



Patient insights on Canadian cancer care: opportunities for improving efficiency

**Canadian and province-specific findings from
the international All.Can patient survey**



Changing cancer care together

The All.Can Canada initiative is made possible with financial support from Bristol-Myers Squibb (main sponsor), Merck, and Johnson & Johnson (sponsors)

About All.Can

All.Can is an international, multi-stakeholder policy initiative aiming to identify ways we can optimize the use of resources in cancer care to improve patient outcomes.

All.Can comprises of leading representatives from patient organisations, policymakers, healthcare professionals, research and industry, and consists of All.Can international, plus All.Can national initiatives currently established in 12 countries including Canada.

At the international level, the All.Can initiative is made possible with financial support from Bristol-Myers Squibb (main sponsor), Roche (major sponsor), Amgen, MSD and Johnson & Johnson (sponsors), and Baxter (contributor), with additional non-financial (in kind) support from Helspy, Intacare and Goings-On.

About All.Can Canada

In April 2018, Save Your Skin Foundation (SYSF), a national, patient-led, not-for-profit group dedicated to leading the fight against non-melanoma skin cancers, melanoma and ocular melanoma, was established as All.Can Canada's Secretariat to lead the initiative in Canada, bringing the methodology and best practices of the international group to be used in Canada to develop concrete tools and platforms to improve cancer care for patients.

SYSF convened a working group to discuss how best to bring All.Can into the Canadian healthcare space. The working group has completed a discovery phase that involved an environmental scan of literature on nation-wide and province-specific health care reports to identify the top reported areas of waste and inefficiency in cancer care. This data was then validated and prioritized through anonymous surveys with cancer care stakeholder groups including pharmaceutical industry representatives, patient representative groups, health care professionals, provincial policy makers, health-technology assessment bodies, and 300+ Canadian cancer patients, whose responses are presented in this report.

The inaugural multi-stakeholder roundtable meeting is planned for November 2019 to build consensus on priorities, develop strategies, and create a multi-year work plan to tackle these inefficiencies. An All.Can Canada steering committee will be assembled with representation from all stakeholder groups to support, guide and oversee the progress of the multi-year project.

Acknowledgements

This report was developed by All.Can Canada, using weighted survey data specific to the provinces of British Columbia, Alberta, Ontario and Quebec provided by Quality Health. We would like to thank the dedicated teams at Quality Health and Health Policy Partnership for their work in coordinating all aspects of this survey, and for their continued commitment to enriching the quality of the study and findings.

Table of Contents

<u>About All.Can</u>	2
<u>About All.Can Canada</u>	2
<u>Acknowledgements</u>	3
<u>About this survey</u>	5
<u>Executive summary</u>	8
All.Can patient survey: findings.....	10
Key opportunities to improve efficiency from the patient perspective:	
1. <u>Swift, accurate and appropriately delivered diagnosis</u>	12
2. <u>Information, support and shared decision-making</u>	18
3. <u>Integrated multidisciplinary care</u>	26
4. <u>The financial impact of cancer</u>	33
<u>Conclusions</u>	39
<u>References</u>	41

About this survey

Purpose:

The aim of the survey was to obtain patients' perspectives on where they felt they encountered inefficiency in their care, looking at the entire care continuum as well as the broader impact of cancer on their lives. The survey questionnaire made explicit that we defined inefficiency as resources that are not focused on what matters to patients.

Survey conduct and oversight:

The design and conduct of the survey was led by Quality Health (www.quality-health.co.uk), a specialist health and social care survey organization working with public, private and voluntary sector organisations to understand and improve patients' experience of their care and treatment. The All.Can international research and evidence working group provided close input and validation for all phases of the survey and analysis.

The survey was conducted internationally, with adapted versions in 10 countries (Australia, Belgium, Canada, France, Italy, Poland, Spain, Sweden, the United Kingdom and the United States). The data represented in this report is exclusively from respondents residing in Canada.

Survey development and patient interviews:

The questions included in the survey were developed based on key themes that emerged from an international literature review and five exploratory pre-survey patient interviews. Iterative versions of the survey were revised based on input from the All.Can international research and evidence working group and other professional stakeholders where appropriate.

The Canadian-specific version of the survey was produced in English and Canadian French and comprised both of common questions and a maximum of five questions specific to Canada. The survey was developed with input from the All.Can Canada initiative and validated by patient representatives in Canada. Additionally, an international 'generic' version of the survey was available in English, French, German and Spanish.

All versions of the survey were reviewed by the All.Can international research and evidence working group to ensure consistency between the different country versions.

Recruitment of respondents:

The survey was made available online, with only a few paper copies distributed where they were requested. Respondents were predominantly recruited via patient organisations and social media (Facebook, Twitter and LinkedIn).

The survey was open to current and former cancer patients, irrespective of age and cancer type. Caregivers and former caregivers were also invited to respond on behalf of those patients who were unable to respond personally or who had passed away. Because caregivers were asked to

complete the survey on behalf of patients, in this report, we use the term ‘respondents’ when describing the survey results to refer to both patients and caregivers who completed the survey. The Canadian survey ran from June to November 2018.

Respondent characteristics:

There were 314 valid responses to the Canadian survey, 255 of which stated they resided in one of the four provinces considered for analysis. The weighted, provincial data from these 255 respondents is what is presented in this report.

Respondent profile:

- Cancer type: breast 37%; haematological 13%; skin 11%; other (various cancer types, all <5%) 39%
- Gender: female 81%; male 19%
- Age: 0–24 = 1%; 25–64 = 61%; 65+ = 37%
- Language: English 87%; French 13%

Reporting of quantitative findings:

Quantitative findings from the survey are based on responses to the closed-ended questions in the survey. Percentages are calculated after excluding respondents who did not answer each particular question. All percentages are rounded to the nearest whole number, therefore the sum of percentages for all answers to a given question may not total 100%.

Results for Canadian provinces, specifically, British Columbia, Alberta, Ontario and Quebec are shown as percentage scores calculated by removing non-specific responses and applying a weighting factor to each remaining option. Due to the methodology applied and the bespoke nature of the questionnaire, the percentages are slightly different to the combined Canadian totals in the International weighted results and it is for this reason that the totals from the International weighted survey results have not been used for comparison in this report.

Please note it is the weighted, provincial data from 255 respondents residing in the provinces selected for analysis that is presented in this report.

Reporting of qualitative findings:

Qualitative findings presented in the report are based on responses to open-ended questions. A thematic analysis was conducted of all qualitative responses to the survey. Final themes were agreed by consensus of the All.Can international research and evidence working group and Quality Health. The most relevant and illustrative quotes from Canadian respondents supporting these themes were then selected to substantiate each section in the report.

Qualitative responses were not quantitatively analyzed due to the significant cost that translations and coding would have entailed on such a large sample. In addition, as not all respondents answered the open-ended questions, it would not be possible to give an accurate estimation of what proportion of all respondents might agree with each comment. Therefore, we have expressed these findings throughout the report as ‘respondents’ in the plural – without quantifying how many this concerned in each instance.

