CRISIS TO CATALYST

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USING LESSONS LEARNED FROM COVID19 TO PRIORITIZE CANCER CARE IN CANADA



ACKNOWLEDGMENT AND FUNDING STATEMENT

This is an independent report and the views expressed are those of the authors alone. It draws on interviews with stakeholders across Canada, leveraging our network of thought leaders to maximize learnings, conferences and events conducted by other parties as well as a literature review.

The information provided aims to be comprehensive but is by no means exhaustive. Rather, the goal is to provide a starting point for dialogue around the lessons learned from COVID19 and how they can be applied to improve cancer care in Canada. We recognize that the issues surrounding cancer care are complex, and there are no easy solutions. There are many factors that contribute to the complex issue of cancer care and policy in Canada, and that the lessons learned from the COVID19 pandemic are only one piece of the puzzle. This report uncovers and spotlights some of the innovative and collaborative responses that have emerged in response to the crisis and offers lessons to promote and protect public health so that they can be leveraged for cancer care in this country.

We would like to acknowledge the many healthcare professionals, researchers, patients, and caregivers who have worked tirelessly throughout the COVID19 pandemic and those who continue to work towards improving cancer care. Their dedication and expertise are essential in helping to address the challenges and opportunities facing cancer care.

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FROM CRISIS TO CATALYST

Using the pandemic as a catalyst for change, are there opportunities to transform cancer care in Canada, leveraging the adaptations and innovations as the driving force. Transforming cancer care with the same urgency as seen during COVID19, by learning from the challenges and successes of the pandemic response.



A coordinated global effort to the COVID19 pandemic led to the availability of lifesaving vaccines in under two years. Could the same results be obtained from better coordination to control cancer?



What key policy and systems level changes were implemented during the pandemic that can be used to improve cancer care?



What can be learned from the COVID19 pandemic to improve the resilience and readiness of cancer care systems in the future?



How did healthcare systems adapt to the pandemic and what were the most effective strategies that could be implemented for cancer control?

What are the key lessons that have been learned during the pandemic, and how can they be applied to improve cancer care in the future (including improved care for marginalized and underserved populations)?



The pandemic brought the world together to prevent, detect and treat the COVID19 virus. Why is cancer less important to prevent, detect and treat than COVID19?

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CANCER CAN NO LONGER BE IGNORED

The COVID19 pandemic has had a profound impact on the world and has brought about unprecedented challenges for healthcare systems worldwide. Faced with an unforeseen wave of infectious disease, healthcare systems have had to quickly adapt and implement a myriad of solutions on a massive scale, including quarantines, contract tracing, artificial ventilation, vaccines, and diagnostic testing. Governments, health authorities, politicians and decision makers mobilized in an unprecedented fashion, to prevent further spread and deaths from the SARS-COV-2 virus. The pandemic exposed significant weaknesses in our healthcare systems, globally, including the challenges and disparities in cancer care. The need for governments to prioritize public health and for a more comprehensive and coordinated approach to addressing the ongoing challenges in cancer care is clear.

The COVID19 pandemic has taught us many lessons about the importance of prioritizing public health and addressing health disparities. Despite being one of the leading causes of death worldwide, cancer has yet to receive the priority it deserves within Canada's provincial healthcare systems. Cancer, the silent pandemic, can no longer be ignored.

In this *colab.paper*, we examine the response to COVID19 and explore how it can be used to inform a renewed political effort to address the growing burden of cancer. We examine the role of governments, healthcare systems, partners, and communities, and shed light on the steps. We argue that by applying the lessons learned from the prioritization of the COVID19 pandemic, Canada can make meaningful progress towards improving outcomes for cancer patients. This will require a coordinated effort among government and nongovernment agencies, healthcare providers, patients and patient groups, and pharmaceutical industry (industry) stakeholders to reimagine cancer care and ensure that resources are appropriately allocated to address this urgent public health issue.

While COVID19 was a deadly and important event, the lessons learned during the pandemic offer solutions to prioritizing cancer (and healthcare) in Canada. Since the onset of the pandemic, social attitudes have shifted and healthcare has increasingly become a priority for Canadians, forcing decision makers to not only reimagine approaches to healthcare delivery but their role in steering an effective response to the growing burden of cancer in Canada. Using this as an opportunity to make significant change, in much the same way that governments and stakeholders have adapted to plagues and pandemics of the past. The COVID19 pandemic has shown us the importance of coordinated responses across different levels of government and the benefits that can come from this type of collaboration.

PLAGUES&PANDEMICS. A BRIEF HISTORY.

The emergence of infectious diseases leading to plagues and pandemics occurred regularly throughout history. These events have had an unparalleled impact on human history, shaping societies and cultures in ways that few other phenomena have. Paradoxically, this 'reset' on society has also sparked progress and innovations not only in science, but economic and political systems as well. This is put in perspective with the following review of some plagues and pandemics throughout history:

The Athenian plague is a historically documented event, occurring between 430-26 BC. Originating in Ethiopia and spreading throughout Egypt and Greece. The plague was widely documented by Athenian historian and general Thucydides, who wrote 'Through knowledge, patience and science we can prevail.'¹

The plague of Justinian is thought to have originated in Ethiopia moving through Egypt, or the Central Asian Steppes and quickly spread throughout the Eastern Roman Empire and its neighbours. After the initial outbreak in 541, intermittent plague outbreaks occurred every 8 to 12 years for two centuries and then disappeared for unknown reasons,² killing an estimated 15-100 million people, representing 25-60% of the population of Europe at the time. The high mortality caused by the disease is said to have contributed to the weakening and eventual decline of the Byzantine Empire.²

The Black Death originated in China in 1334 and swept across Central Asia into

Europe through the land and sea trade routes of the Silk Road in 1347. The Black Death is responsible for some 350-400 million deaths, killing as many as 30-60% of the European population and was followed by successive waves.³ It was at this time that Pope Gregory I introduced the blessing, "God bless you," for those who sneezed in the morning and might be dead by nightfall.⁴ The black death resulted in fundamental change for the working poor, creating a labour shortage that empowered workers, resulting in better working and living conditions.

The Spanish Flu was the first global pandemic in modern history. The pandemic, which may have originated in the United States, spread in at least three (3) distinct waves within a nine (9) month interval.⁵ The first wave (Spring/Summer 1918) caused high morbidity and low mortality, but both the second and third waves (Summer/Fall 1918 and Winter 1918–19) caused high mortality, resulting in approximately 500 million infections (25% of the world population) and 50 million deaths worldwide.⁶ Fifty percent of those killed over two years by the H1N1 influenza A pandemic were 40 years old or younger. The Spanish flu had an immense influence on civilization, with many governments embracing new concepts of preventive and social medicine. Rethinking public health policies, countries like France and Germany introduced centralized healthcare systems and the US adopted employer based insurance plans.⁷

HIV | AIDS started in the early 1980s in the United States causing significant public concern as HIV inevitably progressed to AIDS and ultimately death. A slowly progressing global pandemic cascading through decades of time, different continents, and different populations. HIV affects about 40 million people globally and has killed almost the same number of people since 1981. The HIV | AIDS pandemic not only led to new models of regulation (NOC/c) but also to the creation of a framework for patient advocacy within the research system that never existed before, allowing people with the disease to have a voice in how the disease is researched and treated.⁸

COVID19. In early December 2019, atypical pneumonia were reported in a cluster of patients in Wuhan (China) and were shown to be caused by a new coronavirus, called SARS-CoV-2.⁹ On March 11, 2020, the World Health Organization (WHO) declared this to be a pandemic.¹⁰ Within a few months, COVID19 spread globally leading to more than 662 million contaminations and nearly 7 million deaths worldwide as of January 2023.^{10A} The global threat brought on by COVID19 resulted in extensive government interventions, including lockdowns and other sanitary and societal measures, to safeguard public health, impacting economic development worldwide. Calling on science, innovation and technology to provide rapid solutions, at any cost.

