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Improving the Management of Cancer in the Workplace

Discussion Paper

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Table of Contents

		Page
Executive Summary		
Introduction		4
Section 1	The Impact of Cancer on the Workplace	6
Section 2	Current Research on Workplace Best Practices	14
	Consolidated Employer Best Practices	22
Section 3	Reputable Resources and Best Practice Models	23
Section 4	Guiding Principles and Recommended Practices for Workplace Cancer Management	27
Section 5	Links between Employer and Provincial Cancer Resources	30
Appendix 1	Stakeholder Interview Summary	
Appendix 2	High-level Workplace Cancer Model	
References		

Executive Summary

As the incidence of several cancer types continues to climb, the cost and disruption to workplaces will only increase. An aging labour force, poor lifestyle choices, and environmental exposures will all contribute to this challenge. It will surprise many to know that over 40% of all cancers are diagnosed in the working population (ages 20 to 65), including 70% of all breast cancer cases.

The (really) good news is that improved therapies have resulted in over 810,000 cancer survivors in Canada. But this means employees are now more likely than ever to return to work following cancer treatment, or in many cases stay at work while being treated. Many others take on a caregiver role. Work often has a very positive influence on survivors, including social connections, self-esteem, financial security and access to health benefits. But just like mental illness, a cancer diagnosis can also create workplace challenges, including negative and unfair behaviours among workplace leaders, managers and colleagues. We want to change that.

This discussion paper is intended to be a practical and authoritative guide to help employers, unions, benefit advisors and other stakeholders overcome stigma and improve how cancer is handled. Recent literature, much of it Canadian, documents a significant gap between how survivors want and need to be managed, and their lived experiences with employers, managers and co-workers during treatment and as they return to work.

There are five main sections:

- 1. First, we review the evidence to describe how cancer affects productivity, its prevalence, linkage to lifestyle, and direct (drug) and indirect (absence, disability, presenteeism and worker replacement) employer costs. We discuss how cancer connects to corporate social responsibility and the impact it has on employed caregivers.
- 2. Next, we describe a number of best workplace practices drawn from our review of about three dozen high-quality studies and reports. Most of these are in the References section. We identify many factors associated with successful return to work.
- 3. We have identified several web-based cancer resources and best practice models in Canada, the United States and the United Kingdom.
- 4. We have translated the preceding three sections into practical advice and recommended practices for employers and the workplace parties regarding the important role of health and disability benefits, the need to measure costs, prevalence, practices and outcomes, how to provide psychosocial support, caregiver benefits, and a few foundational human resource policies and practices.
- 5. We briefly note the need for better coordination between provincially-funded cancer treatments and services and those provided by employers.

The report also includes notes from interviews with six stakeholders related to their experiences at work, including how they manage cancer and other chronic diseases and face the rising costs of drugs and disability plans. Appendix 2 provides an initial, high-level workplace cancer model.

We hope this paper sparks discussion and results in better management of cancer and in fact all chronic diseases in the workplace given generally similar links to lifestyle behaviours and management practices. We have taken a page from twenty years of tremendous progress in how mental illnesses are now measured and managed and hope for similar – though much faster – progress in cancer.

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<u>Improving the Management of Cancer in the Workplace</u>

Introduction

"The rise in new cases of cancer will place an increasing burden on Canadian society... There is a need to enhance capacity for primary prevention, early detection and treatment to further reduce overall cancer incidence and mortality." Canadian Cancer Statistics, 2012

Cancer represents an interesting dichotomy. On the one hand, incidence for several cancer types is steadily escalating. However, the development of new, more targeted and effective cancer therapies, coupled with more government investment in cancer prevention, screening, and education has led to a vast increase in survivorship rates for many types of cancer. There is a paradigm shift occurring on how society thinks about cancer. Many people affected by cancer, such as patients and their caregivers, now have an increased opportunity to focus on living with cancer rather than avoiding death. For some, cancer can be fatal, but increasingly it is an acute or episodic illness and a chronic disease.

Workplace resources and health systems must reflect this. Private and provincial health systems cover different treatments and procedures and typically work independently. The system is unnecessarily complex, duplication of diagnostics and procedures¹ occurs (CIHI, 2017), entitlements change,² and there are gaps in the continuum of care from prevention through to palliative stages. All this needs improvement.

In the workplace, many employers support cancer as part of corporate social responsibility to the broader community through financial contributions to cancer charities, encouraging staff to participate in charity events. They also provide health promotion, screening and cancer support programs at work. Yet they often struggle to manage the increasing number of employees diagnosed with cancer who still want (and are often able) to work. Employers usually lack policies and supports that include dependents with cancer as well as caregivers, and so there are important process, navigation and information gaps. As a fatal and chronic disease, cancer is different. Outcomes are often dependent on timely, simplified and coordinated access to necessary care and support resources.

We believe now is the time to move past dialogue to develop and implement practical, actionable, outcomes-focused solutions. In the long run, we believe the most efficient and cost-effective way to prevent and manage cancer is to take a broader population health approach, whereby governments and workplace health stakeholders collaborate and leverage all health system and workplace resources surrounding all individuals affected by cancer, be they the patient, a dependent with cancer or the caregiver. Our more immediate opportunity is organize and improve workplace resources to better serve survivors and caregivers. Through designing a better workplace delivery system, we

¹ A recent review by Choosing Wisely Canada estimated that up to 30% of eight recommended tests, treatments and procedures may be unnecessary, and there were significant variations by region and facility.

² For example, new or improved Employment Insurance Family Caregiver benefits were effective December 3, 2017 and complement the 26-week Compassionate Care benefit.

believe opportunities to interact with government, policy and public health system stakeholders will become increasingly apparent.

The theme and primary focus of our report is on *organizing the system of care*, initially and primarily in the workplace, to address the needs of the whole patient. We have compared today's current state to an ideal state. The gaps are framed as opportunities that need attention from stakeholders.

The purpose of this discussion paper is to:

- 1. Identify key issues and gaps in workplace cancer management, with emphasis on health benefits, return to or staying at work, organizational supports and related policy implications;
- 2. Set out the business case for employers and survivors to more actively prevent and manage cancer;
- 3. Document best and emerging practices in workplace cancer management, both in Canada and elsewhere;
- 4. Identify other considerations to better manage cancer, notably linking workplace and health systems resources; and
- 5. Develop a preliminary framework and guiding principles for effective workplace cancer management.

Section 1 - The Impact of Cancer on the Workplace

We sometimes grumble about going to work, but there is considerable evidence that work can be good for us, even therapeutic. Work is part of our identity; it is normal behaviour and allows us to better control our lives because it creates not just income and assets, but self-esteem, quality of life and social relationships and support. If you wonder about that some days, consider what would happen if you lost your job or your ability to work.

Cancer affects Productivity

It will surprise many that cancer affects a significant proportion of working age Canadians: 43% of all cancers diagnosed in 2010 (73,000) occurred in working age Canadians aged 20 to 64, including 70% of all breast cancer cases (Statistics Canada, special tabulation). In addition, many in the workforce are distracted or absent as they care for children, parents, family and friends with cancer or other serious illnesses. A McGill University survey indicated 16% of Canadians had been caregivers in the past year. Of these, one-third had to care for other family members at the same time, and 20% took at least one month off work to care for the patient.³

In the US, half of 13.4 million cancer survivors are of working age. The annual productivity loss of cancer survivors was, on average, 65% higher for men and 49% higher for women versus those without a cancer diagnosis (Ekwueme et al, 2014). While high in percentage terms, in absolute (US) dollars, the annual productivity loss was quite moderate: \$1,459 for men and \$1,330 for women. Among employed survey participants, Ekwueme et al., 2014) reported that 42% required changes to their work duties and hours and about one quarter said their cancer made them less productive at work. Results were reported after adjusting for age, sex, ethnicity, number of chronic diseases, marital status and education.

Cancer often keeps people from working, at least for a while, and moreover often impairs their ability to be fully productive even long after treatments have ended. While that directly affects workers and their families, it also costs employers and society through absence, disability, productivity losses, presenteeism and premature death. The burden of cancer in Canada was most recently estimated at \$5.4 billion in 2006 (PHAC, 2014), however this figure includes income replacement costs only until the time the cancer patient's vacant position is filled. This estimate therefore excludes most short- and long-term disability (STD, LTD) costs, as well as costs for presenteeism and caregiving. In 2017, cancers were the fourth most expensive type of STD and LTD claim (Manulife, 2018).

Studies have estimated that about 60% of cancer survivors, overall, continue to work during or return to work after cancer treatment (Mehnert, 2011; de Boer et al., 2008). This depends in part on how

³ 2016 Health Care in Canada survey of 1,500 Canadian adults; estimated margin of +/- 2.5%. Available at: http://www.mcgill.ca/hcic-sssc/files/hcic-sssc/hcic 2016 results 08-non-professional caregivers.pdf.

⁴ The methodology of calculating indirect costs changed substantially since the previous edition of the Economic Burden of Illness in Canada, 1998 (Health Canada, 2003). At that time, cancer was ranked 4th most costly overall, with a total economic burden of \$14.2 billion in 1998 dollars.

employers manage survivors. The Institute for Work and Health has recently updated its evaluation of <u>seven principles</u> for successful return to work. **Section 2** explores the research on how employers, cancer patients and survivors and caregivers handle this process.

