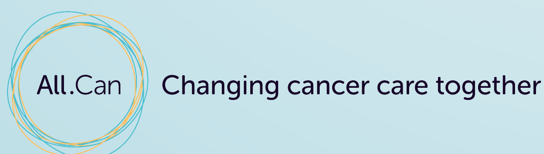
Consolidated Report on Waste and Inefficiency in Canadian Cancer Care:

Multi-Stakeholder Insights and Recommendations



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

TABLE OF CONTENTS

1. About All.Can....3

2. About All.Can Canada....3

3. Acknowledgements....4

4. Executive Summary....5

A. List of Recommendations....6

B. Limitations....7

C. Next Steps....7

D. Conclusions....8

5. INTRODUCTION....9

6. ABOUT THIS REPORT....11

7. METHODOLOGIES....12

A. All.Can International Patient Survey conducted in Canada....12

B. Literature Review....13

.

C. Multi-stakeholder Surveys....13

D. Limitations....16

8. KEY FINDINGS FROM SURVEYS....18

9. LIST OF RECOMMENDATIONS....24

10. NEXT STEPS....26

11. APPENDIX I - Inagural Multi-Stakeholder Roundtable Participants....27

12. APPENDIX II - Literature Review Publications Reviewed....28

1. 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 by focusing on outcomes that matter most to patients – and create greater efficiency in cancer care. This involves examining what system inefficiencies exist, finding examples of how we can improve efficiency in cancer care and implementing concrete policy actions based on these findings.

All.Can is comprised of leading representatives from patient organizations, policymakers, health care professionals, research and industry. The All.Can Group consists of All.Can International, plus All.Can national initiatives currently established in 14 countries including Canada.

2. ABOUT ALL.CAN CANADA

Save Your Skin Foundation (SYSF) is a national, patient-led, not-for-profit group dedicated to leading the fight against non-melanoma skin cancers, melanoma and ocular melanoma. SYSF was established as All.Can Canada's Secretariat to lead the initiative in Canada, bringing the approach and lessons learned by the international group to Canada. To start, SYSF convened a working group to discuss how best to bring All.Can into Canadian health care.

Working group members:

Kathy Barnard, President, SYSF
Amy Rosvold, Director of Marketing and Communications, SYSF
Louise Binder, Health Policy Consultant, SYSF
William Dempster, CEO, or Delegate, 3Sixty Public Affairs
Suzanne Wait, Managing Director, The Health Policy Partnership

Project Support:

Antonella Scali, Health Policy Consultant
Leah Stephenson, Principal Consultant, Leah M. Stephenson Consulting
Natalie Richardson, Managing Director, SYSF

The working group has completed a discovery phase that involved a scan of the literature on nation-wide and province-specific health care reports to identify the top reported areas of waste and inefficiency in cancer care in Canada. These findings were then prioritized through anonymous surveys with cancer care stakeholder groups, including pharmaceutical industry representatives, patient group representatives, health care professionals, provincial policy makers and health technology assessment bodies. This information was also reviewed in light of responses from over 300 Canadian cancer patients who took part in the All.Can International Patient Survey.

Following this discovery phase, SYSF hosted an inaugural multi-stakeholder roundtable meeting on November 14, 2019 to find consensus on priorities and next steps to move All.Can Canada forward. As a result, an All.Can Canada interim steering committee is being assembled with representation from all stakeholder groups to support, guide and oversee the progress of a multi-year project that was derived from the roundtable.

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

3. ACKNOWLEDGEMENTS

This report was developed by All.Can Canada using data from a scan of existing literature on inefficiencies in cancer care, survey data collected from patient group representatives, pharmaceutical representatives, health care professionals, health policy makers and health technology assessment bodies, as well as data from the All.Can International patient experience survey, which was conducted by Quality Health and The Health Policy Partnership.

We would like to thank the dedicated team at The Health Policy Partnership for their guidance and support of this research.