Cancer, in parallel, is a global and deadly disease, and like pandemics, has severe socio economic repercussions. It is expected that the incidence and mortality due to cancer will reach pandemic proportions by 2040. According to the Global Cancer Observatory (GCO), approximately 29.4 million people worldwide will be diagnosed with the disease and an expected 16.2 million cancer related deaths will occur.¹¹ While cancer is a non communicable disease (NCD). both cancer and infectious diseases (like SARS-COV-2) pose a significant threat to public health. Pandemics have received considerable attention and resources, while cancer remains a significant public health issue that needs urgent attention. More efficient and effective medical treatment is only part of the solution. Cancer is no longer just a problem for healthcare systems. To achieve further progress, we need a collective and concerted effort that involves; all levels of government (FPT ministries of health, finance, innovation, science and industry, employment, workforce development and disability inclusion) working together to create

supportive policies and regulations, public and private partnerships collaborating to provide resources and expertise, patients and communities participating in decision making and advocacy, innovative technologies and solutions that improve prevention, diagnosis, treatment and care, policies and strategies that address the social determinants of health and reduce health inequalities, and funding and support for cancer research and innovation.



Cancer is a silent pandemic with no end in sight. To address this ongoing health crisis, we must allocate comparable resources and efforts to cancer as we have to COVID19.

THE BURDEN OF CANCER IN CANADA | THE SILENT PANDEMIC

Cancer is the leading cause of death in Canada, responsible for 28.2% of all deaths¹² with previous estimates showing that 43% of all people in Canada are expected to receive a cancer diagnosis in their lifetime.¹³ This translates to nearly 2 in 5 Canadians being diagnosed with cancer, and 1 in 4 dying from the disease.¹³ The number of new cancer cases and deaths in Canada is also increasing. According to the latest report by the Canadian Cancer Society (CCS), it is estimated that in 2022, more than 230.000 Canadians will be diagnosed and 85.000 will die from the disease.^{13,14} And according to data released by CCS, at the beginning of 2018, over 1.5 million Canadians were living with and beyond cancer, representing almost 1.7 million cancer cases that had been diagnosed in people still alive up to 25 years after their cancer diagnosis.¹⁵

In 2020 alone, 275.000 Canadians were estimated to receive a new cancer diagnosis (this number excludes Québec) and 83.300 to die from the disease.¹⁶ In 2021, new cancer diagnosis saw a decline to over 229.000 and mortality down to 84.600. In 2022, 233.900 Canadians are expected to have received a cancer diagnosis with an estimated 85.100 cancer related deaths.

In Canada, incidence will jump from 274.000 in 2020 to 401.000 by 2040. And mortality will increase from 86.700 deaths to 141.000 in the same time frame. Worldwide, the number of people who will receive a new cancer diagnosis in 2040 will jump to 30.2 million people.



In addition to its impact on health, cancer is costly. The economic burden of cancer care in Canada rose from **2.9 billion in 2005 to 7.5 billion in 2012**, mostly owing to the increase in costs of hospital based care. From a societal perspective, cancer related costs were 26.2 billion in 2021 with 30% of costs borne directly by patients and their families. Economic burden is highest in the first year of care after diagnosis. During this time, costs amounted to almost 4.8 billion in 2021.¹⁷

Since 2020, the COVID19 pandemic has infected over 4.5M Canadians and has killed nearly 50.000 people across the country. During this same period, an estimated 253.000 Canadians have died of cancer related deaths. These statements are not meant to diminish the horrific impact that COVID19 has had globally, but rather to reinforce the significant advances that were made in a short amount of time.

The COVID19 pandemic and the experience with vaccine development have clearly shown us that when we come together, when we pool our efforts and resources, it is possible to make unprecedented progress. A coordinated global effort to end the COVID19 pandemic led to lifesaving vaccines in less than two years.

A google search for COVID19 will bring up databases from across the globe that can provide **real time information on the number of new cases and deaths.** Today, after decades of investment into cancer research and care, no such site exists to provide comparable accurate information, provincially, nationally, or internationally. And in Québec, in 2023, no formal collection of cancer related data exists.

WHY IS CANCER LESS IMPORTANT TO CURE THAN COVID19

Could the same results be obtained from better coordination for action on cancer?

For over a decade, cancer has been the leading cause of death in Canada and yet unlike other jurisdictions, there is no national cancer strategy in place to reduce the burden of cancer on health systems and Canadians. We acknowledge the Canadian Partnership Against Cancer (CPAC), and its contribution to cancer control efforts since its inception. However, CPAC lacks the comprehensive approach and funding as well as the necessary political authority to implement policy changes. Falling short in comparison to other national strategies (EU Beat Cancer, US Moonshot Initiative).

CANCER PREVENTION AND TREATMENT ON US AND EU AGENDAS

Historically, cancer has received alarmingly little political attention, with limited visibility on national and international agendas. Since 2016, politicians in the United States (US) and the European Union (EU) have strengthened their responses to the growing burden of cancer, investing and prioritizing research, prevention, and treatment initiatives to improve outcomes for patients and reduce the incidence of cancer in their populations.

US CANCER MOONSHOT

The Cancer Moonshot initiative aims to accelerate scientific discovery in cancer, foster greater collaboration, and improve the sharing of cancer data. Launched in 2016 under President Barack Obama, the cancer moonshot was initially funded through the 21st Century Cures Act with 1.8B\$ to fund the initiative over 7 years for cancer research in many areas including studies on cancer disparities, new clinical trial networks to drive drug discovery, and innovative projects examining childhood cancer. The initiative also sought to bring together researchers, healthcare professionals, patient advocates, and other stakeholders to collaborate and advance the understanding and treatment of cancer.

The new law streamlined cancer related decision making at the FDA through the formation of an oncology centre of excellence, so that effective treatments can be approved faster, and patients can have more direct access to information about the regulatory process. In 2022, an additional 195M\$ of funding was announced to reignite the Cancer Moonshot initiative, highlighting new goals: to cut today's age adjusted death rate from cancer by at least 50 percent within 25 years and to improve the experience of people and their families living with and surviving cancer.

The Biden Harris administration is working to mobilize an entire government, reestablishing leadership with a *White House cancer moonshot coordinator, and the formation of a cancer cabinet, convened by the White House* and bringing together departments and agencies across government to address cancer on multiple fronts.¹⁸

The Cancer Moonshot Initiative has also established several partnerships and collaborations to facilitate knowledge sharing and promote progress in the fight against cancer. This includes partnerships with pharmaceutical companies, academic institutions, and patient advocacy organizations, as well as international collaborations to share best practices and advance cancer research on a global scale.¹⁹

EU BEAT CANCER

Europe recognized the urgent need for a renewed commitment to cancer prevention, treatment and care that recognized the growing challenges, and opportunities to overcome them. The Beat Cancer Plan, launched in February 2021, was built to respond to the need for; a whole of government approach that focuses on the patient and maximizes the potential of new technologies and insights; strengthens cooperation and opportunities for EU added value; eradicates inequalities in access to cancer knowledge, prevention, diagnosis and care; and delivers improved health outcomes to patients. It reflects a political commitment to leave no stone unturned to take action against cancer.

4€ Billion has been earmarked for the Beat Cancer Plan, which is structured around four key action areas with the most value: (1) prevention; (2) early detection; (3) diagnosis and treatment; and (4) quality of life of cancer patients and survivors. It also has policy objectives built into the plan to enable member states to share resources and expertise, allowing patients across the EU access to better care.

The Beat Cancer Plan, like the US Cancer Moonshot, recognizes the value of partnerships and is based on a 'Health in All Policies' multi stakeholder approach and is the result of an extensive consultation process. But most importantly, Europe's Beating Cancer Plan places the interests and wellbeing of patients, their families, and the wider population at the centre of their actions.¹⁹

In May 2017, health leaders from world governments made a commitment to further invest in cancer control as a public health priority, passing the World Health Assembly Resolution 70.12, CANCER PREVENTION AND CONTROL IN THE CONTEXT OF AN INTEGRATED APPROACH ²⁰ at the 70th World Health Assembly (WHA) in Geneva. The resolution provides a framework for countries to take action on cancer by identifying policy opportunities to scale up access to prevention, diagnosis, treatment, and care services.

The resolution identifies 22 priority actions, grouped into four key areas; data; early detection; timely and accurate treatment; and supportive and palliative care. The WHO calls on governments to embed these priorities into national cancer control plans that can drive the introduction or scale up of services, in line with national priorities and serve as an important platform to coordinate national stakeholders around common goals.