Cancer is Prevalent

Approximately 206,200 new cases of cancer and 80,800 deaths were expected in 2017 (Canadian Cancer Society, 2017). In each year of the last decade, cancer has killed more people each year than any other disease. And yet, there were over 810,000 Canadians in 2009 with a cancer diagnosis over the ten previous years who were still alive. Canada, like many western countries, faces an emerging cancer paradox. This is a set of diseases that disable and kill more people every year, and yet more people survive longer. Cancer can be episodic, chronic and fatal.

Over their lifetimes, men have a 49% chance of a cancer diagnosis and women have a 45% chance (Canadian Cancer Society, 2017). While both incidence (new cases) and mortality rates have been trending downward for the last 25 years, a larger and older population means the total number of cases will continue to climb (Xie, Semenciw and Mery, 2015; Canadian Cancer Society, 2016).

Lifestyle and Cancer

A review of research from several countries indicates 35% to 40% of cancer diagnoses and deaths are preventable through lifestyle changes (World Health Organization, 2007; Parkin, Boyd and Walker, 2011; Lanting et al., 2014; Weiderpass, 2010). While there is some variation in the percentages among the studies, lifestyle generally means behavioural choices that include smoking, poor diet, physical inactivity, excess alcohol, and may include excess weight, exposure to radiation, certain infections, environmental smoke and stress. Using the World Health Organization (WHO) and other reputable reports, Weiderpass (2010) reported that 37% of cancers were attributed to eight lifestyle behaviours in high income nations. These are shown in Table 1.

"Primary prevention through behavioural and environmental interventions... – 'lifestyle' – is beyond a doubt the most cost-effective alternative for preventing a large burden of chronic and degenerative diseases worldwide, including cancer." (Weiderpass, 2010. p. 459)

⁵ Many cancers arise from occupational exposure to toxic chemicals, smoke, radiation, asbestos or other factors. These cancers and their prevention is a critically important issue but outside the scope of this report.

Table 1: Cancers Linked to Behaviour

Behaviour	Population Attributable Fraction	
Smoking	29%	
Alcohol use	4%	
Low fruit and vegetable intake	3%	
Overweight and obesity	3%	
Physical inactivity	2%	
Others (N=3)	2-3%	
Total	37%	

Source: Weiderpass, 2010. Population Attributable Fraction estimates the reduction in cancer if exposure to the behaviour was reduced to the lowest possible minimum. Note the eight behaviours do not add to 37% because part of the population has more than one risk factor.

Other risk factors have come to light since publication of those source reports. These include exposure to ultraviolet light (including tanning beds)⁶ and second-hand tobacco smoke. Exposure to Human Papillomavirus can also cause cervical cancer and is associated with four other cancers (WHO, 2016). Two vaccines are now approved for use in Canada.

An analysis of Canadian data attributed 28% (47,000) of new cancer cases in 2013 to four lifestyle factors (tobacco smoking, alcohol use, excess weight and physical inactivity) with an estimated economic impact of \$9.6 billion (Kreuger et al., 2016). The study noted a two percent reduction in lifestyle-related cancer incidence (from 30% in 2000), which they attributed to reduced smoking and higher levels of physical activity.

Cancer Treatment is Expensive and Costs will Increase

Cancer is increasingly relevant to drug plans, whether government or private. Consider:

- Oncology is the largest therapeutic class by sales (QuintilesIMS Institute, 2016).
- Sixty-eight new treatments were launched between 2011 and 2016. Many of these are being examined in other tumour types (IQVIA, 2017).
- Sales of oncology and supportive care drugs increased 24% between 2012 and 2016 (IQVIA, 2017).
- Of 2,240 drugs in late-stage (Phase II or later) development in 2016, 27% are for oncology, more than the next three classes [central nervous system (12%), anti-infectives and anti-virals (8%) and cardiovascular (6%)] combined (QuintilesIMS, 2016).

⁶ A recent review ("Ultraviolet radiation and skin cancer") is available <u>here</u>.

All this cost information can alarm payers to the point where new cost controls may unduly slow or completely frustrate access to medicines. Clinical, economic and humanistic reviews ensure value from the payer perspective and that patient perspectives have been considered. Drug manufacturers and payers need to cooperate to ensure necessary evidence is readily available and properly evaluated to help sustain drug plans into the future.

Employers need to be aware of how oncology drugs affect their drug plans too. Government drug plans, hospitals or cancer agencies in Ontario and Atlantic Canada either do not cover cancer drugs unless they are infused or administered intravenously in a clinical setting, or they may do so only following a special physician request and require older or potentially less effective drugs to be tried first. In Ontario at least, there is no scientific rationale for this restrictive policy; it is simply history. However, many Take-Home Cancer Drugs are covered with no patient cost in Western Canada or

The <u>Canadian Cancer Society</u> identified twelve Take-Home Cancer Drugs (THCDs) approved by Health Canada between 2000 and 2009. Nine of the 12 cost over \$20,000, and eight cost more than \$30,000. The average cost of a course of treatment with those drugs at that time was \$65,000, about the same as the average annual household income.

Source: CCS, 2009. Cancer Drug Access for Canadians.

Since then, many more new cancer and adjunctive therapy drugs have been approved. The average THCD treatment cost has increased to \$78,190, and costs can exceed \$140,000 when immuno-oncology products are used.

Source: CCS-ON, 2016. Cost of Cancer Drugs 2006-2015 (unpublished).

are simply made part of Quebec's universal drug plan which has an annual patient cost limit of \$1,046 (2016-17). Ontario residents must either wait for a decision through the province's Exceptional Access Program or apply for coverage through the Trillium Drug plan when their out-of-pocket costs exceed about 4% of family income. Inconsistent provincial coverage adds cost and complexity to the administration of employer drug plans.

Cancer also creates many direct and indirect costs for patients.

- 1. One survey of 216 employers noted that 27% terminate the patient's health and dental benefits one year or more after being admitted to long term disability benefits. This varies by sector, with the highest percentage of terminations occurring in: (i) transportation, warehousing, communication and utilities (50%), (ii) wholesale and retail trade (37%) and (iii) Finance, Insurance, Investment and Real Estate (36%).⁸
- 2. A Canadian estimate of the wage loss from cancer (Hopkins, Goeree, Longo, 2010) indicated patient and caregiver costs are significant:
 - o Newly diagnosed cancer patients on average reduced their work time by 36%.

⁷ Since September 2015, the three largest insurers (Sun Life, Great-West Life and Manulife) have all announced more intense drug review processes which include delays in listing new drugs. ClaimSecure (a Pharmacy Benefits Manager and division of McKesson Corporation), recently launched a new formulary that excludes high cost drugs.

⁸ Toronto Region Board of Trade: Benefits and Employment Practices Benchmark, 2015/2016.

- o Caregivers lost 23% of their paid work time.
- Annual household income was reduced by 26.5% for cancer patients versus the general population.
- o In aggregate, new cancer diagnoses generated a wage loss of \$3.18 billion in 2009.
- 3. A Statistics Canada (Jeon, 2014) study that linked various datasets compared employment and earnings between cancer survivors working at the time of diagnosis and a matched comparison group. Differences were measured in each of the three years following diagnosis. The probability of being unemployed is 3% greater with cancer patients at one year post-diagnosis, and increases to almost 5% after three years. Earnings on average were reduced by 12% one year after diagnosis, though the gap narrows in years two and three. Educational level and survival rates by type of cancer affected the results.
- 4. A recent discussion paper by the Canadian Cancer Action Network and Canadian Cancer Society (Manitoba) identified issues that describe the financial impact of cancer:
 - There are ongoing barriers to maintaining or returning to work, including medical appointments and residual post-treatment health effects.
 - o Gaps in government safety nets, including:
 - Employment Insurance (EI) sickness benefits are limited to 55% of earnings, up to \$547 weekly (2018) for up to 15 weeks. 9 To qualify, EI requires a variable number of hours worked in the previous year, 420 to 700 hours depending on region. EI benefits will not be available for subsequent treatments if the cancer patient has not worked the required number of hours in the previous year. The EI Compassionate Care benefit provides up to 26 weeks of benefits when the death of a family member is expected within the next 26 weeks.
 - Canada Pension Plan disability benefit has a very stringent definition of disability: severe and prolonged, indefinite or likely to result in death. This effectively renders most cancer patients ineligible for CPP benefits. For 2017, the average monthly CPP disability benefit was \$954 (2018 maximum \$1335.83). The total payable is based on how much a patient contributed during his or her working career.
 - Provincial social assistance plans provide a very limited income, and typically
 patients must deplete almost all their cash-equivalent assets, including
 RRSPs, before qualifying. However, health and drug benefits are provided.
 - Lack of private health and disability insurance, either from employment, or through an association or individual policy.

10

⁹ In many cases cancer treatment goes beyond the 15 week EI benefit and therefore there is no income replacement for those who then fail to qualify for provincial social assistance.

Replacement Costs

In addition to certain costs for treatment not covered by the healthcare system and income replacement, employers will very often need to replace an employee – most often temporarily – undergoing treatment costs for cancer. That usually means added organizational cost for advertising, recruitment and vetting. Training and/or development costs follow and for a time, any replacement is likely to be less productive than the now-absent patient. If an employer chooses not to replace a worker and in turn distributes added work to other employees, then stress among them may increase and morale may suffer. Productivity may be impacted as well. Beyond the cost of the worker, the cost and opportunity cost of management time for line and human resource (HR) management must also be considered.