4. EXECUTIVE SUMMARY[1]

The prevalence, complexity and costs of cancer are rising. The cost of cancer care in Canada has risen from $2.9 billion in 2005 to $7.5 billion in 2012, mostly owing to the increase in costs of hospital-based care.[2] As the personal, economic and social costs of cancer continue to rise, there is a growing burden on our health care systems and an urgent need to improve efficiencies and reduce waste in cancer care. Most importantly, research suggests that removing wasteful or ineffective interventions could lead to an average gain of approximately two years of life expectancy in industrialized countries.[3] Improving efficiency is not a question of linear cost-cutting, but of allocating resources more efficiently to ensure the sustainability of our health care systems and, ultimately, to improve health outcomes for patients.

All.Can International defines inefficiency as the allocation of resources to anything that does not focus on what matters to patients.[4] Its aim is to find sustainable solutions to improving cancer care. To guide these efforts, All.Can seeks to gain a better understanding of where all cancer care stakeholders perceive waste and inefficiency — and to find practical solutions to address them.

To help achieve this, All.Can International conducted a patient survey across multiple countries, including Canada. Save Your Skin Foundation (SYSF), All.Can Canada's Secretariat, assisted with the Canadian component of this survey. In addition, All.Can Canada ran a number of surveys of different stakeholder groups to obtain a broader array of perspectives on existing inefficiencies.

This report captures themes and insights gathered from these different surveys as a starting point for taking a multi-stakeholder-driven approach to improving the efficiency and sustainability of cancer care in Canada.

---

[1] This executive summary is adapted in part from *Patient insights on cancer care: opportunities for improving efficiency*: *Findings from the All.Can International Patient Survey*. Retrieved from https://www.all-can.org/what-we-do/research/patient-survey /

[2] Oliveira, D., Weir, S., Rangrej, J., Krahn, M., Mittmann, N., Hoch, J., Chan, K., Peacock, S. (2018). The economic burden of cancer care in Canada: a population-based cost study. *CMAJ, 6*(1), E1-E10. doi: 10.9778/cmajo.20170144 Retrieved from: http://cmajopen.ca/content/6/1/E1.full [Accessed September 2018]

[3] All.Can. (2017.) *Towards sustainable cancer care: Reducing inefficiencies, improving outcomes.* Retrieved from http://www.healthpolicypartnership.com/wp-content/uploads/All.Can-_policy_report_Jan_2017.pdf

[4] All.Can. (2017).

A. LIST OF RECOMMENDATIONS

Defining inefficiencies requires a look across the entire spectrum of cancer care to try to identify practices, policies or processes that do not provide meaningful benefits for patients with the resources used. This is no small task — as inefficiencies may occur at the system, institutional or individual level — and at every step along the cancer care pathway.

The following recommendations are based on the top areas of waste and inefficiency identified in the All.Can International patient survey conducted in Canada and through surveys led by SYSF with different stakeholder groups. Although the questionnaires used for the various surveys differed (see Limitations), it is possible to draw out three top areas of waste and inefficiency on the basis of combined responses.

1. Improve coordination among health care practitioners and across the continuum of care

Many respondents expressed inefficiency across the continuum of care, including lack of communication and coordination across health disciplines, difficulty navigating cancer treatments and lack of multi-team-based health care provision.

2. Reduce delays and duplication in drug review and public listing process

The second most commonly identified area of waste and inefficiency was wait times for drug approvals and the duplication of health bodies involved in cancer drug approvals, such as Health Canada, PMPRB, CADTH, INESSS, pCODR, CAPCA, pCPA and public and private insurers. Respondents felt that these duplications and delays resulted in lack of access, and inequitable access to medications and treatments for patients.

3. Ensure swift, accurate and appropriately delivered diagnosis

When asked to select the top areas of cancer care where they saw the most inefficiency, the majority of all stakeholder respondents chose diagnosis — more than any other area of cancer care. Even in stakeholder surveys where another area of cancer care was reported as most inefficient, diagnosis was always among the top three areas of inefficiency reported by respondents.

B. LIMITATIONS

The findings in this report are based on different stakeholder surveys, many of which employed different methodologies to best reach and engage those stakeholders. This report aimed to find commonalities across multiple stakeholders to direct upcoming All.Can Canada multi-stakeholder efforts, not to meet the methodological rigour of a formal research project. The findings in this report are meant to identify the common themes that emerged among various stakeholders consulted. Moreover, these findings are not meant to be exhaustive nor representative of all potential inefficiencies across the cancer care spectrum, or of all proposed solutions to address them. Instead, they are intended as a starting point for further exploration.