SEVEN LESSONS (FOR PRIORITIZING CANCER IN CANADA)

CANADIANS WITH CANCER ARE DYING TO BE A PRIORITY

The care of people with cancer in Canada demands urgent attention from all stakeholders. Regardless of the efforts and successes of other countries (politically led) to prioritize cancer, Canada has yet to make considerable progress in this regard.

Despite the complexity of the issue, the challenge of coordinating efforts provincially, competing priorities and limited government resources, change is needed. However, for real change to occur, it is essential that all stakeholders, government agencies, healthcare providers, researchers, patients and patient groups, and industry work collaboratively, even with these conflicting interests. Governments and government agencies must take the lead in this effort and address these issues as a matter of urgency. By prioritizing cancer as a political issue, Canada can take significant strides towards reducing the burden of cancer and improving the lives of those affected by it. Let us work together to make cancer a national priority and ensure that no Canadian is left behind.

THE SEVEN LESSONS

The COVID19 pandemic has brought to the forefront the critical importance of prioritizing healthcare on political agendas. Governments around the world faced an unprecedented challenge in responding to the crisis, revealing the shortcomings and vulnerabilities of healthcare systems. However, amidst the chaos and devastation caused by the pandemic, there are valuable lessons to be learned that can be applied to cancer.

LESSON ONE

COLAB(ORATION)

Perhaps one of the most critical lessons to occur during the pandemic was the impact of the collaborations that materialized across several sectors. Public private partnerships have been essential in the funding and conducting of research, including vaccines, as well as their procurement and equitable distribution. The scientific community came together to share data, knowledge, and expertise to accelerate our understanding of the virus and in the development of vaccines and treatments. The patient community was recognized as an essential partner in the pandemic response, with patients providing critical insights (how the virus and vaccine affects women differently, long covid amongst a few key items) and participating in clinical trials. These collaborations have been key for effective action against the virus, demonstrating the power of cross sector partnerships in addressing and accelerating complex public health challenges.

INTERNATIONAL COLLABORATION

The COVID19 pandemic accelerated the adoption of numerous policies and innovations, such as the widespread use of telehealth, and created a pressing need for enhanced communication channels within and across various professionals from different organizations. The importance of international cooperation was widely recognized in the global response to the pandemic. Spurring interdisciplinary cooperation and national coordination in many ways, including collaborations between researchers, clinicians, and public health officials as well as between different countries and regions.²¹

Countries have worked together to share information and resources, including sharing scientific data and expertise, developing and distributing vaccines and medical supplies, and coordinating travel restrictions and quarantine measures.

The pandemic has also reshaped the cultural landscape in science, setting aside competition to accelerate the exchange of information and ideas. Necessitating a reassessment of longstanding incentive structures in the scientific community, which have traditionally emphasized individual achievement and specialization, rather than prioritizing collective progress over individual recognition.²²

Within weeks of the first case of COVID being reported, Chinese researchers had identified the virus they suspected of causing the disease and had decoded an initial genome sequence. During the first 24 hours after publication, an evolutionary biologist in Scotland had figured out the similarities between this virus and SARS-CoV-1 and shared the findings immediately online. A researcher in the U.S. openly published the new virus' phylogenetic tree. And another started reverse engineering a live virus from the sequence, letting colleagues around the world know that the first steps towards developing an antibody test were already underway.²³

Collaboration has been key in the fight against COVID19 and can serve as a blueprint for cancer research and policy. By leveraging a similar collaborative approach, we can tap into the collective expertise and resources of various scientific fields and research institutions to accelerate progress towards the development of more effective cancer treatments and effective policies that bring them to the cancer patients who need them.

While COVID19 has demonstrated the value of open science and international collaboration, it has also **exposed the gaps in science policy, a reminder that science, technology, and innovation policy are essential to build** THE PANDEMIC HAS PROVIDED THE MOTIVATION FOR DIFFERENT DISCIPLINES TO COME FOGETHER AND PUT UP A UNITED FRONT AGAINST CANCER. *resiliency and enable sustainability.* Highlighting the need for more equitable and sustainable science policies, which prioritize investments in research and development, and emphasize the **importance of integrating science and technology into policy frameworks.**

PUBLIC PRIVATE PARTNERSHIPS

The onset of COVID19 highlighted a lack of preparedness among government departments and public sector organizations in countries, globally. In this context, the private sector has emerged as a critical partner, leveraging its capacity for innovation and rapid response to develop and enhance existing services. Collaborations between private and public sector entities have been instrumental in strengthening the pandemic response and enabling the development of new solutions to emerging challenges, with Canadian industry stepping in to offer its support, partnership, and expertise. Many of these partnerships between public and private actors worked efficiently to speed up research by using public funding, private capital, and foreign direct investment to enhance production facilities, to streamline approval and administrative processes and to make planning for future supplies more efficient.²⁴

Public private partnerships (PPPs) are collaborations between the public and private sectors in which each party contributes skills, expertise, and resources to achieve a common goal. The purpose of PPPs is to leverage the strengths of both sectors to provide public goods and services more efficiently and effectively than either sector could achieve alone. The benefits of PPPs include the ability to share risks and rewards, to increase the efficiency and effectiveness of public services, to attract private investment, to foster innovation, and to deliver projects on time and within budget. PPPs can also lead to the creation of new jobs, economic growth, and improved quality of life for citizens.

There have been several successful public private partnerships during the COVID19 pandemic in Canada, including

COVID19 Immunity Task Force. The COVID19 Immunity Task Force (CITF) was created in late April 2020 with the goal of catalyzing, supporting, funding and harmonizing research into COVID19 immunity to inform Canadian policymakers, allowing them to make evidence based decisions. The COVID19 Immunity Task Force is a partnership between the Government of Canada, several Canadian universities, and the private sector. The task force is aimed at tracking the spread of COVID19 in Canada and determining the extent of population immunity to the virus. The partnership involves providing funding and resources to support research, as well as coordinating efforts to ensure the timely sharing of data and information.

Helping Canadian Industry produce Ventilators. At the outset of the COVID19 outbreak, the Government of Canada issued a call to action to Canadian businesses and manufacturers to step up production of much needed "made in Canada" medical supplies, including ventilators. Through the national research council, the program was able to provide funding and support to manufacturers to increase production capacity and accelerate the delivery of ventilators to hospitals and healthcare providers. These interactions have led to a collective building and sharing of knowledge and expertise across the organization which has contributed to a number of successes, including CAE (Montréal, QC), a global leader in the delivery of training for the civil aviation, defence and security, and health care markets.

Code Life Ventilator Challenge. The Code Life Ventilator Challenge was a two week international design competition to create a simple, low cost, easy to manufacture and easy to maintain ventilator to serve COVID19 patients. A joint initiative between the Montreal General Hospital Foundation and the Research Institute of the McGill University Health Centre (MUHC), backed by Scotiabank, the Canadian Medical Association (CMA) and MD Financial Management (200.000\$). By the two week deadline, they received more than 2,600 challenge entries from engineers, scientists, programmers, and medical technology experts in 90 countries.

The Government of Canada, through Innovative Solutions Canada, launched specific challenges to harness the innovations of Canadian entrepreneurs to meet the (then) immediate needs of the health system. The government rapidly selected the best projects to accelerate development and testing of promising innovations that would have a direct impact on our health care response.

COVID19 Supply Council. The COVID19 Supply Council is a partnership between the Canadian government and the private sector, bringing together a diverse group of leaders to provide the government with advice on the procurement of critical goods and services required as part of Canada's COVID19 response and recovery. Aimed at ensuring Canada's supply chains remain strong and resilient during the COVID19 pandemic. The partnership involves working closely with the private sector to identify and address supply chain challenges, as well as coordinating efforts to ensure the timely delivery of critical supplies and equipment.

CanCOVID. A network of active researchers, academics, patient partners, decision makers, and industry partners dedicated to an evidence informed response to the COVID-19 pandemic. The purpose is to support the scientific effort and community in their work through encouraging multidisciplinary collaborations and helping to connect people and resources to enable rapid

knowledge mobilization and science to policy action. Providing government partners with a better line of sight to existing and emerging COVID-19 science and research.