The cost of turnover is often estimated at about 150% of salary, but it is very difficult to find hard numbers to support that rule of thumb. The figure depends on what costs are included (direct like a recruiter and HR time, and indirect like productivity), the required education, experience and skills, as well whether the job is entry-level, managerial or executive. The best advice is to develop your own calculator. One example by Hay Group, a global human resources consulting firm, provides a range of 50% of salary for an hourly worker to 150% of salary for a professional or executive position. ¹⁰

1. **Employer Best Practice - Minimize replacement costs.** Ensure an employee diagnosed with a serious illness like cancer feels welcome in staying in their position or returning to work (RTW) after treatment. Provide tangible supports such as flexible time, graduated RTW plans, ergonomic adjustments, assistance with heavy work, and more frequent rest. Communicate with workplace colleagues and managers to set the stage and create reasonable expectations.

Employers understand cancer is more than just a cost

A connection between employee health and well-being and an employer's Corporate Social Responsibility (CSR) agenda has emerged in recent years. While CSR is often positioned as an organization being externally focused to better its community, there is a good deal of research that suggests CSR also benefits the organization's own employees. The World Health Organization (WHO, 2010) released a report on healthy workplaces and added a new element – Enterprise Community Involvement – to its definition of a healthy workplace. The report states:

"Enterprises impact on the communities in which they operate and are impacted by their communities. Workers' health, for instance, is profoundly affected by the physical and social environment of the broader community. Enterprise community involvement refers to the activities in which an enterprise might engage, or expertise and resources it might provide, to support the social and physical wellbeing of a community in which it operates. This particularly

¹⁰ A Hay Group Report citing that range was issued in June 2010 (page 3). See: https://www.haygroup.com/downloads/ca/hay_group_employee_engagement_are_you_missing_something.pdf.

includes factors affecting the physical and mental health, safety and well-being of workers and their families."

Business for Social Responsibility (BSR) is a global non-profit organization comprised of more than 250 member companies and other partners interested in building a just and sustainable world. BSR recommends four critical success factors for CSR (BSR, 2013), one of which is: "Reframe health and wellness as a broader stakeholder and value chain issue and ensure that the company's CSR agenda reflects that shift."

CSR represents a high priority for many organizations, and does not always require a scientific or financial business case. Employers often support health causes for non-financial reasons that include morale, culture and a broader sense of responsibility to their community. Health, and even high-cost drug and disability plans, can occupy a far more strategic place for employers as an integral part of their CSR agenda.

Considering Caregiving

The responsibility of caregiving can be a significant distraction for employees and therefore impact the quality and safety of work. Few studies have been published to properly consider the crucial role played by caregivers and the positive impact they have on the patient and the health care system, but also the challenges created for themselves and their employer. In her comprehensive report on caregiving, Janice O'Keefe noted the significant and often unrecognized costs borne by caregivers:

Informal caregivers are family members, friends or neighbours, most frequently women, who provide unpaid care to a person who needs support due to a disability, illness or other difficulty, sometimes for extended periods. They bear substantial costs — economic, social, physical or psychological. For instance, they are likely to incur out-of-pocket expenses and significant lifetime income losses, and they commonly experience stress, social isolation and guilt. Such personal costs can negatively impact the caregivers' economic security, health and well-being. (O'Keefe, 2011, p. 1).

While there is growing recognition of the impact of caregiving responsibilities on employees, many employers have not yet addressed this explicitly in an organizational policy. Lero et al. (2012) surveyed senior human resource representatives at 291 Canadian employers and found that half of them believed that caregiving is the individual employee's responsibility, and that current workplace practices are adequate to meet the needs of most employees, including whether they are parents, spouses or close friends and caregivers. Relatively few employers currently provide information or access to specialized services beyond what might be available through Employee Assistance Programs.

However 58% of employers believe that caregivers of seniors and chronically ill family members would benefit from improved public policies and workplace practices, which speaks to the emerging awareness of this issue. Further study is needed to create a stronger business case for caregiving as a priority for employers.

Summary

Cancer is not only a disease of old age. Increasingly, it is not a death sentence. Importantly, the cost and burden of cancer is not borne only by our public health care system.

More than most, employers may know that cancer significantly affects productivity and people in workplaces across Canada. It is prevalent, often preventable and increasingly expensive for employer drug and disability plans. Since so many cancers – over 40% – are diagnosed in the working age population, employers and other workplace health stakeholders have an important stake in managing the prevention and treatment of cancer, as well as the recovery process. Those costs and overall burden extend to family members and may include employees as caregivers.

Once aware, many employers may struggle with determining their business and moral perspectives and ensuring they meet their legal responsibility to accommodate returning cancer survivors. They may not yet have appropriate policies and supports in place. **Section 2** will review best practices from a review of published literature including several studies from Canada.

The business case for managing this disease is compelling, but need not be daunting. In fact, many of the principles for cancer management apply equally well to many other chronic diseases also prevalent in the workplace, and costly to employers and employees alike.

Section 2 - Current Research on Workplace Best Practices

Introduction

Cancer and work has attracted a growing body of research in recent years largely as a result of improved survival among working age patients. Sick leave and disability benefits provide crucial income support. There is often a difficult transition both away from work at diagnosis, and in returning to work following successful treatment. Some employees choose to continue to work during treatment for as long as possible, and many are actually able to work through their treatment without having to take a lengthy period of time off. It should be noted, however, that, in order to work during treatment many patients will require some degree of accommodation from their employer. Other challenges may come into play – for example, balancing the employee's will to work and retain a sense of normalcy, with how fatigue and psychological stress may impact the worker, co-workers and managers.

Table 2 summarizes the range of factors associated with return to work. The evidence is discussed in more detail below. A recommended employer best practice follows each finding.

Table 2 – Factors Associated with Return to Work

Negative Factors	Positive Factors
x Unsupportive work environment that can create resentment and stigma	V Management and co-worker training and support
x Loss of attachment to work	√ Employer preparedness
x Inadequate drug, health, EAP and disability programs	√ Acknowledging physical and mental impacts
x Treating return to work as an event, rather than as a process	√ Recognizing the psychological and social benefits of working
x Certain worker and disease characteristics such	√ Accommodation in job role and work setting
as older age, heavy physical labour, short-survivor cancers, lower education and incomes, etc.	√ Access to health and disability benefits

Source: Points are drawn from the following assessment of published literature.

1) Cancer and co-morbidities¹¹ increase the burden of illness

A large, retrospective American study (Dowling et al., 2013) using a population health survey compared the burden of disease for cancer survivors with those who had a diagnosis of heart disease or diabetes. Respondents with comorbidities were identified and health status and physical function, including

¹¹ A co-morbidity is the presence of two or more concurrent health conditions diagnosed in the same patient.

ability to work, was reported. The outcomes were measured after controlling for age, sex, ethnicity and other major comorbidities.

Those with cancer were significantly more likely to have a diagnosis of heart disease (36% vs. 13%) or diabetes (19% vs. 9%) than those with no cancer diagnosis. Generally, those with cancer and either or both heart disease and diabetes reported poorer physical health status, and previously working adults under age 65 reported higher rates of unemployment and lower productivity than those without a cancer diagnosis. Those with short-survival or multiple cancer types reported worse health status and more limitations than other cancer or chronic disease survivors. In contrast, breast cancer survivors in general reported similar functioning and productivity levels as those without a cancer diagnosis.

Mental illnesses can also be comorbid with cancer. International studies have determined that about 30% of cancer patients have a diagnosed mental health condition (Mehnert et al., 2014; Singer et al., 2013; Singer, Das-Munshi and Brahler, 2009). One study concluded that having a mood disorder was 81% more likely in cancer patients than in patients without cancer (Nakash et al., 2014). Combining cancer and mental disorders is associated with lower quality of life, relationship stresses, reduced immune system response and less favourable disease recovery (Philip et al., 2013).

These results suggest health strategies that integrate cancer and other serious health issues are likely to be more effective for patients and employers.

2. **Employer best practice - Consider comorbidities.** Address chronic disease – mental and physical – in an integrated strategy and to adapt work accommodation plans according to cancer type.

2) Work ability testing during treatment can predict return to work

About 150 types of cancer are <u>listed</u> by the Canadian Cancer Society, and survivability varies dramatically between those types (Canadian Cancer Statistics, 2016). But other factors must also be considered. One study indicated that diagnosis and treatment type were stronger predictors of return to work than cancer symptoms. Other studies show patient-level factors can help predict outcomes, such as personal expectation of recovery, and perceptions of work ability and self-efficacy. If employers could predict which employees are more likely to stay at work or return following treatment then available resources could be better organized and directed. Of course, information on the survivor's condition, work limitations and work intentions must remain current and personal health information must be safeguarded.

¹² This correlation does not suggest that cancer causes any other disease or vice-versa. Several common chronic diseases, such as some cancers, heart disease, diabetes and/or obesity, may arise from the same lifestyle habits (e.g., poor diet or inadequate exercise).

A Primer on Qualitative Research

While the greater focus in cancer research has been clinical and statistical, qualitative research (primarily) using interviews or focus groups can provide important insights on context, process, history and detailed personal experiences.

Qualitative researchers use a different approach than their quantitative colleagues. Rather than numbers, participant comments are the data which is then coded to help identify categories and themes. It is appropriate to adjust research questions in light of emerging input and return to participants for more information. Theory development is the endpoint, not the starting point.