C. NEXT STEPS

Participants (see Appendix I) of an inaugural multi-stakeholder roundtable meeting that took place on November 14, 2019 were asked to consider the information presented in this report and to come to the roundtable having answered the following questions for themselves:

- Based on the three top recommendations from combined surveys (coordination across the care continuum, public listing of treatments, diagnoses), what do you see as the top priority for waste and inefficiency in cancer care in Canada?
- Given the findings in the report and the landscape in Canada today, where can we make the greatest gains to address this priority by:
  - Filling a gap; and
  - Leveraging existing opportunities?
- How can you and/or your sector contribute towards addressing this priority?

Participants at the meeting were patients, health care professionals, patient group representatives, former health technology assessment professionals, industry representatives, and researchers. The roundtable meeting built consensus on a priority area of focus plus next steps, and agreed to a preliminary governance approach for All.Can Canada through the establishment of a multi-stakeholder interim steering committee, supported by the Secretariat.

The group achieved consensus on a preliminary area of focus to be:

Optimizing patient entry into Canadian cancer care systems, ensuring swift, accurate, and appropriately delivered diagnosis and that patients experience coordinated, effective support throughout their treatment experience. The preliminary focus will be on ensuring swift, accurate, and appropriately delivered diagnosis as the entry point into the cancer care system.

As a next step, the interim steering committee will be responsible for providing strategic guidance and oversight of an environmental scan to assess the current state related to the consensus statement, then convening a second multi-stakeholder roundtable meeting to assess its findings and determine a plan of action. The Secretariat will be responsible for supporting implementation.

D. CONCLUSION

The combined findings from our stakeholder consultations identified important areas where improvements are needed to optimize the allocation of resources towards outcomes that matter most to patients. We need to give these issues due prominence in future cancer planning, policies and investment decisions to build truly efficient and patient-driven care.

Making changes in these areas of inefficiency would lead to real differences – to patients' outcomes, their experiences of care, the financial burden of cancer on patients and their loved ones, health care systems, work places, communities and, ultimately, Canadian society as a whole.

5. INTRODUCTION[5]

The past few decades have seen considerable advances in the way we diagnose and treat cancer. Yet with the growing prevalence of cancer and ongoing pressures on limited health care budgets, equal access to the latest scientific advances and their affordability has become a challenge. 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.[6] One in every two Canadians is expected to develop cancer during their lifetime, and one in four Canadians is expected to die from cancer.[7] Challenges with limited resources and a demand for cancer care will only increase in coming years. As a result, we need to find new ways to make the most of the resources we have.

Arguably greater efficiency is needed across all disease areas however in cancer this is especially urgent. Cancer is the leading cause of death in Canada — responsible for 30% of all deaths.[8] Advances in the way we diagnose and treat many forms of cancer promise to transform outcomes for many patients in years to come. However, we must find ways to allocate resources more efficiently and reorganize our priorities in terms of long-term investments rather than short-term fixes. Without such transformation we risk not being able to offer future generations the benefits of these advances as governments and private payers will not be able or willing to pay for them.[9]

Improving efficiency across the entire cancer care pathway is a complex challenge that will require meaningful collaboration between all stakeholders. It must start with a clear understanding of what outcomes we are trying to achieve for patients. Moreover, we will need to move away from budget silos and from our current fragmented health care systems; measure the impact of what we do by identifying the right outcomes and investing in the right data; and

---

[5] This introduction is adapted in part from All.Can (2017), *Towards sustainable cancer care: Reducing inefficiencies, improving outcomes.* Retrieved from https://www.all-can.org/publications/towards-sustainable-cancer-care-reducing-inefficiencies-improving-outcomes/

[6] de Oliveira, et al., (2018).

[7] Canadian Cancer Society. (n.d.).

[8] Canadian Cancer Society. (n.d.). *Cancer statistics at a glance.* Retrieved from http://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=bc#ixzz5RZs2GjPG [accessed: September 2018].

