials and health professionals.

Research

Ontario's \$161 million Life Sciences Commercialization Strategy will strengthen the capacity for leading research and create new opportunities for partnerships with international companies and other innovative jurisdictions. The Strategy includes a commitment of \$17 million to establish a province-wide coordinating framework for clinical trials that will streamline ethics reviews and administrative processes for our province's multi-centre clinical trials.

The Canadian Institutes of Health Research (CIHR), through its Personalized Medicine Signature Initiative, and Genome Canada will jointly support research projects in the area of genomics and personalized health. Goals are to develop an evidence base on how to assess and, where appropriate, integrate innovative diagnostics into health policy and practice; stimulate the discovery, validation, and translation of biomarkers, targets and genomic signatures for risk prevention and for diseases; and foster the development and validation of resulting diagnostics and devices.

Quebec's Centre of Excellence in Personalized Medicine (Cepmed), launched a web-based Personalized Medicine Portal for Canadians. The portal provides information and decision making tools that will help patients understand how genetic testing can be used to inform treatment decisions and enable better communication between patients and providers. The Portal, available at www.cepmmed.com, provides information about access to specific genetic tests in each province.

Prevention

Alberta now has legislation that prohibits smoking in cars when children are passengers. That makes nine provinces.

Manitoba, Quebec and Saskatchewan now offer extended coverage for the HPV vaccine to any girls born after 1996 who might have missed the school program and the Northwest Territories has extended coverage to age 22.

British Columbia's Ovarian Cancer Research Program (OvCaRe) called on BC gynaecologists to change surgical practice to fully remove the fallopian tube when performing hysterectomy or tubal ligation. Ovarian cancer deaths could be reduced 50 percent over 20 years by the change in practice. The request stems from new research that discovered the majority of high grade serous tumours, the most deadly

form of ovarian cancer, actually arise in the fallopian tube, not the ovary. BC is likely the first jurisdiction in the world to recommend this practice change for gynecologists. OvCaRe is a collaboration between the BC Cancer Agency, the Vancouver Coastal Health Research Institute and the University of British Columbia

Screening

Colorectal cancer screening programs are fully operational in Ontario, Prince Edward Island, and Nova Scotia with tests available to all citizens. Quebec and Newfoundland and Labrador are in the development phase to introduce colorectal screening. As the programs mature in other provinces, uptake of the screening opportunity should increase.

Saskatchewan's mobile breast screening unit will soon have new digital mammography equipment, ensuring that women from around the province have access to the latest technology.

Diagnostics and Diagnosis

New Brunswick, Saskatchewan and Newfoundland and Labrador are planning the purchase of PET scans.

Stage data for new cancer cases is now routinely captured in provincial cancer registries: Alberta, Saskatchewan, Manitoba, Ontario, Nova Scotia and Prince Edward Island all capture more than 90 per cent of stage data for the top four cancers (breast, colorectal, lung, prostate). When all cancer sites are included, Alberta, Saskatchewan, Manitoba and Prince Edward Island achieve 90 per cent or more. It is worth noting that Manitoba and Prince Edward Island rank at the top, with 100 per cent stage data for all cancers, and Alberta achieves 100 per cent for the top four cancers.

Treatments

Ontario follows Quebec in the use of CyberKnife Robotic Radiosurgery, offering cancer patients an effective alternative to surgery for some cancers. The technology is the world's first and only robotic radiosurgery system and it is designed to treat tumours anywhere in the body with sub-millimeter accuracy.

Twenty-three insurance companies have joined forces to create a larger pool that will be able to cover the cost of expensive drugs. The new system will protect Canadians from losing their private drug plans and protect employers from dramatic premium increases that would normally be the result of an employee developing cancer (or other diseases with expensive treatments).

Nova Scotia's Palliative and Therapeutic Harmonization Clinic (PATH) is an innovative health care service for older people in Nova Scotia with chronic health conditions. The PATH Clinic was established to help older people and their families understand their health status and to guide them through the process of making health care decisions that will protect their best interests and quality of life. The PATH Clinic helps patients and families understand these issues in relation to their own health status and learn to ask the right

questions as new health problems emerge.

New Brunswick is planning a catastrophic drug plan and consulting widely with its citizens on the design and scope of coverage.