Various tools – also different than in quantitative research – are used to establish quality through validity, reliability and rigorous research methods, including careful notetaking, coding, constant comparison, searching for outlier cases, dual case reviews, and assessment for use in other settings.

Qualitative research is simply a different approach to defining "the truth", better suited to social environments like the workplace.

A study in the Netherlands (de Boer et al., 2008) collected information between 1998 and 2002 from 195 cancer patients on cancer type, treatment mode, time to return to work, work ability (WA),¹³ physical workload, and work stress at three time points – roughly six months following a patient's last day of work and again six and twelve months later.

Even 15 to 20 years ago, 24% had either stayed at work or returned to work within six months of diagnosis. At 12 months, 50% were at work and 64% worked 18 months after they first left work. (WA scores improved with time.) Self-reported WA scores at six months strongly predicted return to work at 12 and 18 months independent of age and type of therapy. About two-thirds of those with the highest WA scores (8 to 10) were working at six months and almost all had returned to work within one year. Most (55% to 80%) of the survivors with the lowest scores (0 to 5) did not return to work in the first year, though most (60% to 90%) of those were back within 20 months. This suggests the importance of early assessment, work relevant intervention and education.

Employees are often unaware of the support and resources available to them. Soon after an employer receives notice of an absence or disability claim is a good time to review and explain the employee's benefits coverage, including EAP and health promotion programs. Employees and/or caregivers can be directed to cancer-specific resources, either by the employer when the employee has disclosed the cancer diagnosis, or by a third party such as an insurer if a disability claim has been submitted.

3. Employer best practice - Triage survivors and test work ability.

Studies indicate higher age, lower education, lower incomes, more complex treatment, chemotherapy, persistent symptoms, the presence of short survival cancer types, and physically demanding occupations are more likely to frustrate return to work. Ask cancer patients to complete a validated test of work ability and then target appropriate support and resources at those with the lowest scores. Consider physical and psychological demands and cognitive functions such as concentration and memory in return to work/stay at work strategies. Intervene early.

¹³ De Boer et al. used the Work Ability Index. An overview is available <u>here</u>. The WAI has been validated and asks seven questions to accurately measure perceived ability to work and two-year prognosis, work demands, impairment, 12-month absence, the worker's health status and mental resources.

3) Targeting work-related goals may be better than return to work

Typically, return to work is the stated goal of clinical and vocational rehabilitation efforts. This outcome is important to both employers and patients, work is not just a means to an end, i.e., a pay cheque. Considerable research indicates work is crucial for how people see themselves (van Muijen et al., 2013; Stergiou-Kita et al., 2014). Too often, neither survivors nor employers have a clear idea of how to bring someone back to work or support them with appropriate accommodations.

Wells et al. (2013) conducted a meta-synthesis (the qualitative equivalent of a meta-analysis – see sidebar) of cancer survivors, caregivers and employers about their experiences related to cancer and working. All 25 included studies were assessed for quality and were graded medium or better.

They found that work helps establish a new, more positive "normal" for survivors. It connects people socially, provides task and role variety and improves self-esteem. Work provides financial security and access to health benefits. Still, a significant minority (20% to 30%) of survivors report diminished work ability after returning due to persistent struggles with fatigue, memory and physical strength. Wells et al. developed a model to show the relationships between cancer and (i) self-identity, (ii) the meaning and importance of work, (iii) family and finances, and (iv) work relationships and performance. The model is dynamic in that the importance or inter-relationships between elements may shift over time and by individual.

Based on Wells et al. (2013), employers need to know that:

- 1. Many survivors, especially women, are very conscious of changes not only in their appearance but also in their ability and self-confidence at work. Those changes may take even longer for others to accept, including co-workers and managers.
- 2. Many survivors feel isolated when away from work during treatment and recovery. Workplace contact created a welcome distraction and connection. However, on return, survivors often reported negative attitudes (insensitive, ignorant or stigmatizing) and behaviours (lack of support and accommodation, and sometimes discrimination through silence or gossip) by colleagues and managers.
- 3. Many cancer patients re-evaluate the meaning of their lives and priorities shift during treatment and recovery (see Stergiou-Kita et al., 2014). The importance of work may diminish, especially if return to work is difficult, or goals change. Work aspirations may come into sharper focus. Wells et al. report that most often, survivors realize 'life is short' and work can become frustrating against those new priorities.
- 4. Financial needs never disappear even as other priorities emerge. For many, cancer can be expensive when income replacement is inadequate, drug treatments require significant out-of-pocket costs or travel to distant cancer centres for treatment imposes new costs for hotel, fuel and food. Adequate sick leave benefits were very important (Stergiou-Kita et al., 2014).

Survivors can feel trapped into remaining where they are, and may return primarily to protect access to health benefits, seniority or to provide for certain lifestyle goals.

- 5. Successful work after cancer requires support from employers (work adjustments and qualified HR and occupational health personnel) and colleagues (empathy, dignity). Several studies show that factors such as type of job (manual or professional), physical and emotional demands, and employer size and sector have significant influences on return to work (see Nowrouzi et al., 2009). Legislation in various provinces or for federally regulated employers such as financial institutions and transportation companies may require all but the smallest employers to make workplace accommodations, including duties, hours of work and availability for medical appointments. Survivors reported their physicians and medical care team was ill-equipped to help them return to work and made little effort to accommodate a working patient with convenient appointments, a finding echoed by Stergiou-Kita et al. (2014).
- 6. Survivors reported four main strategies to help them with work demands: (1) communication and negotiation with their employer, (2) accepting their changed capabilities, (3) managing symptoms and rebuilding confidence, and (4) 'working smarter' by pacing themselves and focusing on key parts of their jobs (Wells et al., 2013).

This meta-synthesis concludes that successful return to work: "depends on shifts and adjustments in each aspect of what is already a complex set of factors at the individual (micro), organisational (meso) and societal (macro) level. The most successful strategies to achieve these [work-related] goals are likely to be multi-dimensional... while simultaneously tailored to the individual survivor's life circumstances (Wells et al., p. 1213)."

4. **Employer best practices** - **Policy**. Recognize that work means more than money for returning cancer survivors. Maintain regular contact without pressure with employees away from work, whether for an extended period or even intermittently, especially from colleagues who have experienced similar challenges. Implement supportive policies, including continued access to work communications as well as to health benefits while on disability. Train managers and colleagues to help avoid confusion, frustration, resentment, ignorance and stigma. Be aware of relevant legislation that protects the disabled worker and requires reasonable accommodation for return.

4) A variety of factors affect return to work

Return to work is complicated. It often involves four systems that rarely consider each other or connect effectively: (1) healthcare, (2) legislative and insurance, (3) personal, and (4) workplace (Dewa et al., 2016, citing Loisel et al., 2005). Patients and survivors are usually ill-equipped to navigate these systems and mediate competing priorities, but generally have no choice but to muddle through.

A recent qualitative meta-synthesis (Stergiou-Kita et al., 2014) examined 39 studies that identified survivor return to work experiences and how that process could be facilitated. Quality was assessed and all but one included study was graded as high or very high quality.

The authors identified nine factors associated with successful return to work (Table 3), categorized as personal, environmental or occupational.

Table 3 - Facilitating successful return to work

Personal	Environmental	Occupational
Manageable symptoms	Workplace accommodations	Less stressful work and
Work abilities	Social supports / Family help	reduced work demands
Coping with emotions	Advocacy by health	lob flovibility
Ensuring motivation	professionals	Job flexibility

Source: Stergiou-Kita et al., 2014.

Navigation was a recurrent need. Since cancer is not the same disease nor does it affect everyone the same way, survivors were not sure how well they could work immediately upon their return but also weeks and months afterward as their capabilities and symptoms changed. They needed help navigating benefits and a frank discussion about accommodations.

5. **Employer best practices** - **Accommodation.** Cancer as a disease and its attendant system of care presents many mysteries to the workplace parties. Determine the impact and recovery process on an individual basis. Consider supports and accommodations at a personal, environmental and job level, and help survivors navigate their disability and health care benefits, as well as other available benefits and resources such as second-opinion services and employee assistance plans.

5) Most of the time, employers and cancer survivors are on the same page

While the potential for conflict and misunderstanding between the employer and an absent employee is a feature of all prolonged absences, most of the time the parties want the same things and conduct themselves with integrity and fairness. Beyond private one-off conversations, there has been limited research that identifies the types of accommodations that are made and the processes needed to help survivors stay at or return to work.

Stergiou-Kita et al (2016) conducted 40 interviews with survivors (N=16), health service providers (16) and employers (8). They documented accommodations and their challenges, as well as effective processes. Accommodations included:

- 1. Graduated return to work and flexible scheduling that recognizes ongoing fatigue and cognitive impairments and the need to attend medical or rehabilitation appointments.
- 2. Modified work duties and expectations, including elimination of non-essential tasks.
- 3. Retraining and supports at work that included time for reorientation and training on new procedures or technology, job shadowing and assistance with job tasks.

4. Ergonomic modifications to the work setting and provision of adaptive aids and technologies.

Before their diagnosis affects work, disclosure to the employer, communication and a realistic plan until work departure is helpful. Survivors reported they were often afraid to ask for accommodations because they didn't want to appear different or needy or reveal reduced capacity to work (Stergiou-Kita et al, 2016; Dewa et al., 2016). Employees were also concerned about disclosure, privacy and the impact of cancer on their job tenure (see also Stergiou-Kita et al., 2014).