[9] All.Can. (2017).

use these data to support a culture of continuous improvement, with clear accountability mechanisms in place and payment systems that reward the achievement of outcomes.[10]

All stakeholders have a part to play in achieving meaningful change. That said, lasting changes needs to start with policy makers and those who decide on how resources and funding in health care are allocated today, systemically listening to the experiences and priorities of patients living with cancer, their caregivers, the providers serving them and other relevant stakeholders.

[10] All.Can. (2017).

6. ABOUT THIS REPORT

This report draws on the findings of two survey processes – the All.Can International patient survey[11] conducted in Canada and the Save Your Skin Foundation (SYSF) multi-stakeholder surveys, which were based on themes from a literature review.

The All.Can International patient survey was designed and conducted by The Health Policy Partnership and Quality Health, with inputs and support from SYSF. The design and conduct of all the other stakeholder surveys were led by SYSF.

This report describes the three top themes that emerged from these combined surveys regarding the main areas of waste and inefficiency in cancer care in Canada. Each of the themes identified represents an opportunity for improving cancer care from the perspective of different stakeholders.

The insights gathered in this report guided discussions at an inaugural All.Can Canada roundtable meeting held on November 14, 2019, which aimed to find consensus among key stakeholders to prioritize the top areas of waste and inefficiency across the cancer pathway, develop strategies and identify next steps for All.Can Canada's growing platform. SYSF, with the working group's support, invited key representatives from all cancer care stakeholder groups to come together for this roundtable (a full list of participants may be found in Appendix I).

[11] All.Can. (2019). *Patient insights on cancer care: opportunities for improving efficiency*: *Findings from the All.Can International Patient Survey*. Retrieved from https://www.all-can.org/what-we-do/research/patient-survey /

7. METHODOLOGIES

A. *ALL.CAN INTERNATIONAL PATIENT SURVEY* CONDUCTED IN CANADA

The All.Can International patient survey[12] aimed to obtain perspectives from cancer patients on where they felt they encountered inefficiency in their care. The survey was conducted across 10 countries, including Canada. The Canadian-specific survey questionnaire was produced in English and Canadian French and included both questions from the main survey and a maximum of five questions specific to Canada. The survey was developed with input from the All.Can Canada initiative.

There were 314 Canadian respondents to the All.Can patient survey; their responses were included in the findings presented in the All.Can International patient survey report , Patient insights on cancer care: opportunities for improving efficiency.

Data from respondents in the top four participating provinces were selected for additional analysis. Of the 314 Canadian responses to the All.Can International patient survey, 255 respondents stated they resided in British Columbia, Alberta, Ontario or Quebec. The data of these respondents were presented in the All.Can Canada patient survey report, Patient Insights on Canadian cancer care: opportunities for improving efficiency.

Participation in the survey was voluntary, therefore respondents were self-selected and survey results represent perspectives of patients who wanted to have their views heard and were able to complete the online survey. As such, they do not necessarily reflect the perspectives of all cancer patients. For full details on the survey's methodology, including limitations, please see here.

[12] All.Can. (2019).

B. LITERATURE REVIEW

Below are the themes from a brief review of grey and academic literature on Canada-wide and province-specific health care and cancer inefficiencies (see a full list of publications reviewed in Appendix II).

1. Lack of coordination through health service providers

- Primary care physician should be the main contact for patients regarding co-ordination across the care continuum
- Patients should have control over booking appointments online
- Instructions should be provided electronically ahead of time
- Multiple services should be provided in one appointment

2. Long waits for cancer diagnosis

- Only 46% of biopsies performed within the Ontario Ministry of Health 14-day target
- Misdiagnoses
- Testing not being done in a timely fashion

3. Take-home cancer drugs

- Administrative delays in starting treatments and safety issues
- Inadequate support for the proper and safe use of take-home drugs
- Take-home cancer treatments are not funded equitably across the country and patients must apply for funding through special funding programs
- Full cost of cancer drugs is not covered for patients if they are not administered in hospital

C. MULTI-STAKEHOLDER SURVEYS

The multi-stakeholder surveys conducted by SYSF aimed to obtain perspectives from Canadian stakeholder groups on where the biggest areas of inefficiency and waste in cancer care occur, looking at the care continuum from prevention to survivorship and end-of-life care. The

questions included in the surveys were both multiple choice and open-ended, and were developed based on key themes that emerged from the review of nation-wide and province-specific grey and academic literature on waste and inefficiency in cancer care.