The Organization of Care

The Yukon now has a cancer care navigator at the White Horse General Hospital who helps new patients understand what to expect and confirms their appointments. The health ministry reports a huge uptake and enthusiastic support from patients and physicians. The navigator is always available to patients, providing written materials and helping patients through the early confusion and fear.

Ontario describes a future health system characterized by patient-centred and community-based care, close to home, timely and integrated. Other provinces take the same approach, using similar language. Ontario raises the bar with a promise that funding will follow the patient.

British Columbia's Complementary Medicine Education and Outcomes Program (CAMEO) is a research program focused on knowledge translation, whereby research is turned into user-friendly information that can be shared with patients and health professionals. CAMEO studies the complementary and alternative medicine (CAM) needs of people living with cancer, their support persons and health care providers; it develops programs and resources to help address those needs. CAMEO brings the latest CAM research to the conventional cancer care setting through education courses and lectures, published documents, and individualized information and decision support consultations.

Alberta is opening two new rapid access clinics, in Edmonton and Calgary, for lung cancer. The clinics will eventually provide a single point of entry for all patients. Specially trained nurses and nurse practitioners, with physician support, will assess and triage patients and then navigate them through the many diagnostic tests needed before a treatment decision can be made. Rapid access clinics (or diagnostic assessment centres) are increasingly popular as a consumer-friendly way to reduce wait times and untangle the path between suspicious test results, diagnosis and treatment.

British Columbia's virtual program for integrated cancer care, serving cancer patients in rural and remote areas of the province, will be the first of its kind in North America. InspireHealth's virtual program will include a two-day community-based workshop, integrated clinical services and online classes that will leverage personalized social-networking technologies. After the workshop, patients will receive an in-depth consultation with an integrated physician. Ongoing support, including follow-up physician consultations, will be provided through an online cancer recovery program designed to inspire and assist patients with their commitment to making healthy choices going forward.

British Columbia's Northern Cancer Control Strategy is a partnership of BC Cancer Agency, Provincial Health Services Authority and Northern Health Authority. The strategy is focused on enhancing the continuum of cancer services in Northern BC - including prevention, screening, diagnosis, treatment, supportive and palliative care. In addition, 15 new

telehealth sites have been established in the North, enabling patients to receive consultations and treatment monitoring closer to their homes. Still underway is the development of the Aboriginal Cancer Care Strategy, guided by a community-based committee comprised of Aboriginal representatives from across the North.

Waiting Times

Manitoba's Cancer Wait Time Strategy is the first of its kind in Canada, intended to dramatically improve access for patients, from wherever they may be on their cancer journey - from suspicion of cancer through to treatment. This initiative will integrate and coordinate cancer services across Manitoba, which will reduce wait times and increase access to care. Manitoba is the first province to partner with the U.K. for this type of initiative.

Patient information and navigation

Manitoba is creating rural cancer hubs with navigators who will act as a concierge for the patient, watching the patient journey, guiding and coordinating whenever necessary to ensure timely access to services.

From the Canadian Cancer Society, a top 10 list of breakthroughs for 2011

- A clinical trial involving Aromasin's (exemestane) ability to prevent breast cancer suggests it cuts the risk in high-risk women by 65 per cent.
- A Toronto-based research team establishes a surveillance protocol for families with Li-Fraumeni syndrome—a disease that significantly increases cancer risk—that increases the survival rate to 100 per cent after detection.
- Researchers identify a human blood stem cell that is capable of regenerating the entire blood system.
- A Canadian clinical trial suggests additional radiation in early-stage breast cancer can improve disease-free survival by 30 per cent and reduce the risk of recurrence.
- Variants in the genetic material of ovarian cancer cells provide insight into how ovarian cancer develops.
- A clinical trial funded by the Canadian Cancer Society finds that men with prostate cancer can take a drug holiday and reduce side effects of therapy.
- A new imaging method, Laser Raman Spectroscopy, combined with existing methods is able to identify pre-cancerous lung nodules with 96 per cent accuracy and 91 per cent specificity, when used with existing methods.
- Researchers develop nanoparticles called porphysomes that may effectively target and destroy tumours by converting light from a laser into energy that kills cancer cells.
- A Health Canada study that found young men in Western Canada are the primary users of smokeless tobacco will help develop a tobacco control strategy aimed at young people.
- Researchers turn their attention to genes that decrease the risk of lymphoblastic leukemia in children in hopes of developing treatment options.