Dewa et al. (2016) reported that employees found disability forms difficult to complete, particularly when the employee was in the midst of debilitating treatment. Their advice for employers was to respect privacy and expect that employees will find it difficult to talk about their cancer. Most employees want to work and make a contribution for as long as possible. Employer flexibility and a willingness to help were valued, and so was honesty in terms of identifying employer expectations, concerns and constraints.

Employers like to know that a cancer patient expects to return to work after treatment (Dewa et al., 2016). Employers, especially smaller ones, often found it difficult to make the necessary accommodations, assuming they were aware of their legal need to do this. Requests from survivors or their health professionals were sometimes vague or subjective, such as "work from home" or "minimize stress" or "reduce lifting". Until employers have enough information to eliminate uncertainty about diagnosis and prognosis, accommodations may not be clear and specific enough to meet survivor needs.

Employers had to deal with strained relationships pre- and post-cancer, inadequate policies and their ongoing need to optimize productivity. They were also concerned about setting precedents and sometimes could not adequately modify or substitute work duties especially for high-risk, highly physical or professional positions.

6. **Employer best practices** - **Effective communication and monitoring.** Mitigate the possibility of misunderstanding with clear and timely communication to survivors and their medical advisors. Provide high quality information and retain qualified expertise to develop policies and manage the scope and cost of accommodation. Negotiate a safe return to work in a constructive, ongoing and customized manner with the survivor. Monitor and adjust the

Summary

The first two sections of this report have identified key gaps and barriers to effective cancer prevention and management in the workplace, as well as key features of the business case and best practices for employers. Many of the studies reviewed are Canadian, ensuring the relevancy of findings. Many of the best practices are not unique to cancer, so while employers may use cancer as a catalyst to improve their supports and work environment, that investment will help ill and injured workers across the board.

Managing cancer or any chronic disease with significant workplace costs requires an integrated view to managing health, including prevention, risk factors, and employees with complex and often high-cost health issues. The evidence suggests cancer is frequently accompanied by depression and certainly anxiety, and the lifestyle factors that make cancer more likely also increase the risk for other common chronic illnesses such as diabetes. While it may require specialized expertise to refine, the basic steps are available from reputable websites and from insurers and HR and benefit advisors.

Several studies, particularly the systematic review (Mehnert, 2011) and meta-syntheses (Wells et al., 2013; Stergiou-Kita et al., 2014 and 2016), hinted at how much is not known about return to work and work accommodations from the survivor, employer and health professional perspectives. Accommodations in work duties and work space must reflect reduced mental (depression, anxiety, confusion, memory) and physical (fatigue, pain) capacity for several months or more following treatment. This is particularly challenging for smaller employers who may never have faced this situation, or do so only once every few years. However, the legal duty to accommodate to the point of undue hardship remains.

Many factors affect how well survivors stay at or return to work at a personal, environmental and occupational level. Central to success is timely, sensitive and candid communication and as much planning and early intervention as possible. Fair and consistent policies are critical. Done properly, these steps will not only help bring workers back, but keep them loyal and engaged at work, reduce costs and positively reflect on the employer's reputation.

Consolidated Employer Best Practices

The following six recommendations have been listed together here for ease of reference. The page numbers where they originally appeared are noted.

- 1. **Minimize replacement costs:** Ensure an employee diagnosed with a serious illness like cancer feels welcome in staying in their position or returning to work (RTW) after treatment. Provide tangible supports such as flexible time, graduated RTW plans, ergonomic adjustments, assistance with heavy work, and more frequent rest. Communicate with workplace colleagues and managers to set the stage and create reasonable expectations. (P.11)
- **2. Consider comorbidities:** Address chronic disease mental and physical in an integrated strategy and to adapt work accommodation plans according to cancer type. (P.15)
- 3. Triage survivors and test work ability: Studies indicate higher age, lower education, lower incomes, more complex treatment, chemotherapy, persistent symptoms, the presence of short survival cancer types, and physically demanding occupations are more likely to frustrate return to work. Ask cancer patients to complete a validated test of work ability and then target appropriate support and resources at those with the lowest scores. Consider physical and psychological demands and cognitive functions such as concentration and memory in return to work/stay at work strategies. Intervene early. (P.16)
- 4. Policy: Recognize that work means more than money for returning cancer survivors. Maintain regular supportive contact without pressure with employees away from work, whether for an extended period or even intermittently, especially from colleagues who have experienced similar challenges. Implement supportive policies, including continued access to health benefits while on disability. Train managers and colleagues to help avoid confusion, frustration, resentment, ignorance and stigma. Be aware of relevant legislation that protects the disabled worker and requires reasonable accommodation for return. (P.18)
- 5. **Accommodation:** Cancer as a disease and its attendant system of care presents many mysteries to the workplace parties. Determine the impact and recovery process on an individual basis. Consider supports and accommodations at a personal, environmental and job level, and help survivors navigate their disability and health care benefits, as well as other available benefits and resources such as second-opinion services and employee assistance plans. (P.19)
- 6. **Effective communication and monitoring:** Mitigate the possibility of misunderstanding with clear, regular and timely communication to survivors and their medical advisors. Provide high quality information and retain qualified expertise to develop policies and manage the scope and cost of accommodation. Negotiate a safe return to work in a constructive, ongoing and customized manner with the survivor. Monitor and adjust the accommodation plan as needed. (P.20)

Section 3 - Reputable Resources and Best Practice Models

It is clear that while much is known about best practices, the key is successful implementation, monitoring and updating. The ability to consistently use key foundational information, materials and resources and then tailor supports to individual circumstances appears to facilitate success. With this in mind, we have outlined below six best practice models that have been implemented or piloted in Canada, the United States and the United Kingdom.

Canada

Two Canadian programs are highlighted below based on their comprehensive information and promising outcomes for employers and workplaces.

- 1) Cancer and Work is collaboration between the McGill University and the BC Cancer Agency, survivors and experts across Canada. A new website was introduced in November 2016 that provides a comprehensive resource for survivors, health care providers and employers. It was funded by The Canadian Partnership Against Cancer (CPAC). The website currently includes 450 pages of content and six online assessment tools.
- 2) The <u>Cancer Journey Advisory Group</u>, supported by CPAC, completed three studies relevant to employers in 2012.
 - (1) A literature review, a survey of cancer survivors and caregivers, and focus group consultation investigated return to work (RTW) issues. Their findings included:
 - Most survivors experienced lower incomes after diagnosis. In this survey, those who
 continued to work indicated they needed the money. Most of those off work drew
 income support from short- and long-term disability plans and Employment
 Insurance. The delay between application and receiving money were common
 complaints.
 - Larger employers were much more likely to provide accommodations. Survivors
 sometimes reported difficulties interacting with managers and coworkers. A large
 majority experienced fatigue and cognitive issues after RTW. Nine in 10 caregivers
 reported missing work and reduced income, and many reported similar issues as
 survivors in stress, cognitive impairment and poor support from work colleagues.
 - Many resource gaps were identified, e.g., income support information, critical illness insurance, and disability insurance for the self-employed, and accommodation information for small employers. A working group of survivors, insurers, employers and cancer professionals was proposed to create cancer resources about accommodation and cancer side effects.
 - (2) An environment scan of RTW programs identified and reviewed 90 resources. Sixteen key informants were interviewed about 21 RTW programs.

- Most of the 90 RTW services implemented in Canada focused on mental health, and included programs, services, reports and booklets, guides and information sheets.
- Cancer-related best practices had not been evaluated. Across five countries and various diseases, most RTW material focused on disclosure, stigma, workplace and job accommodation, stress, communication practices and legal issues.
- There was limited focus on an employee's early needs after diagnosis, nor on how employees coped once they were back at work.
- The report recommended development and evaluation of RTW-focused pilot projects involving cancer patients, health professionals and employers.
- (3) Workplace supports were identified through 41 interviews with senior representatives from employers, insurers, law firms and unions. Three focus groups of 27 senior human resource managers were also conducted.
 - Many factors interact to impact employees when work is affected by a serious chronic disease like cancer. These include the employee's health and work responsibilities and desire to return to work, the employer's size, culture and resources, and the flexibility exhibited by managers and co-workers.
 - Employers generally expressed high support for affected employees and understood the employee's absence and return to work created significant financial pressures for both parties.
 - Employers wanted better communication related to their roles and responsibilities in accommodating chronic illnesses, as well as education, training and resources for managers and HR team members.
- 3) The following are examples of regional services that can assist survivors at work:
 - (1) The <u>BC Cancer Agency</u> (bccancer.bc.ca) offers a provincial vocational rehabilitation counsellor by appointment in Vancouver or by telephone for patients outside Vancouver. Services include return to work groups, job search groups and individual support. For information or to make an appointment, call 800-663-3333, ext. 672126.
 - (2) <u>Wellspring</u> (wellspring.ca) operates in southern Ontario as well as Calgary and Edmonton and offers more than 40 programs and services including guidance in areas such as financial management and workplace issues. Programs are offered at no cost.
 - (3) The Ottawa Regional Cancer Foundation (ottawacancer.ca) offers group coaching sessions for cancer survivors and family members. The Work and Cancer Survivorship program is offered several times through the year and covers emerging workplace research, legal issues, team dynamics, post-treatment symptoms and more. Fees are charged for all coaching programs.