Report structure:

The report is organized into four themes that emerged from our findings. These themes closely mirror the closed-ended questions in the survey, which focused on specific areas known from previous research to be important to patient care. However, open-ended free-text questions allowed respondents to mention other areas of importance to them. As these responses were captured in the thematic analysis described above, they also contributed to our selection of the four themes highlighted in this report.

Limitations:

Respondents participated in the survey voluntarily, therefore they are self-selected and represent the perspectives of patients who wanted to have their voices heard and were able to complete the survey. They do not necessarily reflect the perspectives of all cancer patients. As the survey was primarily distributed online, it was limited to those who had access to the internet, were active on social media, or connected with a patient organization that shared the survey. The survey was focused on patient experiences and process of care and therefore did not include any questions regarding specific treatments or interventions. Finally, it is important to mention that this report is focused on reporting the findings of the survey, and as such, we have not conducted an in-depth analysis of what improvements in health outcomes and overall efficiency of care could be achieved if the issues highlighted in this report were adequately addressed. All.Can is committed to exploring these questions further and it is our hope that this report may also encourage others within the research and policy community to do the same.

The survey questionnaires and full methodology may be found on the All.Can website (www.all-can.org/what-we-do/research/patient-survey/about-the-survey/) along with other survey materials not included in this report.

Executive Summary

The past decade has seen transformational advances in cancer care. As the prevalence of cancer increases, governments and health systems around the world are struggling to fund these advances – and notions of value, efficiency and affordability have become increasingly important in the cancer policy debate. Within this landscape, leading researchers and policy experts are trying to identify where inefficiencies lie, in order to pave the way for sustainable cancer care. ¹⁻³

Burden of cancer in Canada

Cancer is the leading cause of death in Canada – responsible for 30% of all deaths.

One in every two Canadians is expected to develop cancer during their lifetime, and one in four Canadians will die from cancer.

In 2015, 2.1 million people in Canada (aged 12 and over) reported living with and beyond cancer. ⁴

The prevalence, complexity and costs of cancer are rising in Canada. The economic burden of cancer care on all payers in Canada is substantial. The cost of cancer care in Canada has risen steadily from \$2.9 billion in 2005 to \$7.5 billion in 2012, mostly owing to the increase in costs of hospital-based care. ⁵ With the growing burden of cancer, and the resultant financial pressures on our healthcare systems, there is an urgent need to improve efficiencies and reduce waste in cancer care in Canada. Moreover, removing wasteful or ineffective interventions could lead to a gain of approximately two years of life expectancy in industrialized countries.⁶ Improving efficiency is not a question of linear cost-cutting, but of finding ways to allocate resources more efficiently to achieve better health outcomes for patients. There is thus an urgent need to ensure that cancer care is delivered as efficiently as possible for the sustainability of our healthcare systems.

Unfortunately, the patient perspective is too often forgotten in current definitions of value and efficiency.⁷ Existing definitions are most often driven by health economists and healthcare professionals, with outcomes measures often based on processes that are easily measurable within healthcare systems, rather than on outcomes known to matter to patients. ⁷⁻⁸ Yet patients are, arguably, the only people who have full sight of the impact of their condition and care experience on their physical, emotional and mental wellbeing. Their perspectives must, therefore, be built into any definitions of value and efficiency.

All.Can defines inefficiency as the allocation of resources to anything that does not focus on what matters to patients.⁹ Our aim is to find sustainable solutions to improving cancer care. To guide these efforts, we need to gain a better understanding of where patients perceive their care is not focused on what matters to them – and find practical ways to remedy any gaps.

The All.Can patient survey was designed with this purpose in mind: we asked patients where they had encountered inefficiencies in their care, and where efforts were most needed to improve efficiency. We made our definition of inefficiency explicit throughout the survey.

This report presents the four main themes that have emerged from our findings. While many respondents reported that their needs were sufficiently addressed, the findings also show that there is clear room for improvement. Each of the themes represents an opportunity for improving cancer care from the perspective of patients

Over 342 Canadian respondents participated in the survey from June–November 2018 resulting in 314 valid responses used in this report. This population has been broken down further to the top four participating provinces with sample sizes large enough for analysis: Alberta, British Columbia, Ontario and Quebec.

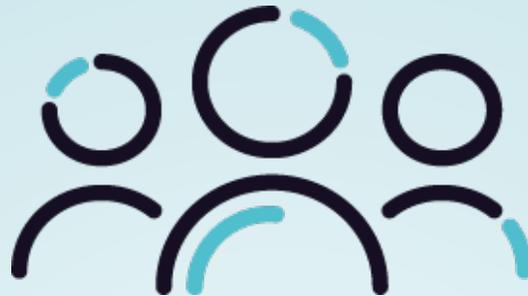
It is our hope that the insights gathered in this report may help guide patient-driven policies to improve the efficiency and sustainability of cancer care.



All.Can Canada Patient Survey: Findings

**Patient insights on Canadian cancer care:
opportunities for improving efficiency**

Key Opportunities to improve efficiency from the patient perspective



1

Ensure swift, accurate and appropriately delivered diagnosis

2

Improve information, support and shared decision-making

3

Make integrated multidisciplinary care a reality for all patients

4

Address the financial impact of cancer



Swift, accurate and appropriately delivered diagnosis

Key findings

- Diagnosis was the top area where respondents reported the greatest inefficiency throughout their cancer care and treatment (30%).
- The way diagnosis is communicated was found to be important. Respondents report a lack of empathy from physicians and poor timing - such as being told they had cancer with a family member present, or having to wait several days to speak to a specialist.
- Two thirds (67%) were not diagnosed as part of any screening program.
- Among respondents whose cancer was detected outside of screening:
 - One in four respondents (27%) said that their cancer was diagnosed as something different – either initially or on multiple occasions.
 - One in seven respondents (14%) had to wait for more than a year to be diagnosed with cancer.

Overview of findings

Diagnosis was the top area where respondents reported the greatest inefficiency (30% of Canadian respondents).

Overall, 22% of respondents were diagnosed as part of a routine cancer screening program.

For those diagnosed outside of a screening program, after first seeing a doctor about the health problem caused by their cancer, half of respondents (43%) said their cancer was accurately diagnosed within a month, a third (34%) said they waited 3 months or longer. Of these, 14% said they waited more than a year for their cancer to be accurately diagnosed.

During the whole of your cancer care and treatment, where do you feel there was most inefficiency?