Disparities

By JAMES D. GOWING, BA, MB, BS, FRCPC

Some disparities are worse than others. This year, we highlight three examples of disparities that create inequities and sustain rather than improve poor health outcomes for some cancer patients.

Cancer Research

As the articles by other cancer groups demonstrate (see the Living With Cancer section), the struggle for research dollars is central to the goal of providing support and hope to patients. Indeed, many of the cancer charities in Canada were formed to raise research funds so that more effective treatments and perhaps cures would be found for these less well-known cancers.

So far, that dream evades groups with a smaller rate of incidence, even if the lethality is very high.

At the other end of the spectrum is lung cancer. The stigma associated with lung cancer is so pervasive that it shrinks the research investment—sustaining the poor outcomes associated with this disease. Decades of emphasis on prevention came at the cost of any attention to survival.

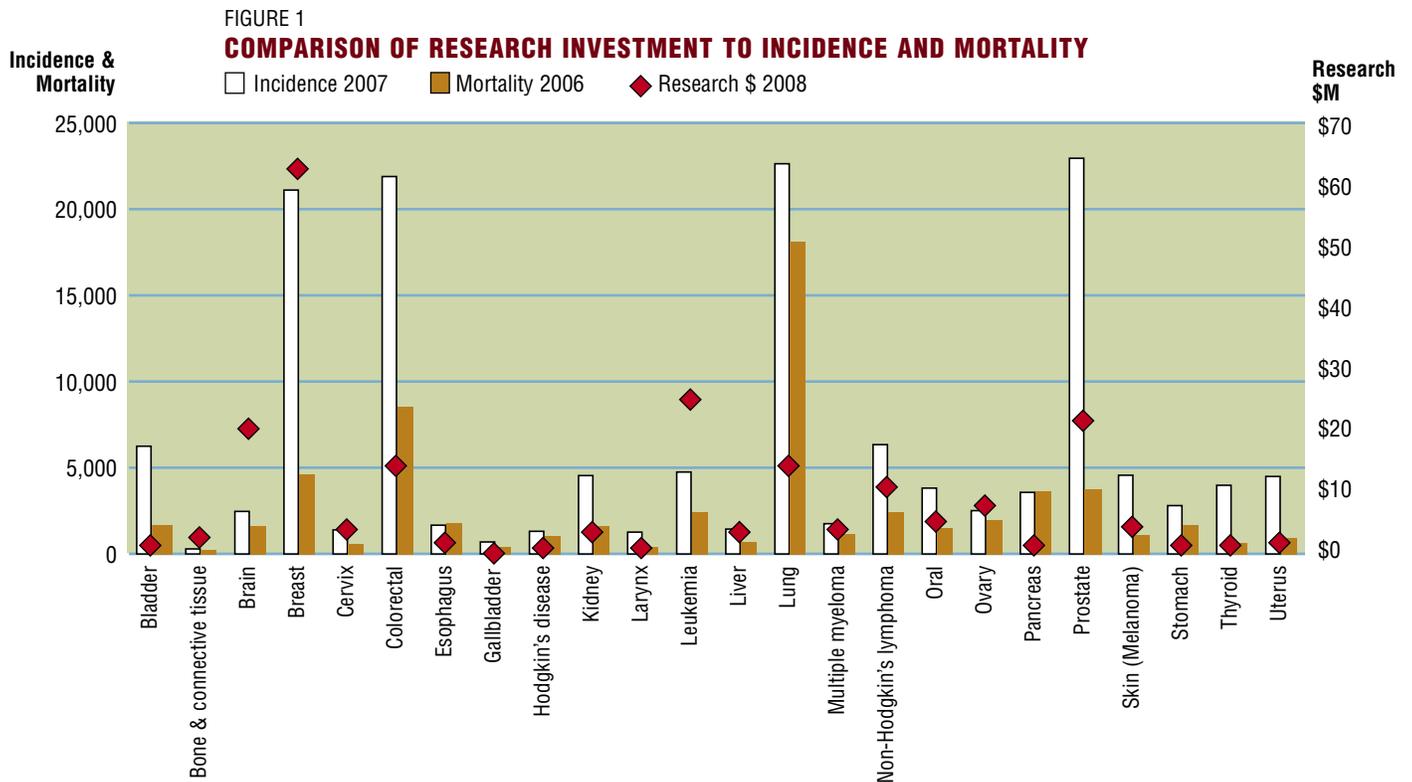
Figure 1 shows the research investment compared to inci-

dence and mortality for 24 types of cancer.^{1,2} At present, the relationship between these three sets of data is perplexing. While nobody would begrudge the success of breast cancer research and the enormous gains in survival rates that resulted, a host of other cancer groups want the same opportunity. Similarly, the emotional response to a child with leukemia or a father with prostate cancer may explain donations from citizens, but does not explain the other 56 per cent of research funding, from governments and public agencies.