Surveys were conducted across Canada with the following stakeholder groups:

- National **patient group** representatives, almost exclusively those dealing with a type of cancer (English language)
- National **pharmaceutical** representatives (English language)
- **Health care professionals** along the cancer care continuum (English language)
- Provincial **policy makers** (English and French language)
- National **health technology assessment** bodies (English and French language)

Recruitment of respondents

The surveys were made available online. Respondents were recruited via direct outreach, outreach via national patient organizations and social media ads. The surveys were conducted between June 2018 and August 2019.

Individual surveys received the following total responses:

Patient group representatives: 13 responses

Pharmaceutical representatives: 7 responses

Health care professionals: 19 responses

Policy makers: 9 responses (10% completion rate)

Health technology assessment bodies: 1 response[13]

Patient group stakeholder survey

- All.Can Canada used themes from the literature review to provide examples to survey respondents of the types of inefficiencies that may exist, but let respondents answer an open-ended question to identify what they felt were the top FIVE areas of inefficiency

[13] A detailed analysis of this response has not been included due to the low response rate for this category of stakeholders.

and waste in cancer care.

Pharmaceutical stakeholder survey

- Similar to the patient group survey, All.Can Canada used themes from the literature review to provide examples to survey respondents of the types of inefficiencies that may exist, but let respondents answer an open-ended question to identify what they felt were the top FIVE areas of inefficiency and waste in cancer care.

Health care professional stakeholder survey

- After several months of low response rate, despite efforts to recruit respondents, All.Can Canada sought the advice of an external organization to assist with survey participation. Under the guidance of 3Sixty Public Affairs, the survey was reorganized into a quick-answer multiple-choice format that included 15 areas of waste and inefficiency for respondents to select up to five areas. The 15 areas of waste and inefficiency were chosen using themes from the literature review as well as results from the previous three stakeholder surveys: patients, patient group representatives and pharmaceutical representatives.

Policy maker stakeholder survey

- The survey was designed with the unique perspective of policy makers in mind, and included areas of Diagnosis and Patient Eligibility, Collaboration and Coordination and Evaluation. This survey was designed in conjunction with 3Sixty Public Affairs with inputs from several senior health policy experts. The majority of questions were presented in a multiple-choice format to ensure quick completion.

Health technology assessment bodies stakeholder survey

- The survey was designed with the unique perspective of health technology assessment professionals in mind, and included areas of Diagnosis and Patient Eligibility,

Collaboration and Coordination and Evaluation. This survey was designed in conjunction with 3Sixty Public Affairs with inputs from several senior health policy experts. The majority of questions were presented in a multiple-choice format to ensure quick completion.

D. LIMITATIONS

The findings in this report are based on different stakeholder surveys, many of which employed different methodologies to best reach and engage those stakeholders. This report aimed to find commonalities across multiple stakeholders to direct upcoming All.Can Canada multi-stakeholder efforts, not to meet the methodological rigour of a formal research project. The findings in this report are meant to identify the common themes that emerged among various stakeholders. Moreover, these findings are not meant to be exhaustive nor representative of all potential inefficiencies across the cancer care spectrum, or of all proposed solutions to address them. Instead, they are intended as a starting point for further exploration.

All.Can International Patient Survey – Canada[14]: 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 national or international patient organization that shared the survey. The survey was focused on patient experiences and processes of care and therefore did not include any questions regarding specific treatments or interventions.

SYSF multi-stakeholder surveys: Respondents volunteered to participate in the surveys. Respondents are self-selected and represent the perspectives of those who wanted to have their voices heard and were able to complete the surveys, which were conducted exclusively online. The results of these surveys have not been weighted and are in no way meant to be

[14] This description is taken directly from All.Can. (2019). *Patient insights on cancer care: opportunities for improving efficiency*: *Findings from the All.Can International Patient Survey*. Retrieved from https://www.all-can.org/what-we-do/research/patient-survey/

either exhaustive or representative of the opinions of all stakeholders. Instead, they are intended as a starting point for further exploration.