- 30% my initial diagnosis
- 22% dealing with the ongoing side effects
- 12% getting the right treatment for my cancer
- 11% dealing with the psychological impacts
- 8% access to patient support groups
- 7% dealing with the financial implications
- 4% the opportunity to take part in clinical trials
- 7% other

Provincial analysis

During the whole of your cancer care and treatment, where do you feel there was most inefficiency?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
My initial cancer diagnosis	30%	34%	26%	37%	17%
Getting the right treatment for my cancer	12%	6%	1%	24%	1%
Dealing with ongoing side effects	22%	11%	10%	14%	50%
Dealing with the financial implications	7%	6%	20%	4%	6%
Dealing with the psychological impacts	11%	18%	18%	9%	6%
Access to patient support groups	8%	5%	7%	6%	13%
The opportunity to take part in clinical trials	4%	5%	10%	1%	4%
Other	7%	16%	8%	6%	4%

Over a third of respondents from Alberta (34%) and Ontario (37%) felt their initial diagnosis was the most inefficient part of their cancer care and treatment, compared to only 17% respondents from Quebec.

A half of respondents from Quebec (50%) felt dealing with ongoing side effects was the most inefficient part of their cancer care and treatment, compared to 14% or fewer respondents from other provinces.

Two in five respondents from British Columbia (20%) felt dealing with financial implications was the most inefficient part of their cancer care, compared to 6% or fewer respondents in other provinces.

A quarter of respondents from Ontario (24%) felt getting the right treatment for their specific cancer was the most inefficient part of their care and treatment, compared to 6% or fewer respondents in other provinces.

The way diagnosis was communicated was very important to respondents.

A theme that emerged from qualitative responses was that respondents sometimes felt that their instincts were not listened to by doctors – even when they themselves thought their symptoms may be related to cancer. This was mentioned particularly by younger respondents.



“Exact diagnosis with details would have been helpful. I was given a low-grade ovarian diagnosis at 30 and was told it will not return. It’s been 11yrs and I have had 4 surgeries, chemo two different times for 18 week each and more surgery to come. With no more options. I should have had a surgical oncologist from the beginning. I had only General surgeons.”



“I recognized my melanoma developing by myself. Luckily my mother had a dermatologist she saw regularly so I was able to get in quickly to be seen. However, I had to beg for my biopsy because this doctor thought my mole was fine, when it was clearly textbook melanoma. That was the scary part. She never would have biopsied it if I hadn't insisted.”

In qualitative responses, respondents often reported a lack of attention and empathy in how doctors communicated the news of their diagnosis. Respondents said they would have liked more time to discuss things and digest information.



“I felt that the oncologist didn’t care enough or was too busy but he was not friendly either.”



“My GP just told me he would be surprised if I didn’t have leukaemia as he looked at a blood test done for another issue... What was I supposed to do with that information?”



“I felt that the diagnosis could have been handled in a more human aspect. The Dr and nurse in the room were pretty desensitized and didn’t take my feelings into consideration with delivering my diagnosis.”



“I was told very matter of factly that the chest x-ray showed a tumour on my lung. She was cold and distant. I asked if it was cancer and she said I needed a biopsy, but probably was, given I was a smoker. I began to cry. She became upset with me and told me that my crying upset her and that she “had to bring it home to her family” and walked out of the room.”

Respondents also expressed concern that information was sometimes withheld from them – including the fact that they had cancer. There were comments indicating that the different steps in their diagnosis were not explained enough, or in an understandable way.



"My family doctor knew but didn't tell me... she left it to the doctor in charge of the breast cancer screening clinic! No one called me and I'm of the age "no news is good news" and finally I had to make an appointment to see the doctor. Really!!!! I honestly think they should have called me and told me to come in right away!"

The timing of delivering the diagnosis is also key. Respondents commented that doctors should make sure people are not alone when receiving their diagnosis and are given a point of contact for any questions that will inevitably arise after they recover from the initial shock.



"I was told over the phone that it was melanoma and I was being booked with a surgeon, but wasn't given any other information, so it was extremely stressful."



"They didn't give me a lot of time explaining. I could have used more or at least been given a place to find info, a pamphlet, website."

Wait times

Of those diagnosed outside of a screening program, nearly half of respondents (43%) said their cancer was accurately diagnosed within a month, a third (34%) said they waited 3 months or longer. Of these, 14% said they waited more than a year for their cancer to be accurately diagnosed.

Provincial insights

After first seeing a doctor about the health problem caused by your cancer, how long did it take to be diagnosed with cancer?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Less than a month	43%	35%	75%	48%	20%
1 to 3 months	23%	38%	11%	24%	22%
3 to 6 months	15%	21%	4%	6%	32%
6 months to a year	5%	3%	5%	6%	5%
More than a year	14%	3%	4%	16%	21%

Wait times for accurate diagnoses were longest with Quebec residents. Over half of respondents (58%) waited 3 months or longer, including 21% who waited for more than a year.

Wait times for diagnosis were lowest in British Columbia, with 75% of residents reporting they waited for less than a month for an accurate diagnosis.



What we know

Late diagnosis and misdiagnosis are common in many cancers and can lead to delays in treatment or limited treatment options, poorer outcomes, lower likelihood of survival and higher costs of care.^{9 11}

Diagnosis may be delayed for various reasons, including patient-related factors (e.g. lack of awareness of symptoms) and system-related factors, including availability of specialists, speed of referral, fast access to imaging, pathology capacity and other factors. The complexity of the process of clinical evaluation, diagnosis and staging may also vary by cancer type.¹¹

Early diagnosis is not equally feasible for all cancer types. Cancers that have clear signs and symptoms and effective treatments (e.g. breast cancer) tend to benefit most from early diagnosis.¹¹

For some cancers (e.g. colorectal), early diagnosis – before symptoms start to show – is crucial to allow time for effective treatment options. This emphasizes the importance of screening for early detection.



Why it matters

For many cancers, early diagnosis can improve survival¹⁰ – for example, a breast cancer study showed that patients who experienced short delays in diagnosis (under 3 months) had 7% better overall survival compared with those who had longer delays (3–6 months).^{11 12}

Early diagnosis is associated with reduced treatment costs – the cost of treating colon, rectal, breast, ovarian and lung cancer at stage IV has been reported as 2–3 times the cost of treating these cancers at stage I.¹³



Information, support and shared decision-making

Key findings

- Half (49%) of respondents felt they were not given adequate information about their cancer care and treatment in a way they could understand.
- Over half respondents (53%) felt they had inadequate support to deal with ongoing symptoms and side effects.
- Nearly half of respondents (47%) felt inadequately informed about how to recognize whether their cancer might be returning or getting worse.

Overview of findings

Respondents often felt overwhelmed by the information they received.

In qualitative responses, **respondents said that they felt overwhelmed because too much information was given at once**, and they would have preferred to receive relevant information at appropriate points along the entire care pathway.



"Better by giving the information at the right time. Not immediately upon receiving "the bad news". Maybe a little then and a little later on. Like having someone come to your house which is a quiet setting and explain what cancer is and what this type of cancer means to you. Also resources that you could get into and how to get to them."