Figure 2 shows the research investment compared to potential years of life lost (PYLL) for 22 types of cancer.^{1,2} The PYLL rate is 50 per cent higher for cancer than for cardiovascular disease, because cancer strikes every age group.³ Again, there is a puzzling disconnect between the research investment and the impact of the disease.

These early deaths cost us in human and economic terms. Charity Intelligence Canada (Ci) identified four cancers that are underfunded: pancreatic, stomach, lung and colorectal. “These cancers represent an opportunity for donors to make real impact by filling a tragic funding gap.”⁴

It should be noted that Ci also recommended palliative care as a field needing urgent funding. This will be a subject for future investigation by CACC.



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PET Scans

Susan Martinuk, author of a recent report on PET scans used for cancer in Canada, writes: “Given that PET imaging can change the management strategy of cancer patients in, at minimum, 36.5 per cent of cases (Hillner et al., 2008a; 2008b; 2009; Worsley et al., 2010), there is an implication that Quebec cancer patients have a very different standard of cancer care than their counterparts in other Canadian provinces.”⁵

In 2012, when New Brunswick buys its second scanner, it will become the only province in Canada meeting world standards for the number of PET scanners per million population.⁵

Ontario, for its significant investment in nine scanners, delivers the service to cancer patients at a rate comparable to Prince Edward Island, which has none and refers patients outside the province. Equally disturbing is the fact that nuclear medicine physicians found two of the research trials being conducted in Ontario were unethical: one for withholding scans from lung cancer patients (a use with well documented benefits); and one for putting breast cancers through scans that could not possibly identify the tumours being sought.

As with a number of other issues in health care, the problem with PET scans is that each province develops its own rules, often moving in fits and starts in response to emerging

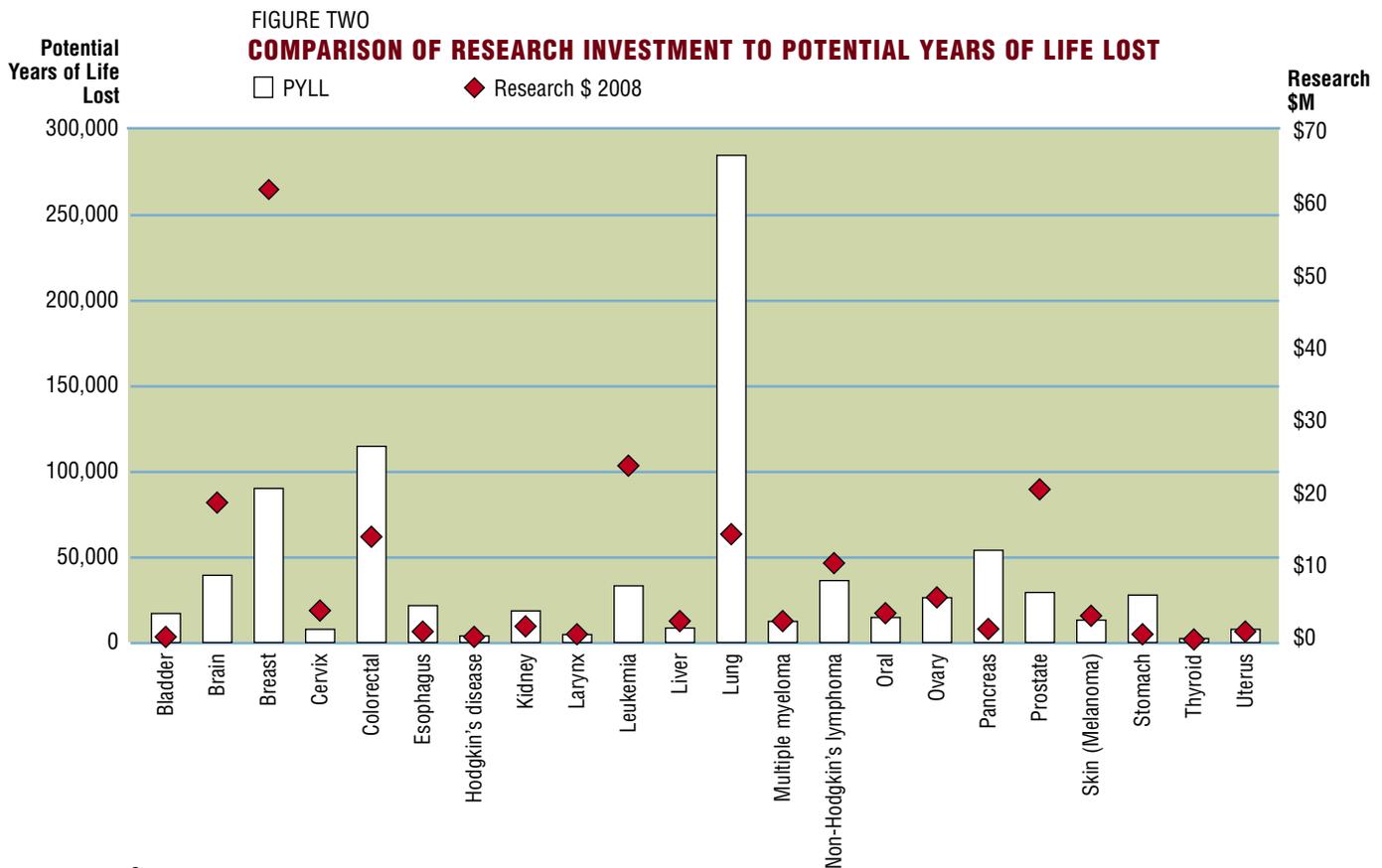
evidence. For example, the approved cancer uses for PET scans in each province are quite varied, ranging from six different cancers in British Columbia to 14 in Quebec and New Brunswick. Within those listings, the variety of purposes for the scan in each disease can also vary.