Furthermore, due to the low response rate of provincial policy makers and health technology assessment bodies, these results were not part of the multi-stakeholder analysis.

Key Findings

Multi-Stakeholder Insights and Recommendations

8. KEY FINDINGS FROM SURVEYS

This table presents the **top three areas** of inefficiency and waste as identified in an analysis of the key themes that emerged from the various stakeholder surveys. Note that since the questionnaires used for each of the multi-stakeholder surveys differed amongst each other, and from the All.Can International patient survey conducted in Canada, these findings are only meant to indicate some common themes that emerged from various stakeholders.

Moreover, these findings are not meant to be exhaustive nor representative of all potential inefficiencies across the cancer care spectrum, or of all proposed solutions to address them. Instead, they are intended as a starting point for further exploration, and illustrate the tremendous potential and scope for greater efficiency across cancer care.

Q. *What do you feel are the TOP areas of waste and inefficiency in cancer care?*

Patients *All.Can patient survey, n=317*	**Patient groups** *stakeholder survey, n=13*	**Pharmaceutical representatives** *stakeholder survey, n=7*	**Health care professionals** *stakeholder survey, n=19*
Long waits and inaccuracies in diagnoses	Delays and duplication in drug review and public listing process	Delays and duplication in drug review and public listing process	Long waits and inaccuracies in diagnoses
Dealing with the ongoing side effects	Long waits and inaccuracies in diagnoses	Lack of communication and coordination across health care providers and centres	Lack of communication and coordination across health care providers and centres
Getting the right treatment for my cancer	Lack of communication and coordination across health care providers and centres	Long waits and inaccuracies in diagnoses	Delays and duplication in drug review and public listing process

A. OVERVIEW OF FINDINGS

The following overview provides information directly from the various surveys reviewed. Relevant and illustrative quotes from respondents are included to add substance to the information.

1. LACK OF COMMUNICATION AND COORDINATION BETWEEN HEALTH CARE PROVIDERS AND ACROSS CENTRES

***All.Can International patient survey* conducted in Canada (n=317):**

49% of patients said they had not always been given enough information about their cancer care and treatment in a way they could understand.

40% of patients said they were only given adequate support to deal with ongoing symptoms and side effects “some of the time” while a further 13% said they were “never” given adequate support.

47% of patients said they were not given information they could understand, or any information at all, about signs and symptoms to look out for to indicate that their cancer might be returning/getting worse.

“There needs to be more communication between health care 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.”

– Patient

***Patient group stakeholder survey* (n=13):**

Over two thirds of patient group representatives (**77%**) said a lack of communication and coordination across health care providers and centres was one of the top five areas of waste and inefficiency in cancer care.

“Lack of coordination, inefficient continuum of care, prevention campaign, unaccountability, no choosing wisely methodology.”

– Patient group representative

Pharmaceutical representative stakeholder survey **(n=7):**

Over two thirds of pharmaceutical representatives (**71%**) said a lack of communication and coordination across health care providers and centres was one of the top five areas of waste and inefficiency in cancer care.

Health care professional stakeholder survey **(n=19):**

Over half of health care professionals (**58%**) said a lack of communication and coordination across health care providers and centres was one of the top five areas of waste and inefficiency in cancer care.

2. DELAYS AND DUPLICATION IN DRUG REVIEW AND PUBLIC LISTING PROCESS

All.Can International patient survey conducted in Canada **(n=317):**

Although not asked specifically about the drug review and public listing process, many patients reported incurring significant financial costs due to drugs and treatments not being available to them where they lived, or at all.

Of those who paid for some of their cancer treatment, **47**% of respondents reported paying for drugs.

39% of all patients reported paying for travel costs due to their cancer treatment. 19% of patients from British Columbia reported being referred outside their home province for treatment.

"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."

– Patient

***Patient group stakeholder survey* (n=13):**
Several patient group representatives highlighted duplications in processes for drug approvals in Canada as one of the top five areas of waste and inefficiency in cancer care.