The COVID19 pandemic has demonstrated the potential of public private partnerships (PPPs) to enhance the delivery of healthcare services in Canada, many demonstrating the potential for outcomes focused, creative ways of mobilizing skills, funds, and capacities to help achieve public health goals. Drawing on the successes and lessons learned from this pandemic, PPPs can be leveraged as a model for improving and addressing the complex challenges facing cancer care in Canada. By pooling resources and expertise through PPPs, we can leverage the strong relationships between industry and government to enable rapid and effective transformations. This can include simplifying procurement, accelerating the development and adoption of new technologies in cancer care, promoting data sharing and collaboration, supporting provincial and national decision makers through a diverse range of public sector partners, and fostering innovation and long term planning. By harnessing the power of PPPs, we can enhance the quality of cancer care, improve outcomes for patients, and strengthen Canada's healthcare system overall.

LESSON TWO

(re)IMAGINING PATIENT PARTNERSHIPS and care

Health disparities and social determinants of health have profoundly and unevenly impacted COVID19 morbidity and mortality. Health disparities and social determinants of health, including poverty, physical environment (smoke exposure, homelessness) and race and ethnicity²⁵ have had a considerable impact on COVID19 outcomes.²⁶ Social distancing and quarantine measures have had a disproportionate impact on people with lower socioeconomic status, who may have less access to resources for remote work or education, and less ability to stock up on food and supplies. This has spurred efforts to improve patient partnership models in healthcare, demonstrating the value of applying a healthy equity lens to engage at risk communities, communicate with them effectively, share data, and partner with them for program implementation, dissemination, and evaluation.²⁷

Examples of engagement across diverse communities, community organizations, and local health departments, hospitals, and universities applied during the pandemic highlight the opportunity to apply lessons learned for sustained changes in how public health and its partners, which includes patient experts (patients with lived experience of the disease), patient organizations, and advocacy groups, can work collectively to prevent disease and promote health for all.

Patient and caregiver engagement in care and program planning is fundamental to person centered care, however the resources, skills, views, priorities and preferences of patients, carers and the communities which support them are not well recognized, valued, or systematically used to improve care. Patient engagement and partnerships in both research and policy creation has proven itself to be crucial, and innovative ways are needed to meaningfully engage and nurture relationships for successful long term patient partnerships in cancer care.²⁸

The pandemic has accelerated the need for patient centered and community based models of care that prioritize collaboration, communication, and partnership in improving health outcomes beyond tokenism. Evolving from the patient engagement movement to include more collaborative partnership models in addition to traditional consultation roles. These partnership roles should aim to place patients on an equal footing with healthcare professionals, researchers, managers and policymakers and include patients, family and caregivers formally contributing to all facets of the health system including the training of healthcare professionals, health research, policy making and regulation.²⁹

As well as the under recognized value of patient partnerships, a lack of consistent terminology for patient engagement and partnerships has added an additional barrier to their effective implementation. The terms patient involvement, engagement and partnerships are often used interchangeably, and their definitions can vary depending on the context. This inconsistency can lead to confusion among healthcare providers, patients, and policymakers about the roles and expectations of patients in healthcare. Furthermore, inconsistent terminology can make it difficult to compare and evaluate the effectiveness of patient engagement and patient partnership initiatives across different healthcare systems and organizations. To overcome these challenges, it is important to establish clear and consistent definitions for patient engagement and patient partnerships that are widely accepted and adopted across the healthcare industry. This will help ensure that patient engagement and patient partnership initiatives are effectively implemented and evaluated to improve the quality of care and support for patients.

While the healthcare industry has recognized the need for patient centered care and the importance of involving patients in care decision making processes, there continues to be a lack of knowledge and understanding of how to effectively partner with patients to improve health systems. This lack of 'know how' in engaging and partnering with patients, has led to a disconnect between health systems, policymakers and patients, resulting in policies and systems that fall short. It is essential for stakeholders to develop the necessary skills to engage and partner with patients meaningfully, if patient centric care is really at the heart of healthcare.

Patient engagement and partnerships are more than just any one project or program. It is about culture change, where patient engagement is more than an expectation, it is innate and an instinct, rather than the exception. This culture change balances the power dynamics between providers and patients and fully recognizes and appreciates the expertise of lived experience that patients, families and caregivers bring as true partners in healthcare.³⁰

The pandemic has shown us the potential of collaboration between scientists, policymakers, and the public in ensuring a rapid response to a healthcare crisis. By applying these lessons learned to cancer, working together to promote innovation in cancer care, develop and implement evidence based policies and raise public awareness of the importance of cancer prevention and early detection. This collaborative approach is crucial for improving outcomes for cancer patients but also for building resilient and sustainable healthcare systems to address Canada's healthcare crisis. A strategy that recognizes health system partnerships will be essential in addressing the complex challenges facing healthcare.

Reimagining patient care also requires us to rethink how care is delivered. Hospitals became increasingly preoccupied with treating and caring for patients with COVID19, and in order to not overburden already burdened hospitals, non COVID primary and specialty care services were downscaled or halted, with continuing impact from these backlogs. Consequently, affecting the screening, diagnosis and treatment of cancer causing ongoing pandemic related delays. While the focus has been on hospitals, primary care clinicians, who serve as the gatekeepers to healthcare, have played a vital and multifaceted role in the pandemic response, also ensuring the continuity of care throughout the crisis. *Health systems with strong primary care achieve better health outcomes and improved health equity at lower cost*.^{30A} Primary care is not only a critical component to our healthcare systems, but also to cancer care delivery. Primary care physicians are often the first point of contact for those presenting with

Our Care

NEW NATIONAL DATA: More than 6.5 million adults in Canada don't have a regular family doctor or NP – that's more than 1 in 5 adults.

- 22% of people in Canada age 18+ do not have a family doctor or nurse practitioner (NP) who they see regularly for care.
- » More people in Québec, British Columbia, and the Atlantic region reported not having a family doctor compared with people in Ontario and the prairie region.

Explore the data yourself: data.ourcare.ca



cancer, thus essential in the early detection of cancer. They are also critical in providing wraparound services to those with cancer, in turn reducing healthcare utilization costs and improving patient outcomes. The importance of primary care, while always recognized, has been brought back to the forefront, confronted with the reality that not all Canadians have access to primary care. Results from the <u>OurCare</u> national survey reveals that 6.5M Canadians, or more than one in five, do not have access to a primary care clinician for routine care. Access to primary care is an essential component of a healthcare system, especially during a pandemic, and must be able to meet the challenges of ageing populations, a growing burden of cancer and increasing health conditions. For health systems to be resilient against ongoing health crises beyond COVID19, a strong primary and community health care – the frontline of all health systems – is essential. Prioritizing primary care in a post pandemic world is essential to ensure that all Canadians have access to quality healthcare services.

LESSON THREE

RESILIENCE & SUSTAINABILITY. BUILDING STRONGER HEALTH SYSTEMS

COVID19 has caused an unprecedented global crisis, with social and economic disruptions, vulnerable healthcare systems already struggling to contain costs and meet demand have had their limitations and weaknesses exposed, and millions of lives lost. With the rapid spread of the virus, businesses were forced to adapt operations at meteoric speed, restructuring and reinventing themselves seemingly overnight. The importance of resiliency and sustainability across different sectors such as healthcare, finance, technology and manufacturing were highlighted during the pandemic and the need for systems to be agile, adaptable, and flexible to respond to rapidly changing circumstances was paramount with organizations scaling innovation at speed.

In the aftermath of the pandemic, the ability to adapt will be the key to resilient and sustainable business models, including healthcare. While resilience is a core concept in disaster risk reduction, its application in health systems is relatively new.

Resiliency refers to the ability of the healthcare systems and organizations to adapt and respond effectively to challenges, crises, and unexpected disruptions, while maintaining essential services and functions.³¹ A resilient healthcare system is one that can quickly and effectively respond to challenges, such as pandemics, natural disasters, or supply chain disruptions, without compromising the quality of care.