The report recommends a national strategy to create consistent policies, collective purchase agreements and develop geographically equitable access to the FDG radiotracer. Education initiatives for physicians and the public are recommended to facilitate informed, strategic choices.

Drug approvals

For five years, nine provinces (all but Quebec) have been working with a special cancer drug review committee to ensure one common set of recommendations about the clinical merits and cost-effectiveness of new cancer drugs. An important goal was to eliminate the duplication and somewhat erratic results of province-by-province reviews. A desirable side effect would be the eventual alignment of cancer drug coverage across the country. An expectation—though never promised—was for timely decision-making about the funding of a new cancer drug.

Over those five years, the interim Joint Oncology Drug Review (JODR) and now the pan-Canadian Oncology Drug Review (pCODR) have delivered recommendations on a regular basis. pCODR released its first recommendation in



Sources

Potential Years of Life Lost 2006: Canadian Cancer Statistics 2011. Canadian Cancer Society.

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January 2012 and is working on eight others.

The provinces, with their constitutional autonomy on health spending, are free to accept or reject any recommendation.

The provinces have not yet made a commitment to a timeframe for responding to recommendations. At this time, there is no commitment from the provinces to forego their own review of clinical impact and cost-effectiveness. There is early evidence that the timing of funding decisions for new cancer drugs will continue to be highly variable across the country.

The timely uptake of recommendations— whether positive or negative—depends on a commitment by the provinces to one fundamental piece of the plan: avoiding duplication of time and effort in the drug review process. Will they take direct action on pCODR recommendations or reevaluate each product through their existing drug review committees?

pCODR should be commended for an open, collaborative approach to their responsibilities, having worked closely with oncologists, researchers, drug plan managers, patient

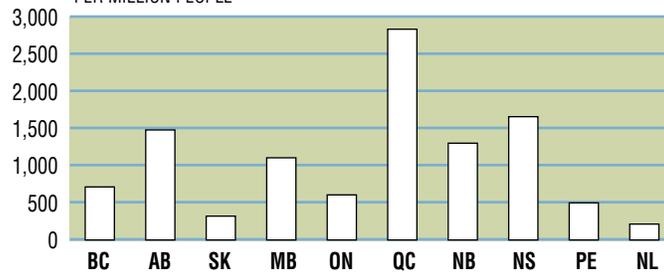
groups, epidemiologists, pharmacists and many others in the year before their first drug review. That opportunity alone, setting aside the years with JODR, provided ample time for the provinces to design a more streamlined response to future recommendations.