Respondents also spoke of a disconnect between the language used by their doctors and what they could understand. They often did not know where to begin or what to ask, as the experience of cancer was new to them.



"The disconnect between the language my haematologist uses and common language has been frustrating."



"I accompanied my mother to all of her treatments and appointments. Information was given to us in a way that I could usually understand, but my mother often did not. I was able to explain it to her."

There were also comments that the information provided was not always tailored to the patient's individual experience or stage of treatment.



"I felt I received too much information. Lots of pamphlets! Some of the information was not relevant to my situation. I felt overwhelmed by trying to find information only relevant to my cancer in the giant stack of pamphlets. To go through all the information was beyond what I was up for, so most of it remained unread."



What we know

Information needs vary from one patient to another and are influenced by many factors.¹⁴ They also change along the care pathway.¹⁵

Many studies show that patients often do not fully comprehend what their diagnosis, prognosis and treatment mean. This can be due to them not fully understanding the terminology used, not receiving all relevant information or not being able to recall what they have been told during medical appointments.^{15 17 18 19}



Why it matters

Part of quality healthcare delivery is understanding what patients want to know and providing that information at the right time in an understandable way.^{20 21}

Information can help patients feel in control of their disease, reduce anxiety, create realistic expectations, and promote self-care and engagement in their care.^{15 16}

Fulfilling patients' needs for information is also associated with improved treatment adherence^{14 22 23} and better clinical outcomes.^{15 23}

Provincial insights

Have you always been given enough information about your cancer care and treatment, in a way that you could understand?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Yes	51%	65%	68%	51%	34%
No. I was given information, but could not understand it all	21%	7%	19%	36%	4%
No. I was not given enough information	28%	29%	13%	13%	61%

A lack of information about cancer care and treatment that patients could understand was highest among respondents from Quebec with two thirds (65%) reporting they were **not given adequate information** in a way that they could understand.

Respondents needed more information and better guidance on how to deal with ongoing side effects – especially after treatment was over.

Dealing with ongoing side effects was perceived as a major source of inefficiency, with 22% of respondents saying it was the greatest source of inefficiency in their care. This was the second highest-reported area of inefficiency overall, after diagnosis (30%).

Over half of respondents (53%) did not feel they had been given sufficient support to deal with ongoing symptoms and side effects.



“I was given a much rosier expectation of my quality of life and side effects than the reality I have experienced (and continue to experience). And through the support group I have joined, I am actually luckier than many! Also, most of the additional support I have accessed I had to find myself.”

Provincial insights

Do you feel you have always been given enough support to deal with any ongoing symptoms and side effects, even beyond the phase of ‘active’ treatment (if applicable)?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Yes, always	18%	18%	17%	24%	10%
Yes, most of the time	28%	15%	41%	31%	23%
Yes, some of the time	40%	35%	33%	32%	62%
No, never	13%	32%	9%	13%	5%

A reported lack of support to deal with ongoing symptoms and side effects was highest in respondents from Alberta and Quebec where two thirds of respondents (66% in Alberta and 67% in Quebec) felt they had only sometimes received support, or not at all.



What we know

Evidence shows that cancer patients and/or survivors have high unmet needs, particularly at the end of their treatment. In particular, patients may be left to deal with consequences of treatment that could have been managed or avoided altogether.^{24 25}

Long-term consequences and effects of having cancer and its treatment can include physical effects, chronic fatigue, sexual difficulties, mental health issues and pain.

Problems can persist for up to 10 years after treatment, or even longer, and may lead to social isolation and financial difficulties due to disruption to work.²⁶



Why it matters

Without adequate assessment of patient needs – both during and after active treatment – suboptimal service use (overuse or underuse) may occur. This can have a negative impact on patient outcomes and costs incurred for healthcare systems.²⁷

More individualized approaches to follow-up versus a one-size-fits-all approach may have benefits as well – for example, by supporting patients in self-managing their condition, it is projected that two outpatient appointments per patient per year could be saved.²⁵

Most importantly, patients' wellbeing will be greater if they get support that is relevant to their needs and promotes healthy lifestyles and independence.²⁵

Respondents were not always given adequate information about pain management and palliative care.

In the qualitative comments, respondents suggested that their worries or the pain they experienced were sometimes dismissed.



"My cancer doctor and my family doctor dismiss my pain from stage 4 breast cancer, which was spread to my bones (hip/pelvis)."



"I have significant bone pain that comes and goes. Just gave me narcotics. Never followed up with me. Never offered alternative methods."



What we know

Many cancer patients experience unnecessary pain. Studies suggest that one in three cancer patients don't receive pain medication appropriate to their pain level.²⁸

Palliative care is often assumed to be solely focused on end-of-life care – but, in fact, it is much broader. The World Health Organization defines it as an approach that improves quality of life for people (and their families) with life-threatening illnesses – including pain relief and psychosocial support.²⁹

Guidelines recommend that the need for palliative care should be built into treatment plans early in the course of illness, in conjunction with therapies that are intended to prolong life, such as chemotherapy or surgery.^{29 30}



Why it matters

Early integration of palliative care can lead to improved symptom control and reduced distress through treatment and care delivery that matches patients' preferences – and, overall, improved patient outcomes, quality of life and survival.^{31 32 33}

It can also significantly improve patients' understanding of prognosis over time, which may impact treatment decisions about end-of-life care and lead to less aggressive treatment.^{33 34}

Respondents often lacked information about how to tell whether their cancer might be coming back.

Another important information gap frequently expressed in qualitative comments was how to deal with possible signs and symptoms that cancer might be recurring. This led to significant fears for respondents, not knowing whether a symptom they experienced was harmless or a cause for greater concern.



"What to expect, health wise, after all treatment is done. Example, how mentally to cope with fear of cancer returning."

Provincial insights

Have you always been given enough information, in a way that you could understand, about signs and symptoms to look out for that your cancer might be returning/ getting worse?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Yes	53%	46%	62%	43%	67%
No. I was given information, but could not understand it all	12%	11%	11%	20%	1%
No. I was not given enough information	35%	42%	27%	37%	32%

Two thirds of respondents from Quebec (67%) felt they had been given adequate information about how to recognize whether their cancer might be returning or getting worse, while less than half of respondents from Ontario and Alberta felt the same.



What we know

Studies have shown that patients' information needs are often highest, and least well met, during the phase following active treatment.²³ An effective handover from secondary care to primary care, with regular and timely follow-up, is therefore necessary for all patients.²⁷



Why it matters

Without appropriate follow-up after discharge, patients can feel lost or abandoned, and ill prepared to manage their condition, after weeks of intensive treatment and frequent interactions with their care team.³⁵

Respondents were not always given information about available patient groups or peer support.

In addition to information and support they may have received from their care team, respondents expressed the value of being able to speak to people who had been through a cancer diagnosis themselves.