Sustainability, on the other hand, refers to the ability of the healthcare system to maintain and improve essential services and functions over time, while using resources efficiently and responsibly. A sustainable healthcare system is one that can meet the current needs of patients while ensuring that resources are conserved for future generations.³²

The resilience of health systems during the pandemic can provide critical lessons to help strengthen countries' preparedness, response and approach to future health challenges, including the growing burden of cancer. Application of lessons learned during the pandemic are necessary to enhance resilience, the ability to transform and evolve will be critical in meeting long term structural challenges to health systems.

Health System Sustainability. A health system's ability to improve population health, by continually delivering the key functions of providing services, generating resources, financing and stewardship, incorporating principles of financial fairness, equity in access, responsiveness and efficiency of care, and to do so in an environmentally sustainable manner.

Health System Resilience. A health system's ability to prepare for, absorb, adapt to, learn, transform and recover from crises born of short term shocks and accumulated stresses, in order to minimise their negative impact on population health and disruption caused to health services.

source. Sustainability and Resilience in the Canadian Health System. Partnership for Health System Sustainability and Resilience November 2022



Building the resilience and sustainability of our health systems has never been more urgent. The pandemic has required health systems to rapidly adapt and respond* (resilient) to the unprecedented challenges and changing demands of the pandemic. Surge capacity for critical care was raised while non emergent care including diagnostic tests, operations and procedures were deferred.

Flexibility and agility in the healthcare workforce, including the ability to scale up and down resources, such as hospital beds, medical equipment, and healthcare workers, as needed, were essential in facilitating the development of new care models, enabling HCPs to provide essential services to patients while minimizing the risk of transmission. These models hold enormous promise for expanding access, bringing down costs and improving the quality of care and may shape the future of healthcare beyond the pandemic.

Little data and evidence available to inform policy choices and decision making at the start of the pandemic led to an increased focus on health data availability, reporting, and timeliness to inform policy choices and resource allocation. The need for timely data to inform decision making accelerated the use of real world data (RWD) to investigate diseases and treatments and inform policy making.

Fee schedules were altered to encourage virtual visits to reduce the risk of transmission, protect patients with chronic disease and conserve personal protective equipment (PPE, rapidly expanding the use of telemedicine and virtual care.³³

Although the COVID19 pandemic led to positive transformations, it also revealed vulnerabilities in our health systems, particularly how our health systems were underprepared, understaffed, and under resourced.³⁴ Overall, these vulnerabilities have highlighted the urgent need for investments in healthcare infrastructure, personnel, and resources to ensure that health systems are prepared to respond to future crises.

UNDERSTAFFED

A resilient health system is dependent on a resilient healthcare workforce. Healthcare workers, who have been on the frontlines of the pandemic response, providing critical care to patients while facing unprecedented challenges and the risk of infection are the backbone of any healthcare system, and their ability to provide quality care is essential to ensuring that the system can respond effectively to public health crises and other challenges. Workforce shortages pose one of the biggest threats to resilient health systems, with three million extra workers required across the OECD.³⁴

UNDER RESOURCED

Many countries increased their investments in workforce, digital infrastructure, and equipment in response to the pandemic. These investments were necessary to ensure that health systems could respond to the surge in demand for healthcare services and to support the delivery of care in new and innovative ways. In order to maintain these investments, governments and healthcare organizations will need to prioritize health system resilience and sustainability as a key policy objective. This will require sustained funding for health systems, as well as ongoing efforts to evaluate and improve the effectiveness of healthcare investments. By maintaining investments in the workforce, digital infrastructure, and equipment, we can build on the gains made during the pandemic and ensure that health systems are well prepared to respond to current and future challenges. Investment in health systems will require resources upfront and over the long term. While resources required are significant, the return on investment can be substantial both in normal times and during crises. Investing in healthcare infrastructure, technology, and workforce development can improve the overall health of the population, increase economic productivity, and reduce the burden of disease on society.

UNDER PREPARED

Three months (September 2019) before the outbreak of SARS-COV-2, the Global Preparedness Monitoring Board (GPMB) issued a warning to the international

community that a pandemic was only a matter of time, and that the world was not prepared. They were right.

Lack of investment in healthcare and prevention led to our unpreparedness during the pandemic. The adverse effects felt during the pandemic has underscored the importance of making smart investments to reinforce the resilience of health systems. This will help safeguard the health of populations, build strong foundations for health systems, and support frontline healthcare workers. Investing in more resilient health systems is essential for creating stronger and more resilient economies. By doing so, we can realize significant economic and societal advantages.³⁴

The pandemic has expedited the pace of innovation and adaptation in healthcare systems, resulting in closer collaborations among stakeholders, prioritizing the needs of patients and their families, and utilizing data to drive decision making while emphasizing health equity. These efforts have led to the development of more resilient and sustainable models of care. The lessons learned from the pandemic are expected to have enduring implications for the future of healthcare delivery.

LESSON FOUR

DATA. the foundation for evidence based action

Data has played a significant role in shaping the public health response and informing decision making during the pandemic. The collection and analyses of data in real time has been essential in guiding policy decision making, resource allocation, and public health interventions. Governments and public health agencies around the world have collected data that has been crucial in tracking the spread of COVID19, identifying hotspots, and understanding its impact on different population groups. Data has also been vital in developing COVID19 vaccines, with researchers using genomic sequencing data to identify and track variants of the virus. Additionally, data on vaccine effectiveness, side effects, and adverse reactions has informed vaccine distribution strategies and helped to build public trust in the vaccine.

DATA DRIVES BETTER DECISIONS

Throughout the pandemic, the gathering and analysis of data has played a critical role to forecast COVID19 cases, model potential scenarios, including case counts and hospitalization rates, monitor mobility patterns, including travel data, to reduce the virus's spread, contact tracing to identify individuals who may have been exposed to the virus and to track the potential spread. We also saw countries learning from one another, sharing tools and approaches that allowed them to use data for action quickly. The use of real time data was accelerated during the pandemic to provide available economic and health data to inform decision and policy making. This allowed governments to respond nimbly, to use predictive models and to seek patterns to allow them to assess and identify valuable patterns to shape and inform decision and policy making quickly and continuously. The use of real time data was also used to influence population behaviour, urging citizens to "flatten the curve." While the use of data proved to be an effective tool to respond to the pandemic it also highlighted issues that make it a challenge to collect, share, and use health data for the benefit of Canadians.

Data visualization tools, such as dashboards, have also been widely utilized during the pandemic, providing timely and accurate information to inform public health responses. In Canada, various dashboards were developed to track COVID19 cases, hospitalizations, and deaths, as well as vaccination rates. These dashboards have been successful in communicating valuable information to the public and guiding decision making. Their application in cancer can create a powerful tool that monitors a set of key indicators at the Canadian level and would help to chart successes and disparities. **(WHAT GETS MEASURED GETS DONE)**. The success of these transparent and accessible dashboards in communicating crucial information to the public in real time, guiding decision making, and mitigating the impact of the pandemic on public health and the economy cannot be overstated.

The pandemic has also exposed the limitations of existing digital infrastructure and highlighted the need for increased investment in digital public health infrastructure, including interoperable health information systems, secure data sharing protocols, and reliable broadband access. By investing in digital health and data tools, we can better prepare for future public health crises and improve health outcomes for all.

Data standardization is a complex process that requires collaboration between healthcare providers, researchers, and policymakers. It involves developing standardized protocols for data collection, ensuring that data is accurately recorded, and implementing quality control measures to ensure data accuracy and completeness. While abundant data is available, integrated and holistic data strategies are needed to maximize the value of the information and decision making derived from this data. The COVID19 pandemic has underscored the importance of data standardization and interoperability in the healthcare industry but has also highlighted the challenges associated with this.

Lessons derived from the COVID19 response in Canada and elsewhere, exposed the need for a shared approach to accelerate the use of data science in public health. Providing the opportunity for governments to refresh and strengthen their existing data strategies, utilizing data science tools and approaches to collect, manage and use data to strengthen health systems.

CLOSED WORLD. OPEN SCIENCE

Open science is a growing movement within the scientific community that aims to make research fully transparent, reproducible, collaborative, and accessible to everyone. However, the health sciences have been slower to adopt the principles of open science than other scientific disciplines due to various complex incentive structures that discourage it. Despite this, the COVID19 pandemic has highlighted the importance of open science, and its feasibility has become undeniable.