Progress on the question of timely decisions that correspond to pCODR advice will be a measure of the true value of pCODR.

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FIGURE 3
PET SCANS IN CANADA, 2009
PER MILLION PEOPLE



Source: Martinuk SD. The use of Positron Emission Tomography (PET) for Cancer Care Across Canada, Time for a National Strategy. AAPS, Inc. and TRIUMF, 2011.

PET SCANNING STATISTICS FOR CANADA IN 2009 ⁵

	BC	AB	SK	MB	ON	QC	NB	NS	PE	NL	TOTAL OR AVG
Population	4.5M	3.7M	1.0M	1.2M	13.1M	7.9M	0.75M	0.94M	0.14M	0.5M	33.73M
#Clinical scanners	1**	3	0** *	1	9	12	1**	1	0*	0** *	28
#Scans funded in 2009 (approx)	3,100	5,500	300	1,300	7,250	22,400	1,000	1,600	70	100	42,620
Cost per scan	\$1,400	\$1,350	\$1,250	\$1,800	\$1,220	\$956	\$1,600	\$1,800	\$1,836	\$1,850	\$1,506.20 AVG
#Scans per million people	689	1,486	300	1,083	553	2,835	1,333	1,702	500	200	1,068 AVG
#PET scanners per million people	0.22	0.81	0	0.83	0.7	1.5	1.33	1.06	0	0	0.83 AVG
#Scans per scanner	3,100	1,833	0	1,300	806	1,867	1,000	1,600	0	0	1,643 AVG

*Sends patients out of province for scans

**Expecting a/another PET scanner

Note that the data and calculations above reflect PET statistics obtained for the year 2009.

A recent survey of PET facilities confirmed that these statistics remained essentially the same in 2010.

Noteworthy

By DAUNA CROOKS, RN, DNSc

Neglected Issues

The Report on the State of Public Health in Canada 2011: Youth and Young Adults—Life in Transition, discusses major health issues of concern for the age group 12–29.¹ Specifically, it refers to physical, sexual, reproductive and mental health, injury and substance abuse. The authors identify the influence of determinants of health in influencing and modifying health outcomes. In that report, policy changes, interventions and supports that make health and life transitions more positive and sustainable are outlined. For example, policies around safety, tobacco and sexual health have saved lives, particularly when introduced early in the life course. Supports including personal, social, educational, economic and other sources are recognized for the power they have in achieving a commitment to health.

An examination of research in cancer presents a very different viewpoint. The majority of cancer research funding is spent on basic science, causation, diagnostic improvement and treatments reported at approximately 95 per cent.² While this work is important, the translation to patient care takes interminable amounts of time. Minimal funding is available or offered for supportive care research, which addresses the determinants of health and has much to do with recovery, management of stress and coping with the disease, treatment, survivorship and end of life issues.

Studies on unmet needs of cancer patients have shown a consistent pattern from the 1990s to today.^{3,4,5,6} Those needs include, foremost, health information and help with psychological issues, specifically fears of cancer returning or spreading. Active care and symptom management and support to cope with symptoms, help with physical and daily living needs, help with interpersonal communication issues and concern for those close to them were also priorities for patients.

Specific groups of cancer patients vary in their ability to attract research interest and funding.

Where advocacy groups have made significant strides in promoting breast cancer research at the biological and psychosocial levels, other disease sites such as lung cancer garner little attention. In the case of lung cancer, stigma is as evident in the disinterest of research funders as it is in professional caregivers and general populations on a personal or clinical level. Complementary and alternative medicine receives minimal research funding yet we know that patients continue to use or turn to these therapies as therapeutic supports. There remain many unanswered questions for patients, families and caregivers.

This issue of the Report Card addresses topics that have the potential to support persons and agencies to understand and address issues important to patients. Hopefully, the Report Card will stimulate policy development and research funding where a difference can be made immediately obvious to patients and families.

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CANCER ADVOCACY COALITION OF CANADA

60 St. Clair Ave. East, Suite 204, Toronto, Ontario M4T 1N5
Tel: (416) 538-4874 Toll Free: 1-877-472-3436
canceradvocacy@on.aibn.com www.canceradvocacy.ca