"I found Bladder Cancer Canada on my own and they have been very supportive. At no time did my doctor refer me to them even though he is on their board of directors."



"I was told to call the Cancer Society and they would connect me with someone. However I found much more useful support and accessible support through Facebook online groups. It was through one of those groups that I was given access to this survey."



Why it matters

Even with the support of family and friends, many people who have cancer find it helpful and comforting to talk with others that have already gone through the experience first-hand, to discuss all aspects of how to deal with cancer and its impact on life. Patient organisations often help provide this peer support to patients. They can fill important gaps in patients' needs, providing emotional support and financial advice, as well as valuable information about treatment options and available services.³⁶

Not all healthcare professionals may feel comfortable or able to distribute patient support-group information. This presents a missed opportunity as doctors often are usually the main source of information connecting patients to support groups.³⁷



3 Integrated Multidisciplinary Care

Key findings

- Over half of respondents (59%) felt they did not have adequate access to other health care professions, ie. dietitians, physiotherapists, or mental health services when they needed it.
- Respondents wanted more information about what they could do to support their treatment and recovery in terms of diet, exercise and complementary therapies.
- 61% reported that they needed some form of psychological support during/after their cancer care but, of those, 35% said it was not available.
- Many respondents expressed concern for the impact their cancer had on their families, and wanted psychological support for them as well.

Overview of findings

Respondents often reported a lack of communication between their primary care physician and specialists – particularly in countries with a primary-care-led model like Canada. Respondents reported the impact of this lack of communication from diagnosis onwards – and again after they had left the hospital setting and were in the follow-up stage of care in the community setting.



“I live in a rural community and I was expected to get to my out-of-province surgery without any help. Was not told my hospital stay would be more than a month. After being discharged I was promised home care was set up, it was not. I had to go to a local clinic and ask for help with ongoing wound care. There needs to be a plan made for each cancer patient, so a person doesn't have to explain to each healthcare person what is going on and why the cancer patient needs help.”



“There needs to be more communication between healthcare providers... don't tell the patient to ask the surgeon, who then refers you back to your doctor, and this keeps going on and on.”



“Well it would of been nice to not have “lost” in the system after having my breast removed. Six months after my surgery, I had to call the hospital that I had the surgery in to be told I must be mistaken because we don't have you in the system. Good thing I kept all my papers and patient # for them to “find” me again.”

Access to supportive health professionals (ex. dieticians, physiotherapists, or mental health services) was often perceived as inadequate by respondents.

One in six (14%) of respondents said they did not have any access to supportive health professionals, while nearly half (45%) said they only had access sometimes. In qualitative findings, respondents commented that they would have liked to be told what role these different professionals or services could play in aiding their recovery.



“I had no idea after my surgery what I could do next. Could I exercise, if so what were my limitations etc.? I had severe anxiety and was not offered any type of help in this regard. I was so scared and had no direction whatsoever.”



“I should have been sent to endocrinologist for hair loss, vitamin deficiencies instead of waiting for this to happen.”

In addition, respondents reported that they were not always provided with enough information about how they could optimize their care through diet, exercise, mindfulness and complementary therapies. In many countries, respondents had to pay out-of-pocket for these services.



“I developed lymphedema in my breast, but was told no it wasn't so for weeks I struggled with a very swollen red and painful breast... then finally I asked my private physio if she had any ideas. Lo and behold she sent me to have a Lymph massage. This helped so much and 10 years on I'm still having private lymph massage about every 5-6 weeks, which of course is not covered by private or Medicare. I hate to think how much I've spent over the last 10 years. It would appear that unless you have leg or arm lymphedema there is little or no assistance.”



“The second half of my treatment was 'take home' therefore cost me out of pocket - not covered by Ontario health plan. Costs of this medicine were prohibited and caused me to stop treatment. Also had to pay for physiotherapy and for psychosocial support.”

Provincial insights

If you have needed other support (e.g. from dietitians, physiotherapists, or mental health services), is this always available to you when you need it?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Yes, always	41%	37%	59%	48%	20%
Yes, sometimes	45%	46%	31%	41%	61%
No, not at all	14%	17%	10%	11%	19%

Only one in five respondents from Quebec (20%) said they were always able to access support from allied health professionals such as dietitians, physiotherapists or mental health providers, compared to 59% of respondents from British Columbia and 41% of all Canadian respondents.



What we know

The added value of complementary therapies is widely recognized among international cancer societies. For example, the American Cancer Society recommends a selection of evidence-based complementary therapies: music therapy, meditation, yoga and relaxation, massage, acupressure and acupuncture.³⁸

Complementary approaches can be important for patients' care, wellbeing and recovery.⁵⁸ Doctors do not necessarily need to provide these components of care, but they should be able to signpost patients to relevant services.³⁹

Psychological support was often unavailable to respondents.

A recurring comment from respondents was that their psychological or emotional needs were not sufficiently addressed by their cancer care team.

More than a third of respondents (37%) who felt they needed psychological support said it was unavailable to them.



"Mental health needs more research and development for cancer patients."



"I should have been given an immediate referral to a support group. Instead I had to go looking on my own."

Provincial Insights

Many cancer patients say that they need ongoing psychological support throughout their care, and maybe even afterwards. If you have needed this, has it always been available to you?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Yes, always	32%	21%	20%	37%	34%
Yes, sometimes	32%	43%	54%	26%	22%
No, not at all	37%	36%	26%	37%	43%

Of survey respondents who needed ongoing psychological support during their care, 37% of respondents from Ontario and 34% of respondents from Quebec said that it was always available. Comparatively, only 20% of respondents from British Columbia and 21% of respondents from Alberta found it to be always available.

Even when psychological support was available, it was not always felt to be helpful.

In qualitative comments, respondents mentioned being referred to professionals who did not have a sufficient understanding of cancer to provide any meaningful help to them or their families. In some instances, support was inappropriate or even hurtful to respondents.



“I should have been referred to an emotional support program but instead I was sent “by accident” to a suicide prevention team. I had to tell them that I was not suicidal, they sent me back to my Dr, and she asked me why I turned down the treatment she offered...argh!”



“Received almost no psychosocial support or even told it was available. When I searched for and found psychosocial support at hospital I was too many months past active treatment to receive any form of counselling. Care focused only on monitoring for cancer.”



What we know

According to the International Psycho-Oncology Society (IPOS), 40–60% of cancer patients and family members experience psychological distress that could benefit from intervention, but only a minority receive psychological support and care.⁴⁰ This is despite psychological distress screening being recommended for all cancer patients from diagnosis onwards.⁴¹



Why it matters

Mental distress is common among cancer patients, and can result in difficulty in processing information, decisional regret about treatment choices, fear of cancer recurrence, chronic pain and difficulty with social reintegration.⁴¹

Cancer patients are three times more likely to suffer from depression compared with the general population. Cancer patients with depression have 39% higher mortality,⁴² higher healthcare utilization, and higher healthcare expenditure than patients who do not have depression.⁴³ For example, a study in the United States found that adult cancer survivors had an estimated 31.7% greater total expenditure compared to those without depression.⁴³

A higher incidence of anxiety and depression is reported in adolescents and young adult cancer survivors compared with older populations. This can inhibit their ability to get an education and gain employment.⁴⁴ Furthermore, psychological care is especially crucial in the post-treatment phase, due to fears over not being able to conceive children, body image dissatisfaction and anxiety.⁴⁴

The impact of cancer on families and loved ones was a common concern for respondents.