***Pharmaceutical representative stakeholder survey* (n=7):**
Over half of pharmaceutical representatives (**57%**) said delays and duplication in the drug review and public listing process was one of the top five areas of waste and inefficiency in cancer care.

"Unacceptable delays for drugs to get listed by the government – multiple levels of decision between Health Canada, HTAs, CDIAC, pCPA, provincial implementation, institutional implementation."

– Pharmaceutical representative

***Health care professional stakeholder survey* (n=19):**
Over half of health care professionals (**53%**) said delays and duplication in the drug review and public listing process was one of the top five areas of waste and inefficiency in cancer care.

3. LONG WAITS AND INACCURACIES IN DIAGNOSIS

***All.Can International patient survey* conducted in Canada (n=317):**
Almost one third of patients (**30%**) said diagnosis was the most inefficient area of their cancer care, making it the top area of inefficiency reported by patients.

"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."

– Patient

***Patient group stakeholder survey* (n=13):**

Almost half of patient group representatives (**46%**) said diagnosis was one of the top five areas of waste and inefficiency in cancer care.

"Late and misdiagnosis especially among rare and ultra-rare cancers"

– Patient group representative

***Pharmaceutical representative stakeholder survey* (n=7):**

Almost a third of pharmaceutical representatives (**29%**) said diagnosis was one of the top five areas of waste and inefficiency in cancer care.

"It can take a long time to properly diagnose some cancers, and there is inconsistency with respect to which cancers are screened"

– Pharma representative

***Health care professional stakeholder survey* (n=19):**

More than half of health care professionals (**58%**) said diagnosis was one of the top five areas of waste and inefficiency in cancer care.

9. LIST OF RECOMMENDATIONS

This section presents recommendations on the top areas of waste and inefficiencies as identified by stakeholders.

1. Improve coordination among health care practitioners and across the continuum of care

Many respondents expressed inefficiency across the continuum of care, including lack of communication and coordination across health disciplines, difficulty navigating cancer treatments and lack of multi-team-based health care provision.

2. Reduce delays and duplication in drug review and public listing process

The second most commonly identified area of waste and inefficiency was wait times for drug approvals and the duplication of health bodies involved in cancer drug approvals, such as Health Canada, PMPRB, CADTH, INESSS, pCODR, CAPCA, pCPA and public and private insurers. Respondents felt that these duplications and delays resulted in lack of access, and inequitable access to medications and treatments for patients.

3. Ensure swift, accurate and appropriately delivered diagnosis

When asked to select the top areas of cancer care where they saw the most inefficiency, the majority of all stakeholder respondents chose diagnosis — more than any other area of cancer care. Even in stakeholder surveys where another area of cancer care was reported as most inefficient, diagnosis was always among the top three areas of inefficiency reported by respondents.

Conclusions

Findings from these surveys highlight some important areas of focus that need improvement as identified by cancer care stakeholders from personal or professional experience. They also align with key findings of cancer care inefficiency in the literature.

We need to give these issues due prominence in future cancer plans, policies and investment decisions to build truly efficient and patient-driven care. We need to develop integrated health and social policies to address the wide-reaching impact cancer can have on all aspects of people's lives, and on our health care budget.

Making changes in these areas of inefficiency could lead to real differences – to patients' outcomes, their experience of care, the financial burden of cancer on patients and their loved ones, health care systems, work places, communities and, ultimately, Canadian society as a whole.

10. NEXT STEPS

In advance of the inaugural multi-stakeholder roundtable meeting that took place on November 14, 2019, we asked attendees to consider the information presented in this report and to come to the roundtable meeting having answered the following questions for themselves:

- Based on the three top recommendations from combined surveys (coordination across the care continuum, public listing of treatments, diagnoses), what do you see as the top priority for waste and inefficiency in cancer care in Canada?
- Given the findings in the report and the landscape in Canada today, where can we make the greatest gains to address this priority by:
  - Filling a gap; and
  - Leveraging existing opportunities?
- How can you and/or your sector contribute towards addressing this priority?