United States

4) Workplace Transitions for People Touched by Cancer

This <u>program</u> was developed by Anthem, Inc., Cancer and Careers, Pfizer, SEDL (an affiliate of American Institutes for Research), and the U.S. Business Leadership Network (USBLN).

An eToolkit was developed for managers and human resources personnel and tested at six large US employers in 2015. Its purpose was to help cancer survivors stay at or return to work. The eToolkit built on existing company policies and procedures, and provided information and resources on topics such as privacy, disability, medical leave and insurance along with practical ideas for workplace adjustments and accommodations.

Almost 600 employees with a history of cancer completed a baseline and a follow-up survey five months later about quality of life and various work characteristics including accommodation. Managers were surveyed to assess eToolkit characteristics, including usability and acceptability.

The pilot study found that participants received the requested accommodation and found their work environments to be supportive. Quality of life increased and the likelihood of not receiving a requested accommodation decreased between the baseline and the follow-up surveys. However, the survey could not determine if these findings were attributable to the eToolkit itself. Satisfaction with the eToolkit was very high among the managers who participated in this study.

5) Cancer Continuum of Care: Employer Strategies for Managing the Modern Disease

The <u>National Business Group on Health</u> (NBGH) reported on a full range of workplace issues that a cancer diagnosis brings, and developed a workplace model (below) for cancer management. While aimed at US employers, many of the resources, including the model below, may be useful in Canada, or could be adapted relatively easily.



Source: NBGH. See: https://www.businessgrouphealth.org/cancer/.

6) Managing Cancer at Work was developed by Johns Hopkins Medicine in Baltimore, MD and BlueRush Digital Media in Canada. This new workplace cancer program includes an optional consult with a Nurse Navigator. A 12-month pilot program in the US was recently completed for employees of Johns Hopkins Medicine and Pitney Bowes (Jinnett, Bradley and Shockney, 2015).

During the pilot, it was reported that more than 90% of Johns Hopkins' employees using the program worked while being treated.

United Kingdom

7) Macmillan Cancer Support: Macmillan at Work

Macmillan is a UK charity that provides advice, information and resources to support cancer patients and caregivers. <u>Macmillan at Work</u> provides employers with training, consulting services, information and support, and various resources including an e-newsletter and cancer toolkit.

Section 4 - Guiding Principles and Recommended Practices for Workplace Cancer Management

These Guiding Principles and Recommended Practices have been developed by the authors to identify practical ways for all workplace health stakeholders to better address cancer. Our recommendations reflect the research summarized in this paper, stakeholder insights, and the authors' own experience.

1. Health Benefits

a. Coverage: Cancer treatments are covered based on clinical and economic value, using consistent standards of evidence.

b. Facilitate access:

- Connect and explain the resources available through drug, paramedical, EAP benefits and other resources.
- Remove barriers to access for medically appropriate treatments. With informed consent, direct individuals to targeted resources.
- c. Proven cancer prevention and management techniques such as screening or targeted educational programs are an integral part of benefits and health plan design. Incentives are provided where appropriate.
- d. Considering employee incomes, reasonable out-of-pocket thresholds are established such that cost is not a barrier for patients to obtain needed medications.
- e. Specialty Pharmacy Patient Support
 - o Provide programs and case management resources.
 - Proactively monitor patient adherence and side effects.
 - Provide information on programs that can assist patients with the costs of prescription drugs.
 - Ensure that program staff have oncology--specific knowledge in order to coordinate with other resources as part of a comprehensive cancer solution.
 - o With appropriate consent, enable caregivers to interface on a patient's behalf.
- f. Identify and manage co-morbidities, both physical and mental.
- g. Engage physicians: Make relevant plan information available at time of prescribing, including prior authorization criteria.

2. Disability

- a. Provide adequate sick leave and disability benefits to avoid employees returning to work prematurely. Protect access to health benefits, seniority, etc.
- b. Adopt cancer-specific protocols, based on clinically validated information and guidelines. Train disability case managers to actively manage cancer cases.
- c. STD/LTD protocol should include routine operational coordination with the EAP provider.

- d. When employee behavioral issues or difficulties in learning, problem-solving and decision-making arise that affect treatment compliance, consult psychologists, social workers, behavioural health specialists or health coaches.
- e. Establish flexible accommodations to stay at work or return to work.
 - Open discussions and negotiations with survivors as early as possible to build trust and establish needs of both parties.
 - Ask cancer survivors to complete a validated test of work ability, including
 physical demands and cognitive functions. Consider changes to work role and
 work environment to accommodate reduced capacity to work.
 - Develop and monitor the accommodation plan; revise as needed.
 - Ensure access to work assessment and vocational and physical rehabilitation.
 Results should be appropriately shared between survivor, employer and health professionals.
 - Assess patient-level factors: personal expectation of recovery and perceptions of work ability and self-efficacy.
- f. Provide Partial Disability benefit to allow for intermittent employee ability to work during cancer treatment and recovery.

3. Measurement

- a. Establish a baseline of overall cost and burden of cancer and other chronic diseases.
- b. Determine relevant goals and priorities for survivors and caregivers, and identify "best practices" in cancer program design.
- c. Link all cancer and related health costs and measures, and assess the broader impact on key human resource and organizational performance metrics.
- d. Evaluate policies, programs and practices at regular intervals.
- e. Consider interviewing survivors as a means to better understand the impact of cancer and how employers can improve their support and resources.
- f. Seek to demonstrate benefit beyond the workplace, e.g. evaluate impact of workplace cancer initiative on public health system utilization.

4. Psychosocial Support

- a. Workplace health strategy should incorporate cancer and typical co-morbidities into its approach to chronic disease management.
- b. Employee Assistance Plans should be available and, with informed consent, proactively deployed to help connect and support survivors on leave or at work, and family caregivers.
- c. Ensure clear, timely and appropriate communication to supervisors, co-workers and medical advisors about a cancer patient's or survivor's work intentions and needs.

- d. Target more work-related support and resources at those with the greatest needs and who are likely to return. Provide different support to employees with short-survival cancers.
- e. Keep employee connected to work when on leave.
- f. Provide training and support to managers and co-workers.

5. Caregivers

- a. Ensure caregivers are made aware of legislated leaves offered by the federal and provincial governments, including CPP and EI programs.
- b. For follow-up: Further study of the burden of cancer on caregivers is needed to create a stronger business case for caregiving as a priority for employers.

6. Policy

- a. Consider the financial, operational and cultural impacts of cancer and other relevant chronic diseases in human resource policy, programs and practices.
- b. Consider different needs of employees and family members diagnosed with cancer.
- c. While many cancers have lifestyle risk factors, ensure the work environment is appropriately protected from occupational hazards in compliance with all laws and regulations. Ensure that personal protective equipment is functional and readily available and that employees are properly trained.
- d. Implement a policy to support caregivers.
- e. Develop a policy on service provider performance criteria.

Section 5 – Links between Employer and Provincial Cancer Resources

Each province in Canada has a somewhat different cancer management model. There are provincial agencies in some but not all provinces. Agencies in BC and SK provide all cancer-related services and drugs. In other provinces, chemotherapy drugs are administered through hospital formularies. Regardless of model, all provinces provide access through specialized cancer centres to intravenous cancer drugs at no cost to patients. Ontario¹⁴ and all four Atlantic Canadian provinces do not cover orally-administered cancer drugs, leaving these to private insurance plans or personal expenditure.

For employers operating in more than one province this creates the same general challenge as integrating workplace drug and health benefit plans with provincial medicare systems.

Table 4 – Provincial Cancer System Components

Province	Ministry: Cancer Agency/Network/Centre –Program(s)
ВС	Ministry of Health: BC Cancer Agency
АВ	Alberta Health Services: CancerControl Alberta / Outpatient Cancer Drug Benefit Program
SK	Ministry of Health: Saskatchewan Cancer Agency
МВ	Manitoba Health: CancerCare Manitoba / Home Cancer Drug Program
ON	Ministry of Health and Long-Term Care: Cancer Care Ontario
QC	Ministère de la Santé et des Services sociaux: Direction québécoise de cancérologie
NB	Department of Health: New Brunswick Cancer Network
NS	Ministry of Health and Wellness: Cancer Care Nova Scotia / Drug Assistance for Cancer Patients / Palliative Care Drug Program
PEI	Ministry of Health and Wellness: PEI Cancer Treatment Centre
NL	Ministry of Health and Community Services: Eastern Health Cancer Care Program
Interprovincial	Canadian Association of Provincial Cancer Agencies (CAPCA)

Note: CAPCA provides links to all provincial members <u>here</u>.

In June 2016, the Canadian Cancer Society (Ontario) and CanCertainty organized a round-table discussion on the current state of access to orally administered ("take-home") cancer drugs (THCDs) and to identify collaborative opportunities to improve access to those products. Thirty-four people attended, including representatives of the Ontario Ministry of Health and Long-Term Care, Cancer Care Ontario, private insurers, patients, patient groups, employers, pharmacists, the pharmaceutical industry and oncologists. The report of that meeting is available here. The Report identified a number of issues and obstacles, including a lack of equity for patients, a difficult and sometimes lengthy

¹⁴ Ontario's Exceptional Access Program may cover certain oral cancer drugs not covered by the Public Drug Benefit formulary for a limited duration for those eligible for the Ontario Drug Benefit Program.

administrative process, increasing out-of-pocket costs and a lack of integration between provincial and private drug plans. Among the "Next Steps" in the report was a call to better coordinate benefits between Cancer Care Ontario, Ontario Public Drug Programs and private insurers, including the development of consistent, evidence-based approval process for THCDs.