In addition to needing psychological support themselves, respondents said that psychological support should be offered to their spouses and children. This comment was made by both patients and caregivers completing the survey.



“My husband sat at several appointments with a book about palliative care on his lap. He did not know how to bring up the discussion but not once did anyone talk to him about what his thoughts were about his diagnosis or treatment options. I brought it up several times but was always quieted by the oncologist who seemed to be in denial that it was even an option.”



“It was just as hard on my family, especially my husband. No help was offered to him.”



Why it matters

Many studies show the negative impact that parental cancer has on the lives of children and the whole family unit, including siblings, necessitating support for the entire family.^{45 46}

Caregivers to people with cancer, in particular, have a unique burden placed on them – and their new role in providing practical, emotional and other support can negatively affect their own psychological, physical and financial health. Reasons for experiencing increased burden are multifaceted, and can be due to coping with the emotional impact of a loved one who is suffering, taking on this new ‘full-time job’ of providing care to a patient with cancer and/or taking on additional household responsibilities with no extra support. On average, these caregivers provide 8.3 hours of care each day for 13.7 months.⁴⁷

As a result, caregivers can have high unmet needs.⁴⁷ They frequently report psychological issues, including fear, hopelessness and mood disturbances. Studies also show that rates of anxiety and depression among family caregivers are comparable or higher than those of the patient for whom they provide care. Physical health complications are also common – including sleep difficulties, fatigue, cardiovascular disease, decreased immune function and increased mortality.⁴⁷

One in four, or 8.1 million Canadians are care givers, 6.1 million of whom are juggling their work and caregiving responsibilities.⁴⁸ Canadian carers spent \$12.6 million in 1 year on expenses related to their caring role.⁴⁹ Canadian carers contribute \$25 billion in unpaid labour to our health system.⁴⁹



4

The Financial Impact of Cancer

Key findings

- Travel costs (39%) and loss of employment income (18%) were the most frequently reported non-treatment-related costs for respondents.
- Two thirds (67%) of respondents from Ontario reporting having to pay for cancer drugs.
- Cancer had a negative, and often long-term, impact on productivity for respondents and their caregivers. In some cases, a diagnosis of cancer created lifelong financial insecurity.

Overview of findings

Many respondents were shocked by the dramatic financial impact cancer had on their lives.

Respondents were asked about the financial impact of cancer on their lives, and in the qualitative responses many reported that they had incurred significant costs due to cancer.



“Not all treatment options for kidney cancer are available or approved where I live. All oral (at-home treatments) are not funded the same as in hospital IV treatment. The orals are very expensive and I have no private insurance. Provincial programs are available but not always accessible and always slow to get approvals.”



“Travel insurance no longer available. Had to pay for assistive devices, compression garments, bandages, taxis, etc.”

Of those who paid for some of their cancer treatment, nearly half (47%) of respondents reported paying for drugs, 13% paid for diagnostic services and 40% paid for alternative treatment and support.

Provincial insights

What types of cancer care treatment did you have to pay for yourself?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Drugs	47%	39%	32%	67%	27%
Anything contributing to diagnoses not covered by private or public plan	13%	25%	23%	8%	8%
Alternative treatment and support (homeopathy, naturopathy, psycho-social support, physiotherapy, etc.)	40%	36%	45%	25%	65%

Of those who paid for part of their cancer care, two thirds of respondents from Ontario (67%) reported paying for drugs, compared to 39% or less from respondents another provinces.



“The second half of my treatment was 'take home' therefore cost me out of pocket - not covered by Ontario health plan. Costs of this medicine were prohibited and caused me to stop treatment. Also had to pay for physiotherapy and for psychosocial support.”

Travel costs and loss of employment were the most frequently reported non-treatment-related costs for respondents.

Provincial insights

Were there any other financial implications of your cancer care and treatment?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Loss of employment	18%	32%	19%	14%	17%
Travel costs	39%	42%	43%	43%	30%
Childcare costs	2%	8%	0%	1%	2%
Loss of insurance	4%	4%	9%	4%	1%
Other	16%	15%	7%	17%	21%

A third of respondents from Alberta (32%) reported a loss of employment due to cancer care and treatment, compared to 18% of respondents from other provinces.

Only a third of respondents from Quebec (30%) reported travel costs due to their cancer care and treatment compared to 39% of respondents from other provinces.

One in ten respondents from British Columbia (9%) reported a loss of insurance due to their cancer care and treatment compared to 4% of respondents from other provinces.

Some respondents reported having to travel to another province to receive treatment, often repeatedly.

Provincial Insights

At any point were your referred outside of your province for treatment?	Combined Provincial	Alberta	British Columbia	Ontario	Quebec
	%	%	%	%	%
Yes	7%	2%	19%	3%	9%
No	93%	98%	81%	97%	91%

Less than one in ten respondents (7%) were referred outside of their home province for treatment. However, this number was much higher for respondents from British Columbia where two out of five of respondents (19%) reporting being referred outside their home province.

For some respondents, cancer continued to have a financial impact for many years after they had completed treatment

Some patients reported having to pay for complementary care not covered by their health insurance, or not being able to fully return to work.

The financial impact of cancer was sometimes devastating, as respondents had to make huge sacrifices to pay for their care and the associated travel.



“I had just moved to another city and the side effects of the medication (extreme fatigue) kept me from getting the opportunity to seek new employment and did not receive any unemployment insurance.”



“Travel insurance more expensive, require physio, loss of income from retiring early.”



“Transportation to a care facility was 500 miles away and costly to travel back and forth.”

For some respondents, cancer had a negative, and often long-term, impact on productivity for them and their caregivers.

Two out of five respondents (18%) reported that they had suffered financially due to loss of employment related to their cancer.

Respondents sometimes reported not only a loss of their own income, but reduced income for their caregivers, who had to assume greater responsibility by caring for a spouse with cancer alongside maintaining daily household tasks and often caring for children on their own. Self-employed respondents and caregivers felt the impact of this most strongly.



“Daughter had to take a great deal of time off work to take her to appointments and treatments. She is self-employed so lost income.”

A prior diagnosis of cancer created lifelong financial insecurity for some respondents.

In addition to the cost burden of cancer itself, respondents sometimes commented that having had cancer had a long-term impact on their ability to get a mortgage or affordable insurance – and many worried about their future financial security as a result.