Participants at the meeting were patients, health care professionals, patient group representatives, former health technology assessment professionals, industry representatives, and researchers. The roundtable meeting built consensus on a priority area of focus plus next steps, and agreed to a preliminary governance approach for All.Can Canada through the establishment of a multi-stakeholder interim steering committee, supported by the Secretariat.

The group achieved consensus on a preliminary area of focus to be: ***optimizing patient entry into Canadian cancer care systems, ensuring swift, accurate, and appropriately delivered diagnosis and that patients experience coordinated, effective support throughout their treatment experience. The preliminary focus will be on ensuring swift, accurate and appropriately delivered diagnosis as the entry point into the cancer care system***.

As a next step, the interim steering committee will be responsible for providing strategic guidance and oversight of an environmental scan to assess the current state related to the consensus statement, then convening a second multi-stakeholder roundtable meeting to assess its findings and determine a plan of action. The Secretariat will be responsible for supporting implementation.

11. APPENDIX I MULTI-STAKEHOLDER ROUNDTABLE PARTICIPANTS

Attendees:

- Kathy Barnard, President, Save Your Skin Foundation
- Elizabeth Lye, Lymphoma Canada
- Eva Villalba, Director General, Coalition Priorité Cancer au Quebec
- Natalie Richardson, Save Your Skin Foundation
- Chantele Burroughs, Save Your Skin Foundation
- Antonella Scali, Executive Director, Canadian Psoriasis Network
- Martine Elias, Executive Director, Myeloma Canada
- Josee Pelletier, Bristol-Myers Squibb
- Louise Binder, Health Policy Consultant, Save Your Skin Foundation
- Wendy Morton, Associate Director, National Policy Planning, Merck Canada Inc.
- Suzanne Wait, Managing Director, The Health Policy Partnership
- Shivani Kapoor, Janssen Canada
- Alex Chambers, Novartis Pharmaceuticals Canada (formerly of CADTH)
- Dr. Tony Fields, retired medical oncologist and former medical head of Cancer Care Alberta
- Anita Simon, Health Policy Consultant (with oncology research background)

Consultants:

- Leah Stephenson, Leah M. Stephenson Consulting, meeting facilitator
- Gerry Jeffcott, 3Sixty Public Affairs, meeting reporter

12. APPENDIX II – LITERATURE REVIEW – Publications Reviewed

All.Can. (2017.) *Towards sustainable cancer care: Reducing inefficiencies, improving outcomes,* pp. 22-23. Retrieved from https://www.all-can.org/publications/towards-sustainable-cancer-care-reducing-inefficiencies-improving-outcomes/

The cost and performance of Canada's health care system. https://www.cna-aiic.ca/~/media/cna/files/en/the_costs_performance_canadas_health_system_e.pdf

Improving Health System Efficiency in Canada: Perspectives of Decision-Makers. Canadian Institute for Health Information. https://secure.cihi.ca/free_products/improving_health_system_efficiency_en.pdf

New research shows many women with breast cancer don't need chemo. Here's what this means for BC Cancer patients. BC Cancer, July 2018. http://www.bccancer.bc.ca/about/news-stories/stories/new-research-shows-many-women-with-breast-cancer-don%E2%80%99t-need-chemo-here%E2%80%99s-what-this-means-for-bc-cancer-patients

Enhancing Surgical Care in BC. Improving Perioperative Quality, Efficiency, And Access. A Policy Paper by BC's Physicians, June 2011. https://www.doctorsofbc.ca/sites/default/files/enhancingsurgicalcare_web.pdf

Two indicators of hospital resource efficiency in cancer care. By R. Rahal, J. Xu, S. Fund and H. Bryant in collaboration with the System Performance Steering Committee and Technical Working Group. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4059799/

Global News: Auditor General Bonnie Lysyk says for cancer biopsies not meeting targets. https://globalnews.ca/news/3900171/cancer-biopsies-auditor-general/

International O.R. Insights: Innovative research team addresses critical healthcare issues in British Columbia. By Martin L. Puterman, Pablo Santibanez, Scott Tyldesley and John French. https://www.informs.org/ORMS-Today/Public-Articles/April-Volume-39-Number-2/International-O.R.-Insights-Cancer-care-challenges

Published February 2020 by All.Can Canada

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)