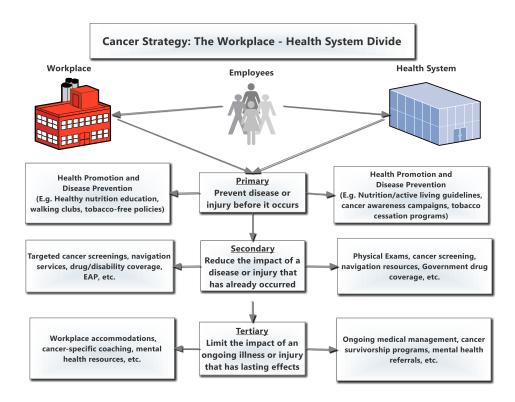
Since the June 2016 meeting and subsequent report, the Canadian Cancer Society and CanCertainty have continued to collaborate, attending meetings with senior-level staff at the Ministry of Health and Long Term Care and Cancer Care Ontario. Several issues are being discussed including access to THCDs, patient education, the Exceptional Access Program, and the Trillium Drug Program. Some progress is being made, however advocacy to improve the delivery and access to THCDs in Ontario will continue.

An important issue for employers is the sustainability of their drug programs. THCDs are very expensive – though often very effective – therapies with general coverage in just half the provinces. In the medium and long term, a workplace cancer model should promote a consistent and equitable approach to coverage for the most effective cancer drugs regardless of their form (IV or oral).

Beyond access to drugs, an effective cancer model focused on the whole person should accommodate patients and survivors who want to work with convenient treatment and ongoing appointments at hospitals and with physicians. This will include communication that helps cancer patients and survivors know their entitlements from governments and their employer. A patient-centred approach requires workplaces and health system resources¹⁵ to be aligned:

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¹⁵ For this illustration we have assumed public health is incorporated into the health care system.



There exist significant opportunities to enhance outcomes and better manage overall costs by coordinating cancer resources to support the physical and mental health of the "whole patient." This merits further exploration in Phase 2.

Appendix 1 – Stakeholder Interview Summary

Part of our information was through interviews with an employer, an insurer, two benefit/health strategies consultants, a caregiver representative and a union representative. The questions and aggregated responses appear below and themes arising from the interviews have been included in the report. The bulleted comments are paraphrases or quotations from the participants and have not been fact-checked or challenged by the authors of this paper.

- 1. To what extent do you feel cancer is an issue for workplaces in general? For your organization/your clients' organizations specifically? In scope and importance, how would you compare the impact on both employees and employers of cancer to other diseases in the workplace?
 - Benefits/Health Consultant and employer: Growing awareness of cancer as a significant issue both for patients and caregivers, mostly due to drug and disability cost. However, there is still a sense that "we can't do much about cancer".
 - Cancer also a big issue since many cancers develop in part/in whole due to widespread exposure to workplace toxins (e.g. asbestos, agent orange)
 - Lack of compensation and support for victims coming more to light now.
 - Root causes of cancer often overlooked, e.g. employee exposed to asbestos but cancer blamed on smoking.
 - 11% of Canadian caregivers are dealing with cancer, according to The Canadian Caregiver Network.
 - Some early movement in Canada but not moving as quickly as other countries in providing policy and resource support for caregiving (from Deloitte).
 - o BIG increase in workplace issues for caregivers.
- 2. Do you think patients are well equipped How familiar are they with their health benefit plan coverage or other available employer services? How could this be improved?
 - Benefits/Health consultant: Not well equipped to navigate the health care system when faced with cancer? Big gaps are lack of psychosocial support and lack of effective patientlevel communication on various steps in the cancer journey – tests, results.
 - Important to promote/facilitate access to existing resources and develop new ones –
 most likely best done via insurers (since several touchpoints, e.g. drug, disability, etc.) but
 HR needs to be supportive and proactively encourage insurers to do this.
 - Caregiver: Need for patient advocates to help ask questions of health practitioners, navigate resources and programs (both public and private).
 - Big issue with caregivers in dealing with the health system:
 - Not knowing where to go or how to access the resource(s).

- Caregivers still often encounter roadblocks in dealing with health professionals. The system is still largely geared to patients and health professionals often refuse to talk to caregiver even when patient has expressed consent/desire to do so.
- 3. What are the main challenges you/your clients are facing in managing cancer? Please specify how this is impacting your/your clients' organizations.
 - Union: Big issue is lack of willingness/ability to accommodate employees who want to work during treatment.
 - Not much in the way of cancer-specific information/ resources from insurers (a little when
 a disability or drug claim but not otherwise); however, insurers are getting a better handle
 on mental health and have some resources in place. It was suggested that cancer could
 be better linked to these resources.
 - Caregiving is an issue but awareness by employers is only beginning to emerge. Caregiver comment: "Much discussion with clients but not much movement yet in employer policy/protocols."
 - o Big issue: barriers to working when employees are on STD/LTD.
 - More evidence of both presenteeism and absenteeism by caregivers. Caregiving burden often involves stress, often leading to more significant mental health issues.
 - Lack of defined support for caregivers may exacerbate this.
 - In some organizations, caregiving is not "valued" and caregivers can have issues (e.g. with co-workers, supervisors) when they take time for caregiving. This happens even when organizational policies are in place.
- 4. Do you/your clients have policies or resources in place to manage cancer and/or chronic diseases? Are you considering implementing any (more) in the next 2 to 3 years? Please describe these.
 - Benefits/Health Consultant and employer: Few employers have any cancer-specific policies, or for that matter policies relating to chronic disease. They rely on insurer for return to work strategy.
 - o Issue with lack of "partial disability" benefits for cancer STD/LTD claims. Some niche players have this (RBC) but most large carriers don't.
 - "Disability practices often seem more about managing paper than managing people."
 - Union: Accommodation Committees set up to overcome "inherent employer reluctance to listen to the worker." Mostly though, they work very well and are able to align employee accommodation needs and employer needs.
 - Employee ability to work during treatment is often noted; however, without partial disability clause, LTD plans often cannot handle intermittent employee ability to work.
 - o Union: Has never seen a resource designed to help managers cope with worker cancer.

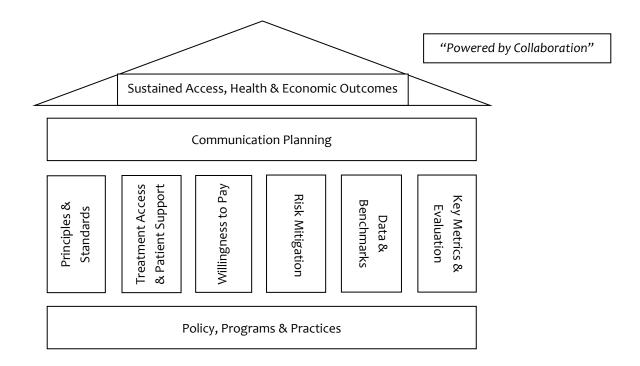
- o Psychosocial support through EAP only. Nothing specific to cancer.
- 5. As you know, many new drug treatments are coming to market to address various cancers. These drugs are highly effective and can enable an employee to work and be productive; however, these drugs are expensive.
 - a. How concerned are you about the cost and affordability of new cancer medicines in private plans?
 - Cancer costs not that big an issue yet larger issue is drug cost overall but concern beginning to emerge due to more cancer in plan spending.
 - Benefits/Heath Consultant: "There's more acceptance of cancer drugs." Perceived by some as a one-time claim; "More tolerance for cancer than for many other conditions."
 - Caregiver: "Pharmacists spend more time dispensing drugs with caregivers than with patients".
 - o Very concerned about drug costs, access and affordability.
 - o Confusion about oral vs infused and who pays.
 - Need more info about available treatment options, and options for financial support including clinical trial possibilities.
 - Also need more info on non-financial patient support programs.
 - b. Immuno-oncology represents a new dimension in cancer therapy in that these therapies use the natural capability of the patient's own immune system to fight cancer. These drugs are often more effective but are very expensive and they may not be covered by your province or an employer plan. Do you feel that private plans have a role to play in providing coverage for these drugs? Public plans? Both?
 - Not specific to immuno-oncology but Issue with insufficient support from health system for rare diseases in general.
 - Ultimately, there will need to be a role for both public and private plans. Need better coordination between the two, especially for rare diseases –sees immuno-oncology in this light.
- 6. As you may know, cancer diagnoses can have important impacts on absence and short- and long-term disability plans. The threat of cancer can be very distracting at work, increasing presenteeism for patients and caregivers. Are you concerned about the cost of these plans?
 - Yes; there is a steady stream of employees on STD/LTD with cancer.