Open science has facilitated rapid and collaborative sharing of scientific knowledge, data, and tools among researchers worldwide, which has led to the development of effective vaccines, treatments, and public health interventions at an unprecedented pace. Scientists and governments have overcome the usual barriers to open science, aligning incentives with social benefit and demonstrating the necessity of collaboration. This has resulted in an unprecedented number of researchers working together towards a common goal, with numerous resources and information sharing technologies at their disposal. Never before have this many researchers across the globe worked together towards one common goal with as many resources and information sharing technologies at their disposal. The unprecedented level of global collaboration and resource allocation during the pandemic has demonstrated the immense potential for scientific progress when researchers work together to achieve a shared objective.

As well as open science, the research community was quick to adapt to COVID19 restrictions, with the majority of conferences effectively adopting a virtual format. This format to eliminate geographical, financial and administrative barriers has increased accessibility, diversity, and inclusivity, providing access to the same groundbreaking information to anyone, at anytime, anywhere.

LESSON FIVE

(DISRUPTIVE) INNOVATION for transforming cancer care

The COVID19 pandemic has also been a major catalyst for innovation, resulting in unprecedented transformation and adoption of digital health and process innovations. In just a few months, the COVID19 crisis brought about years of change in the way companies in all sectors and regions do business, accelerating digitization of customer and supply chain interactions, as well as internal operations.^{35a} The COVID19 pandemic has dramatically transformed the world we live in, affecting every aspect of our lives, including the way we work, learn, and interact with others. During this challenging time, disruptive innovations have played a crucial role in enabling us to adapt to this new normal. These technologies have revolutionized the way we communicate, access healthcare, and conduct business, allowing us to stay connected and productive while staying safe and socially distant. From remote work

and virtual education to telemedicine and e-commerce, disruptive innovations have had a profound impact on our daily lives during the pandemic.

DIGITAL TRANSFORMATION

The digital transformation has been accelerated by the pandemic and suggests that it could continue to accelerate beyond the current recovery. Growing evidence shows that the pandemic has pushed firms in all sectors to overhaul their business models more aggressively than planned. An unprecedented catalyst for digital transformations across all sectors, as organizations sought to adapt to the new reality of remote work, social distancing, and reduced physical interactions. From healthcare to education, entertainment to retail, and finance to manufacturing, the pandemic has accelerated the adoption of innovative digital technologies that have fundamentally changed the way we live, work, and interact with each other. These digital transformations have not only helped businesses and organizations survive the pandemic but have also paved the way for a more connected, efficient, and resilient future.

The slow adoption of innovative health technologies prior to the pandemic can be attributed to a combination of disparate regulations, prolonged procurement processes, and poor access to funding that have prevented numerous enterprises from introducing digital innovations to revolutionize healthcare. This underscores the unhurried pace at which the commercialization of health tech had been unfolding in Canada.

DIGITAL HEALTH

The pandemic has led to considerable growth of the digital health industry in Canada, with jurisdictions removing bureaucracy that had impeded digital innovation. COVID19 forced both providers and regulatory bodies to turn to alternative ways of providing healthcare while limiting exposure to the virus. This has led to reduced bureaucracy around procurement, privacy and security, and billing codes to support payment for virtual care. Within weeks of the onset of the pandemic, virtual care, through the use of telephone and video visits, rose from less than 2% of all ambulatory visits at the start of 2020 to as high as 70% by mid May of the same year.³⁵

Virtual care is a component of digital health, but important distinctions exist between digital health and virtual care. Digital health is defined as "the use of information technology/electronic communication tools, services and processes to deliver healthcare services or to facilitate better health." While virtual care is "any interaction between patients and/or members of their circle of care, occurring remotely, using any forms of communication or information technologies." Virtual care is a subset of digital health that includes provision of care over many media, including video, audio, and asynchronous messaging.^{35A} Digital health also includes giving patients

ownership of their personal health data and ensuring data interoperability across Canada.

Digital health is an increasingly essential component of a high performing healthcare system. Digital health care technologies promise benefits across Canada's public health care system including cancer care. However, digital health innovation is relatively nascent in cancer care, which represents the fastest growing area of healthcare spending. Opportunities for digital health innovation in oncology include patient facing technologies that improve patient experience, safety, and patient clinician interactions; clinician facing technologies that improve their ability to diagnose pathology and predict adverse events; and quality of care and research infrastructure to improve clinical workflows, documentation, decision support, and clinical trial monitoring.³⁶

According to the government of canada's website 'policymakers should enable public health care providers to best leverage the forces of competition. By ensuring that providers can adopt the newest innovations, the Canadian health care system can foster the development of the next generation of digital products and services. Such procompetitive policies will allow health care providers to offer the best quality care to their patients, regardless of whether it is delivered through a digital service or an in person visit. To foster competition in the digital future, Canada's public health care policy needs to be modernized. When policymakers adapt rules, it is important that health care providers are given the flexibility to choose the tool or method of care that is most appropriate. In turn, this will allow providers to take advantage of competition in driving investments in innovation. This leads to better patient outcomes, lower costs, and a more promising future for the Canadian *public health care system.*³⁷ Despite the federal government's acknowledgment of the critical importance of digital health, the current, fragmented, provincial approach to health care creates barriers to the efficient procurement of technologies, interoperability, and data sharing, hindering actual innovation. This heavily siloed system not only disadvantages the healthcare system and Canadian digital health companies but also patients who depend on lifesaving innovations and quality of life improvements offered by these technologies in a growing global digital health industry.

The rapid shift towards digital healthcare has implications for healthcare systems in Canada, including the potential to improve the efficiency and quality of care, reduce costs, and enhance patient outcomes. However, the widespread adoption of digital technologies requires significant investments in infrastructure, training, and governance. In addition, the shift towards digital healthcare may exacerbate existing health inequalities, as patients who lack access to technology or have low health literacy may be left behind. Healthcare systems must address these challenges to ensure that digital technologies benefit all patients and improve health equity.

ROLLING REVIEWS

The need for increased regulatory agility was recognized during the pandemic, and Health Canada has recognized this need as an opportunity to modernize and streamline its regulatory processes. A rolling review is a regulatory process in which health authorities review data from clinical trials for a vaccine or treatment as it becomes available, rather than waiting for the full data set to be submitted at the end of the trial. This allows regulators to start the review process early and speed up the overall timeline for approval.

The operational pressures of the pandemic have necessitated rapid decision making and flexibility, and regulatory agencies around the world have responded by offering new ways of working to help combat the pandemic. The rolling review procedure is an important and successful example of this, allowing Health Canada to expedite the regulatory approval process for COVID19 vaccines and treatments while still ensuring that they meet rigorous safety and efficacy standards.

The success of the rolling review process during the pandemic has also demonstrated the potential for greater regulatory agility in the future. Health Canada has indicated that it plans to build on the lessons learned during the pandemic and to continue to modernize its regulatory processes to better meet the needs of patients and industry stakeholders.

CERTAIN UNCERTAINTY

During the pandemic, Canadian regulators, health technology assessment (HTA) bodies, and payors have demonstrated a willingness to embrace uncertainty and adopt innovative strategies to respond to unforeseen challenges. Health Canada implemented expedited review processes for certain medical devices and drugs to ensure timely access to critical therapies.

On March 30, 2020, Health Canada pursuant to subsection 30.1(1)³⁸ of the Food and Drugs Act made the annexed Interim Order Respecting Drugs, Medical Devices and Foods for a Special Dietary Purpose in Relation to COVID19, which addressed the exceptional importation of drugs, medical devices, and foods for a special dietary purpose (e.g., infant formula) in relation to COVID19. The March 30 Interim Order allowed certain drugs and devices that do not fully meet regulatory requirements to be imported and sold in Canada. In September 2021 new amendments to the Food and Drug Regulations in Canada were published to create a permanent pathway for

the exceptional importation and sale of foreign authorized drugs and medical devices into Canada in response to a shortage. These regulations entered into force on March 2, 2022.