“Cannot get a new mortgage insurance, new travel insurance or new life insurance. We have become outcasts in the eyes of insurance companies.”



What we know

With the growing number of cancer survivors, there is increasing recognition of the need for social policies to help former cancer patients return to work after their care and protect them from financial insecurity.⁵⁰

In Italy, for example, there is a law allowing patients to switch from full-time to part-time work while undergoing treatment, and go back to full-time work as soon as they are able. It has been recommended that all countries implement similar measures.⁵¹ The Netherlands, meanwhile, is one of the first countries with a government Plan of Action for ‘Cancer & Work’.⁵²

Unfortunately, not all countries have legal frameworks for the reintegration of cancer survivors into the workplace, although more countries are developing legislation to support and protect this right to return to work.⁵¹



Why it matters

Although many cancer patients are able to return to work after their care, this is not the case for all. Lost productivity due to cancer is estimated to cost €52 billion per year in the EU.⁵³

People surviving cancer are 1.4 times more likely to be unemployed and three times more likely to receive disability benefits than the general population.⁵⁴ Based on the French VICAN 2 study, 22% of those aged 18–57 reported losing their job when their cancer was diagnosed, rising to 92% 15 months after diagnosis.⁵⁵

A study in the United Kingdom found that almost one in three (30%) people living with cancer had a loss of income as a result of their diagnosis and lost on average £860 a month. A third of people (33%) stopped working permanently or temporarily.⁵⁶ These data underline the need for social policies that protect patients from financial insecurity during and after their cancer care.

Conclusions

This report presents findings from 255 Canadian respondents that were considered for provincial analysis on where they felt that inefficiency occurred in their care.

These findings are intrinsically important, as they represent patients' perceptions about the efficiency of their care. Patients live the reality of health care delivery. Their insights are both unique and valuable. If we want to be true to our aim of delivering care focused on what matters to patients, we must consider these patient insights alongside economic and clinical data, and ensure that we account for them in our definitions of efficiency and inefficiency. From a policy perspective, we should not only be looking at health system reform; we also should look at how policies and societies need to adapt to adequately provide for people living with and beyond cancer.

Our findings reflect similar findings from surveys and reviews in the literature^{26 39 57 58} and reveal a number of opportunities where improvement is needed from the patient perspective:

1

Ensure swift, accurate and appropriately delivered diagnosis

Diagnosis was the top areas of inefficiency reported by respondents. For respondents whose cancer was diagnosed outside of a screening programme, speed of diagnosis had an impact on respondents' entire experience of care.

2

Improve information-sharing, support and shared decision-making

Respondents expressed the need for better information and support to help them feel more engaged in their care. Information on what to expect in terms of side effects and risk of recurrence, and what to do after the phase of active treatment was over, was particularly needed.

3

Make integrated multidisciplinary care a reality for all patients

Respondents asked for more focus on the emotional and psychological impact of cancer and better integration of allied health and complementary services into their care.

4

Address the financial implications of cancer

Respondents commented on the significant and lasting economic burden often caused by cancer, and the need for greater support early in their care to facilitate their return to work and adapt their lives following cancer care.

Throughout the survey, respondents' comments underscored the wide-reaching impact cancer can have on all aspects of their lives. This is also reflected in economic data: social costs represent 60% of the total cost of cancer.⁵³ Integrated health and social policies that recognize the broad impact of cancer on individuals will be essential⁵¹ if we are to curb the costs of cancer on our society.

Finally, we should not forget that simple solutions can often go a long way in improving efficiency – leading not only to economic gains but, most importantly, to better outcomes for patients.

To find out more

All.Can Canada is eager to continue working with others based on these survey findings. Full patient stories, International Survey data and more is available on the All.Can global website. We would be happy to share further information about the survey. To find out more, please contact us at amy@saveyourskin.ca.

References

1. Choosing Wisely. Homepage. Available from: <https://www.choosingwisely.org/> [Accessed 29/03/19]
2. Choosing Wisely. 2013. New ASCO Choosing Wisely List details five cancer tests and treatments routinely performed despite lack of evidence. Available from: <http://www.choosingwisely.org/new-asco-choosing-wisely-list-details-five-cancer-tests-and-treatments-routinely-performed-despite-lack-of-evidence/> [Accessed 29/03/19]
3. OECD. 2017. Tackling Wasteful Spending on Health
4. Government of Canada. 2018. Fact sheet: Cancer in Canada. Available from: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/fact-sheet-cancer-canada.html> [Accessed 01/06/2018]
5. Claire de Oliveira, MA, PhD*, Sharada Weir, MA, DPhil et al. The economic burden of cancer care in Canada: a population-based cost study. CMAJ. Available from: <http://cmajopen.ca/content/6/1/E1.full> [Accessed September 2018]
6. Medeiros J, Schwierz C. 2015. *Efficiency estimates of health care systems*. Brussels: European Commission Directorate-General for Economic and Financial Affairs
7. Addario BJ, Fadich A, Fox J, et al. 2018. Patient value: Perspectives from the advocacy community. *Health Expectations* 21(1): 57-63
8. Porter ME. 2010. What is value in health care? *New England Journal of Medicine* 363(26): 2477-81
9. All.Can. 2017. *Towards sustainable cancer care: Reducing inefficiencies, improving outcomes*. London: All.Can
10. Cancer Research UK. 2018. Why is early diagnosis important? [Updated 26/06/18]. Available from: <https://www.cancerresearchuk.org/about-cancer/cancer-symptoms/why-is-early-diagnosis-important> [Accessed 10/02/19]
11. World Health Organization. 2018. *Guide to Cancer Early Diagnosis*. Geneva: WHO
12. Richards MA, Westcombe AM, Love SB, et al. 1999. Influence of delay on survival in patients with breast cancer: a systematic review. *The Lancet* 353(9159): 1119-26
13. Birtwistle Mike, Alexandra E. 2014. *Saving lives, averting costs - An analysis of the financial implications of achieving earlier diagnosis of colorectal, lung and ovarian cancer*. London: Cancer Research UK
14. Husson O, Mols F, van de Poll-Franse LV. 2011. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol* 22(4): 761-72
15. Jefford M, Tattersall MHN. 2002. Informing and involving cancer patients in their own care. *The Lancet Oncology* 3(10): 629-37
16. Treacy JT, Mayer DK. 2000. Perspectives on cancer patient education. *Seminars in Oncology Nursing* 16(1): 47-56
17. Pieterse AH, Jager NA, Smets EM, et al. 2013. Lay understanding of common medical terminology in oncology. *Psychooncology* 22(5): 1186-91
18. Chapman K, Abraham C, Jenkins V, et al. 2003. Lay understanding of terms used in cancer consultations. *Psycho-Oncology* 12(6): 557-66
19. Epstein AS, Prigerson HG, O'Reilly EM, et al. 2016. Discussions of Life Expectancy and Changes in Illness Understanding in Patients With Advanced Cancer. *J Clin Oncol* 34(20): 2398-403.
20. Campbell-Enns HJ, Woodgate RL, Chochinov HM. 2017. Barriers to information provision regarding breast cancer and its treatment. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer* 25(10): 3209-16.
21. Rutten LJJ, Arora NK, Bakos AD, et al. 2005. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient Education and Counseling* 57(3): 250-61.
22. Tokdemir G, Kav S. 2017. The Effect of Structured Education to Patients Receiving Oral Agents for Cancer Treatment on Medication Adherence and Self-efficacy. *Asia Pac J Oncol Nurs* 4(4): 290-98
23. Halbach SM, Ernstmann N, Kowalski C, et al. 2016. Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. *Patient Education and Counseling* 99(9): 1511-18