- 7. As a fatal and chronic disease, cancer is sometimes seen as "different." Do you feel cancer is a special condition that requires employers to have different or stand-alone management Can you suggest any important gaps in how cancer is currently managed? To what degree are [should] policies, resources and programs [be] linked or integrated to help employees with cancer or other serious health conditions?
 - o Need to emphasize cancer prevention more, e.g. better coverage of vaccines.
 - Need more policies that accommodate fatigue and provide flexibility, e.g., "chemo breaks" – short, intermittent absences based on employee's ability to work effectively.
 - It would be great if resources were more linked/integrated should be tied to the first instance that an employee comes forward. All resources should be marshalled through a central resource and should be worker-driven.
 - A gap is in the on and off issues affecting patients and caregivers. Often no ongoing tangible support unless there is a crisis.
 - Cancer generally entails some form of accommodation by employers. Often this is not
 effectively managed for patients, let alone caregivers! Important for employers and
 payers to recognize the burden on caregivers.

Appendix 2 – High-level Workplace Cancer Model

The following model has been developed independently by Smofsky Strategic Planning and H₃ Consulting to guide our investigation.

Key Factors to Improve Workplace Cancer Strategy©



References

- Business for Social Responsibility (BSR), 2013. A New CSR Frontier: Business and Population Health.
 Available at:
 https://www.bsr.org/reports/BSR A New CSR Frontier Business and Population Health.pdf
- Canadian Cancer Action Network and the Canadian Cancer Society, undated (2012). Five-year action
 plan to address the financial hardship of cancer in Canada. Available at:
 http://www.cancer.ca/en/get-involved/take-action/what-we-are-doing/financial-hardship-of-cancer-in-canada-mb/?region=mb.
- 3. Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2016. *Canadian Cancer Statistics* 2016. Toronto, ON: Canadian Cancer Society.
- 4. Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017. Canadian Cancer Statistics 2017. Toronto, ON: Canadian Cancer Society.
- 5. Canadian Institute for Health Information, 2017. *Unnecessary Care in Canada*. Available at: https://www.cihi.ca/sites/default/files/document/choosing-wisely-baseline-report-en-web.pdf.
- 6. de Boer AGEM, JHAM Verbeek, ER Spelton, ALJ Uitterhoeve, AC Ansink, TM de Reijke, M Kammeijer, MAG Sprangers, FJH van Dijk, 2008. Work ability and return-to-work in cancer patients. British Journal of Cancer 98: 1342-47.
- 7. Dewa CS, L Trojanowski, AJ Tamminga, J Ringash, M McQuestion, JS Hoch, 2016. Advice about work-related issues to peers and employers from head and neck cancer survivors. *PLoS ONE* 11(4): e0152944. doi:10.1371/journal.pone.0152944.
- 8. Dowling EC, N Chawla, LP Forsythe, J de Moor, T McNeel, HM Rozjabek, DU Ekwueme, KR Yabroff, 2013. Lost productivity and burden of illness of cancer survivors with and without other chronic conditions. *Cancer* 119(18): 3393-3401.
- 9. Krueger H, EN Andres, JM Koot, BD Reilly, 2016. The economic burden of cancers attributable to tobacco smoking, excess weight, alcohol use, and physical activity in Canada. *Current Oncology* 23(4): 241-49.
- 10. Hopkins RB, R Goeree, CJ Longo, 2010. Estimating the national wage loss from cancer in Canada. Current Oncology 7(2): 40-49.
- 11. Institute for Work & Health, 2014. Seven 'principles' for successful return to work. Available at: http://www.iwh.on.ca/seven-principles-for-rtw.
- 12. Integrated Business Institute, Cancer Presents Complex Work Challenges. Available at:

https://www.ibiweb.org/events/cancer-presents-complex-workplace-challenges

- 13. IQVIA, 2017. Global Oncology Trends 2017. Available at: https://www.iqvia.com/institute/reports/global-oncology-trends-2017-advances-complexity-and-cost.
- 14. Jeon S-H, 2014. The effects of cancer on employment and earnings of cancer survivors. Statistics Canada, Analytical Studies Branch Research Paper Series, Catalogue # 11F0019M No. 362.
- 15. Jinnett K, M Bradley, L Shockney, 2015. Cancer in the Workplace: Supporting Treatment for Positive Employee and Employer Results. Webinar presentation, November 30, 2015. Integrated Benefits Institute/Center for Workforce Health and Performance. Available at: http://www.tcwhp.org/cancer-workplace-supporting-treatment-positive-employee-and-employer-results.
- 16. Keefe JM, 2011. Supporting Caregivers and Caregiving in an Aging Canada. IRPP Study 23. Montreal: Institute for Research on Public Policy. Available at: http://irpp.org/wp-content/uploads/assets/research/faces-of-aging/supporting-caregivers-and-caregiving-in-an-aging-canada/IRPP-Study-no23.pdf.
- 17. Lero DS, N Spinks, J Fast, M Hilbrecht, D-G Tremblay, 2012. The Availability, Accessibility and Effectiveness of Workplace Supports for Canadian Caregivers. Available at:

 https://worklifecanada.ca/cms/resources/files/703/The_Availability_Accessibility_and_Effectiveness_of_Workplace_Supports_for_Canadian_Caregivers.pdf.
- 18. Macmillan Cancer Support Macmillan at Work. Available at:
 http://www.macmillan.org.uk/about-us/what-we-do/how-we-work/work-and-cancer/macmillan-at-work.
- 19. Manulife, 2018. Personal communication, J. Whitney, Group Benefits Product Manager. March 28, 2018.
- 20. Mehnert A, 2011. Employment and work-related issues in cancer survivors. *Critical Reviews in Oncology/Hematology* 77(2): 109-130.
- 21. Mehnert A, E Brähler, H Faller, M Härter, M Keller et al., 2014. Four-week prevalence of mental disorders in patients with cancer across major tumour entities. *Journal of Clinical Oncology* 32(31): 3540-46.
- 22. Nakash O, I Levav, S Aguilar-Gaxiola, J Alonso, LH Andrade, et al., 2014. Cormobidity of common mental disorders with cancer and their treatment gap: findings from World Mental Health Surveys. Psycho-Oncology 23: 40-51.

- 23. National Business Group on Health, Cancer Continuum of Care. Available at: https://www.businessgrouphealth.org/cancer/index.cfm
- 24. Nitkin P, M Parkinson, IZ Schultz, 2011. Cancer and work: A Canadian perspective. Canadian Association of Psychosocial Oncology. Available at: https://www.cancerandwork.ca/cancer-andwork-ca/cancer-andwork-ca/cancer-andwork-canadian-perspective/.
- 25. Nowrouzi B, N Lightfoot, K Cote, R Watson, 2009. Workplace support for employees with cancer. *Current Oncology* 16(5): 15-22.
- 26. Philip EJ, TV Merluzzi, Z Zhang, CA Heitzmann, 2013. Depression and cancer survivorship: importance of coping self-efficacy in post-treatment survivors. *Psycho-Oncology* 22: 987-994.
- 27. Public Health Agency of Canada, 2014. Economic Burden of Illness in Canada, 2005-2008. Available at: http://www.phac-aspc.gc.ca/publicat/ebic-femc/2005-2008/assets/pdf/ebic-femc-2005-2008-eng.pdf.
- 28. QuintilesIMS Institute, 2016. Outlook for Global Medicines through 2021. Available at: https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/global-outlook-for-medicines-through-2021.pdf?la=en&hash=6EA26BACA0F1D81EA93A74C50FF60214044C1DAB& =1516221079457.
- 29. Singer S, J Das-Munshi, E Brähler, 2010. Prevalence of mental health conditions in cancer patients in acute care a meta-analysis. *Annals of Oncology* 21: 925-930.
- 30. Singer S, C Szalai, S Briest, A Brown, A Dietz et al., 2013. Co-morbid mental health conditions in cancer patients at working age prevalence, risk profiles, and care uptake. *Psycho-Oncology* 22: 2291-97.
- 31. Stergiou-Kita M, A Grigorovich, V Tseung, E Milosovic, D Herbert, S Phan, J Jones, 2014. Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *Journal of Cancer Survivorship* 8: 657-70.
- 32. Stergiou-Kita M, C Pritlove, D van Eerd, L Holness, B Kirsh, A Duncan, J Jones, 2016. The provision of workplace accommodations following cancer: survivor, provider and employer perspectives. *Journal of Cancer Survivorship* 10: 489-504.
- 33. van Muijen P, NLEC Weevers, IAK Snels, SFA Dujits, DJ Bruinvels, AJM Schellart, AJ van der Beek, 2013. Predictors if return to work and employment in cancer survivors: a systematic review. European Journal of Cancer Care 22: 144-160.
- 34. Weiderpass E, 2010. Lifestyle and cancer risk. *Journal of Preventative Medicine and Public Health* 43(8): 459-71.

- 35. Wells M, B Williams, D Firnigl, H Lang, J Coyle, T Kroll, S MacGillivray, 2013. Supporting 'work-related goals' rather than 'return to work' after cancer? A systematic review and meta-synthesis of 25 qualitative studies. *Psycho-Oncology* 22: 1208-19.
- 36. Workplace Transitions for People Touched by Cancer, Pilot Study Report, 2015. Available at: http://www.journeyforward.org/sites/journeyforward/files/workplacetransitions_pilotstudyreport-final-1_0.pdf.
- 37. World Health Organization, 2010. Healthy workplaces: a model for action for employers, workers, policy-makers and practitioners. http://www.who.int/occupational_health/publications/healthy_workplaces_model.pdf
- 38. World Health Organization, 2016. Human Papillomavirus (HPV) and cervical cancer. Fact Sheet. Available at: http://www.who.int/mediacentre/factsheets/fs380/en/.