As part of the government's broad response to the pandemic, Health Canada introduced innovative and agile regulatory measures.³⁹ Adaptive regulatory pathways that allowed for the approval of treatments and vaccines based on limited clinical data were implemented, with a commitment from manufacturers to continue to collect and analyze data as it became available. This approach allowed for quicker access to potentially lifesaving treatments and vaccines while still ensuring the ongoing evaluation of their safety and efficacy.⁴⁰

Health Canada also utilized international data and evidence from other regulatory agencies to inform their decision making, rather than relying solely on their own data. This allowed for a more efficient review process and reduced duplication of efforts. Through the European Medicines Agency's (EMA) Opening our Procedures at EMA to Non EU authorities (OPEN) project, Health Canada was able to participate in the EMA's assessment of COVID19 related medicinal products, including vaccines. And through the International Coalition of Medicines Regulatory Authorities (ICMRA) a global organization that brings together regulatory authorities from around the world to collaborate and share information on the development and regulation of medicines, including vaccines and treatments for COVID19. With the aim to expedite and streamline the development, authorization, and availability of COVID19 treatments and vaccines worldwide. ICMRA members are also focused on improving regulatory processes and decision making to enhance the efficiency and effectiveness of the regulatory system. This includes sharing best practices, developing new regulatory tools and approaches, and collaborating with other stakeholders to address regulatory challenges related to COVID19 and other health threats.⁴¹

Canadian decision makers relied on a range of tools and approaches, including scenario planning, modelling, data analysis, and expert consultations to mitigate the unprecedented levels of uncertainty, complexity, and ambiguity brought on by the pandemic. These tools and approaches have helped decision makers to better understand the potential consequences of different policy options and to identify the most effective strategies for controlling the spread of COVID19 while minimizing harm to individuals and the economy.

In addition, decision makers in Canada have sought to engage the public and other stakeholders in the decision making process to ensure that their decisions are informed by diverse perspectives and the latest scientific evidence. This has included regular updates and briefings from government officials, consultations with key stakeholders, and open forums for public input. (see CanCovid above) In the world of healthcare, uncertainty in regulatory, HTA and reimbursement processes is a certainty. These decisions often involve complex and evolving criteria. Effective communication is critical in navigating this uncertainty and minimizing the risk of ineffectiveness. Lacking or poorly received communication amongst stakeholders can lead to misunderstanding, mistrust, and delays in decision making, which ultimately impacts patients. To avoid ineffectiveness, it is essential for stakeholders to engage in transparent and open communication, working in collaboration towards a shared goal of improving patient outcomes in a resilient and sustainable health system.

THE ROAD TO INEFFECTIVENESS IS PAVED WITH ILL RECEIVED COMMUNICATIONS

VALUE BASED HEALTHCARE

The COVID19 pandemic has provided healthcare systems with an opportunity to deliver better value to patients by adopting a value based healthcare approach. Despite the challenges encountered during the pandemic, healthcare systems have made significant strides towards establishing a patient centered and data driven model for delivering healthcare. They have defined centralized goals based on patient outcomes and collaborated with various stakeholders, such as policymakers, providers, payors, and life science companies. The pandemic has also validated the key features of value based healthcare, which were previously deemed too complex to implement. Through a targeted approach and focus on outcomes, healthcare systems have improved how they manage the disease and have conducted successful vaccination programs.⁴²

The pandemic has proven that delivering value based healthcare is not abstract or challenging but can quickly succeed when stakeholders align towards the common goal of achieving improved patient outcomes. Healthcare system stakeholders can build on this momentum by exploiting the lessons from the COVID19 response and transforming their organizations and healthcare models to achieve higher value care strategically and comprehensively.

CLINICAL TRIALS

Like every other aspect of healthcare, clinical trials have also been profoundly impacted by the pandemic, leading to widespread disruption and delays in ongoing clinical trials. The COVID19 pandemic has prominently highlighted many fundamental issues that exist in clinical trial research under the current system and its incentive structures, and data sharing. The problems and limitations that have existed for clinical trial research have arguably become much more visible, spurring a wave of innovation and adoption of innovative technologies and trial designs in response to the pandemic. The pandemic also highlighted the extent to which our current site based clinical trial model is costly, limits populations served and burdens trial participants.

One of the most significant changes to clinical trial design in response to the pandemic has been the widespread adoption of virtual visits and remote monitoring. With many clinical trial sites shut down or operating at reduced capacity, virtual visits and remote monitoring have become essential tools for maintaining study integrity and participant safety. These technologies allow patients to participate in clinical trials from the comfort of their own homes, reducing the need for in person visits (and minimizing the risk of COVID19 exposure). The adoption of decentralized trial models has also been implemented, this allowed participants to receive study treatments and assessments in their own homes or at local healthcare facilities. These models can be particularly useful for studies that require frequent monitoring or administration of study treatments, as they reduce the need for participants to travel to study sites. Decentralized trials can also be more cost effective than traditional trials. The importance of patient centricity in clinical research, which was widely recognized during the pandemic has led to the adoption of novel approaches to patient engagement and communication. With many participants hesitant to visit hospitals or clinics due to the risk of COVID19 exposure, clinical trial sponsors have had to be more proactive in their communication with participants. This has included providing clear and timely updates on study progress and safety, as well as offering flexible study timelines and procedures to accommodate participant needs.

Regulatory authorities have also had to adapt to the pandemic related changes in clinical research. In many cases, they have provided guidance on remote monitoring and data collection, as well as expediting review of COVID19 related treatments and vaccines. These adaptations have helped to ensure that clinical research can continue despite the pandemic related challenges.⁴³

The adoption of new technologies and trial designs in response to the pandemic has the potential to transform the field of clinical research in the long term. Drawing on the lessons learned from COVID19 pandemic to describe how the research community has responded to the outbreak and the need to embrace coordination and collaboration instead of competition in medical and public health research. Decentralized trial models and virtual visits could make clinical research more accessible and patient friendly, particularly for participants who live in remote or underserved areas. Remote monitoring and data collection could also lead to more efficient and cost effective clinical trials.

ADDRESSING INEQUITIES. (the social determinants of health)

The COVID19 pandemic has exposed disparities in the social determinants of health, resulting in noticeable inequities in COVID19 health outcomes among different population groups. This can be attributed, in part, to variations in the ability to comply with public health and social measures aimed at curbing viral transmission, such as practicing hand hygiene, wearing face masks, maintaining physical distance, and closing public spaces like schools and workplaces. The pandemic's broader consequences have disproportionately affected social determinants of health, further exacerbating existing health disparities. In addition, social determinants have significantly affected access to and uptake of vaccines throughout the country.⁴⁴

HEALTH EQUITY CANNOT BE TREATED AS THE END POINT, BUT RATHER MUST BE A COMMITMENT THAT INFUSES AND GUIDES EVERYDAY INDIVIDUAL, INSTITUTIONAL AND SOCIETAL ACTION, IN THE HEALTHCARE SECTOR AND BEYOND⁴⁵ This has led to increased recognition of the impact of social determinants of health and health disparities on patient outcomes, highlighting the pressing necessity for policies and measures to address these disparities and has spurred efforts to improve shared decision making. Throughout the pandemic predictive models of the spread of the disease to inform containment measures were used throughout the country.

In policy and healthcare decision making, it is essential to consider the impact of social determinants of health and patient preferences and needs. As models are utilized to guide unprecedented public health interventions, it becomes even more crucial to acknowledge what these models inform us of and, equally importantly,

what they do not. For these models to be beneficial in making policy decisions of unprecedented magnitude, it is vital to engage in critical discussions regarding the forms of evidence that they may exclude and the potential unintended consequences of such exclusions.⁴⁶ By taking into account the broader context of social determinants of health and patient preferences and needs, we can ensure that our policy and healthcare decisions are equitable and effective for all.

The pandemic has provided an impetus for healthcare providers and systems to take a more comprehensive approach to patient care and to partner with patients to address the social determinants of health that impact their lives. This approach should include shared decision making and patient centred care, aiming to better understand patients' needs and preferences and to involve them in decisions about their care with models that are both culturally and linguistically appropriate. By

recognizing the need to engage patients to address social determinants of health, health outcomes can be improved.