24. European Society for Medical Oncology. 2010. Improving Rare Cancer Care in Europe: Recommendations on Stakeholder Actions and Public Policies. 10
25. National Cancer Survivorship Initiative (NCSI). 2013. *Living with and beyond cancer: taking action to improve outcomes* Online
26. Macmillan Cancer Support. 2013. *Cured but at what cost?* London: Support MC
27. Macmillan Cancer Support. 2014. *Assessment and care planning for cancer survivors: A concise evidence review* Online
28. Cancer World. 2017A. Pain! The Denial needs to end. Available from: <http://cancerworld.net/cover-story/pain-the-denial-needs-to-end/>
29. World Health Organization (WHO). WHO Definition of Palliative Care. Available from: <https://www.who.int/cancer/palliative/definition/en/> [Accessed 24/05/19]
30. Ferrell BR, Temel JS, Temin S, et al. 2017. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology* 35(1): 96-112
31. ESMO. 2012A. Gastrointestinal stromal tumors: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Ann Oncol* 23 (7): vii49-55
32. Hoerger M, Greer JA, Jackson VA, et al. 2018. Defining the Elements of Early Palliative Care That Are Associated With Patient-Reported Outcomes and the Delivery of End-of-Life Care. *Journal of Clinical Oncology* 36(11): 1096-102
33. Temel JS, Greer JA, Muzikansky A, et al. 2010. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine* 363(8): 733-42
34. Temel JS, Greer JA, Admane S, et al. 2011. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care. *J Clin Oncol* 29(17): 2319-26.
35. Mages NL, Castro JR, Fobair P, et al. 1981. Patterns of psychosocial response to cancer: Can effective adaptation be predicted? *International Journal of Radiation Oncology*Biophysics* 7(3): 385-92.
36. European Society for Medical Oncology (ESMO). 2017. Patient Guide on Survivorship. Available from: <https://www.esmo.org/Patients/Patient-Guides/Patient-Guide-on-Survivorship> [Accessed 01/04/19].
37. Oliver K. 2019. Personal communication: 13/03/19.
38. Greenlee H, DuPont-Reyes MJ, Balneaves LG, et al. 2017. Clinical practice guidelines on the evidence-based use of integrative therapies during and after breast cancer treatment. *CA Cancer J Clin* 67(3): 194-232.
39. Breast Cancer Network Australia. 2018. *State of the Nation Report*. Camberwell, Victoria: BCNA.
40. Travado L, Breitbart W, Grassi L, et al. 2017. 2015 President's Plenary International Psycho-oncology Society: psychosocial care as a human rights issue—challenges and opportunities. *Psycho-Oncology* 26(4): 563-69
41. Alias A, Henry M. 2018. Psychosocial Effects of Head and Neck Cancer. *Oral and Maxillofacial Surgery Clinics of North America* 30(4): 499-512.
42. Smith HR. 2015. Depression in cancer patients: Pathogenesis, implications and treatment (Review). *Oncology Letters* 9(4): 1509-14
43. Pan X, Sambamoorthi U. 2015. Health care expenditures associated with depression in adults with cancer. *J Community Support Oncol* 13(7): 240-47
44. Ismail Y, Hendry J. 2018. Support needs of adolescents' post-cancer treatment: A systematic review. *Radiography* 24(2): 175-83.
45. Visser A, Huizinga G, Van der Graaf W, et al. 2005. *The impact of parental cancer on children and the family: A review of the literature*
46. Shah BK, Armaly J, Swieter E. 2017. Impact of Parental Cancer on Children. *Anticancer research* 37(8): 4025-28.
47. Applebaum AJ, Breitbart W. 2013. Care for the cancer caregiver: a systematic review. *Palliative & supportive care* 11(3): 231-52
48. Carers Canada. Carer Facts. Statistics Canada, 2013. Available from: <https://www.carerscanada.ca/carers-facts/> [Accessed 15/08/2019]

49. Hollander, Marcus J, *et al*, 2009. Who Cares and How Much? *Healthcare Quarterly*, Vol.12, No. 2, p. 48. Available from: https://caregiversns.org/images/uploads/all/Hollander_Who_Cares_How_Much_2009.pdf [Accessed 15/08/2019]
50. Braspenning I, Tamminga S, Frings-Dresen M, *et al*. 2018. *Rehabilitation and return to work after cancer – instruments and practices. European Risk Observatory report*. Luxembourg: Publications Office of the European Union
51. European Society for Medical Oncology (ESMO) and European Cancer Patient Coalition (ECPC). 2017. *Survivorship - ESMO Patient Guide Series*. Brussels: ECPC.
52. oPuce. Volwaardig werk na kanker. Available from: <http://opuce.nl> [Accessed 25/03/19]
53. Luengo-Fernandez R, Leal J, Gray A, *et al*. 2013. Economic burden of cancer across the European Union: a population-based cost analysis. *Lancet Oncology* 14(12): 1165-74
54. European Agency for Safety and Health at Work. 2018. How can cancer survivors best be supported to return to work? [Updated 25/05/18]. Available from: <https://osha.europa.eu/en/about-eu-osha/press-room/how-can-cancer-survivors-best-be-supported-return-work> [Accessed 01/04/19]
55. Albreht T, Kiasuwa R, Van den Bulcke M. 2017. *CanCon: European Guide on Quality Improvement in Comprehensive Cancer Control*. Ljubljana: National Institute of Public Health
56. Macmillan Cancer Support. 2015. *Cancers hidden price tag: revealing the costs behind the illness*.
57. Youth Cancer Europe. 2018. *White paper on the needs of young people living with cancer*. Online
58. Chadder J, Zomer S, Lockwood G, *et al*. 2018. Understanding the Experiences of Cancer Patients as They Transition From Treatment to Primary and Community Care: A Pan-Canadian Study of Over 13,000 Cancer Survivors. *Journal of Global Oncology* 4(Supplement 2):



Changing cancer care together

Published September 2019 by All.Can Canada

The All.Can Canada initiative is made possible with financial support from Bristol-Myers Squibb (main sponsor), Merck, and Johnson & Johnson (sponsors)