Additionally, healthcare systems are increasingly adopting community based approaches to care delivery, which consider the social and economic factors that affect patients' health. These models prioritize the role of community health workers and other lay health workers in improving access to care and addressing social determinants of health.⁴⁷

LESSON SEVEN

the best defence (PREVENTION)

The COVID19 pandemic has put an unprecedented strain on healthcare systems worldwide. To reduce the burden on these systems, prevention strategies such as social distancing, and mask wearing were implemented. These prevention strategies helped to flatten the curve and reduce the number of COVID19 cases. Additionally, the development and distribution of vaccines for COVID19 provided an effective way to prevent illness and hospitalization, further reducing the burden on healthcare systems.

While prevention is not unique to the pandemic, the emphasis during the pandemic has increasingly recognized prevention as a critical component of healthcare systems. Preventive measures not only improve health outcomes for individuals but also reduce the costs associated with treating preventable illnesses and chronic diseases. Preventive care can identify health problems early when they are easier and less expensive to treat, and can reduce the need for costly interventions, such as surgery or hospitalization.

Prevention must be a key strategy for healthcare systems, not only during a pandemic but moving forward, including in cancer care, where prevention is critical. Measures such as cancer screenings, public education campaigns that increase awareness of risk factors, such as poor diet, smoking, and promoting healthy behaviors (e.g., sunscreen) can have a significant impact. Genetic testing to identify increased risk of certain types of cancers allowing for earlier and more targeted interventions. and personalized medicine can also improve outcomes and reduce the need for ineffective or potentially harmful treatments. Investing in prevention not only leads to better health outcomes but also helps to reduce healthcare costs and ensure the long term sustainability of our health systems.

SIDE NOTES(on special populations)

MENTAL HEALTH

The issue of mental health has been brought to the forefront of public consciousness. Social distancing, lockdowns, and fear of infection have all had a significant impact on mental health, with many individuals experiencing increased stress, anxiety, and depression. No longer a taboo, the pandemic has highlighted the critical importance of mental health, and the necessity to address these mental health challenges to ensure patients receive the best possible care and support. The mental health challenges faced by individuals living with cancer have been exacerbated during this time. Disruptions in cancer care, including delays in diagnosis and treatment, has led to increased stress and anxiety. In addition, fear of infection has led to increased isolation and social distancing, which can aggravate feelings of loneliness and depression. Mental health is a critical aspect of cancer care, studies $\frac{48.49}{48.49}$ have shown that individuals living with cancer are more likely to experience psychological distress, including anxiety and depression. This distress can have a negative impact on cancer treatment outcomes, quality of life, and overall wellbeing.

GERIATRIC POPULATIONS

The COVID19 pandemic has had a devastating impact on long term care facilities, bringing into sharp focus the vulnerability of older adults. As healthcare systems adapted to the challenges of the pandemic, many implemented measures to protect older patients, including prioritizing them for testing and treatment. In the elderly, cancer is one of the predominant causes of mortality and morbidity, and its incidence increases with ageing. In 2019, 61% of new cancer cases in Canada was expected to occur among people aged 65 years and older.⁵⁰ The number of Canadians in this age group has nearly doubled in the past 20 years and is expected to nearly double again in the next 20 years, with a corresponding increase in the number and proportion of older Canadians with cancer.⁵¹

As healthcare systems consider the lessons learned during the pandemic, there is an opportunity to translate the prioritization of older patients into improved cancer care for geriatric patients, who often present with comorbidities and compromised organ function and are less likely to receive optimal doses of chemotherapy, or eligible for clinical trials. Despite requiring special consideration with tailored policies and approaches in cancer care, the aging population is often overlooked. Age based disparities in survival, clear patterns of suboptimal treatment and unmet medical, informational, emotional, and physical needs suggest that more work is necessary to optimize care for older Canadians.⁵⁰

WOMEN'S HEALTH

The important influence of sex and gender on health has come to the forefront during the COVID19 pandemic, revealing numerous disparities in healthcare, including the underrepresentation of women in clinical trials. This lack of inclusion has led to significant gaps in our understanding of women's health, resulting in inadequate treatment options for female patients.

In a 2014 report, researchers at the Brigham and Women's Hospital in Boston chronicled the exclusion of women from health research and its impact on women's health: The science that informs medicine – including the prevention, diagnosis, and treatment of disease – routinely fails to consider the crucial impact of sex and gender. This happens in the earliest stages of research when females are excluded from animal and human studies, or the sex of the animals is not stated in the published results. Once clinical trials begin, researchers frequently do not enroll adequate numbers of women or, when they do, fail to analyze, or report data separately by sex. This hampers our ability to identify significant differences that could benefit the health of all.

Women have been disproportionately affected by COVID19, with higher rates of infection and mortality than men. Despite this, clinical trials for COVID19 treatments have continued to exclude women. In a published study in Vaccines, researchers found that of the 75 clinical trials for COVID19 vaccines only 24% presented their main outcome data disaggregated by sex, and only 13% included any discussion of the implications of their study for women and men. Considering the sex differences in adverse events after vaccination, and the gendered aspects of vaccine hesitancy, these oversights in clinical research on vaccines have implications for recovery from the COVID19 pandemic and for wider public health.⁵² A gendered lens should be applied when designing research, including determining what data to collect. This includes consideration of how research design and conduct may be explicitly or implicitly sex/gender biased, for example through exclusion of those who are pregnant or breastfeeding, or how research may potentially exacerbate existing sex/gender related disparities or knowledge gaps. Of the studies on COVID19 vaccines, only one examined adverse events related to the reproductive system, and the authors did not disaggregate these findings by sex/gender, or by age. Surveillance studies have also not reported data on menstrual irregularities or fertility, which have been amplified online and by the media. $\frac{53}{2}$

WHAT THIS LOOKS LIKE IN THE REAL WORLD. Heart disease is the second leading cause of death of women in Canada,⁵⁴ and the leading cause of premature death in women (Canada), and half of women who experience a heart attack have their symptoms go unrecognized.⁵⁵ However only one third of cardiovascular clinical trial subjects are female and only 31% of cardiovascular clinical trials that include women

report results by gender and sex according to the Bringham report. And even fewer studies account for the intersectional factors that further impact health such as ethnicity, socioeconomic status, etc. As a result, approaches to prevention, diagnosis, treatment, and care often do not equally apply to women's bodies, gender identities or roles.54

In 2021, at the height of the pandemic, the World Health Organization (WHO) outlined six (6) priority areas for healthy equity and equality for women's health.⁵⁶ These six priority areas include; addressing gender inequalities in the COVID19 response and recovery; elevating the position of women in the health and care workforce; preventing and responding to violence against women; ensuring quality sexual and reproductive health for all; reducing noncommunicable



System failure: Healthcare inequities continue to leave women's heart and brain health behind

diseases among women; and increasing women's participation and leadership in science and public health.

Women have historically been excluded from clinical research and the pandemic has further highlighted these disparities, emphasizing the need for more inclusive research, screening and treatment practices.

LESSONS LEARNED FROM CANCER

Vaccine hesitancy is a significant public health challenge that has implications for both infectious disease prevention and cancer prevention. The human papillomavirus (HPV) vaccine is one example of a vaccine that has faced significant hesitancy, which has resulted in suboptimal uptake and missed opportunities for cancer prevention. Despite effective mandates, there has been widespread resistance to HPV vaccination, and like the COVID19 vaccine, it has been highly politicized. HPV vaccine hesitancy has been linked to a range of factors, including safety concerns, lack of awareness, and misinformation primarily spread through social media.

One key lesson learned from HPV vaccine hesitancy, is the importance of coordinated and consistent messaging, and the importance of addressing safety concerns. Effective communication can help to build trust and confidence in vaccines, and education can help to dispel myths and misinformation. By providing accurate information about vaccine safety and potential side effects, healthcare providers can help to mitigate concerns and improve vaccine uptake. Vaccine hesitancy is likely to remain a significant public health challenge in the future, and there are several considerations that need to be addressed. One consideration is the importance of addressing the root causes of vaccine hesitancy, such as misinformation and mistrust of healthcare providers and public health officials. Another consideration is the importance of equity in vaccine distribution. Ensuring that vaccines are accessible and available to all populations, including those who may face barriers to access, is essential to addressing vaccine hesitancy.

HPV vaccine hesitancy offers important lessons for addressing vaccine hesitancy more broadly, including in the context of the COVID19 vaccine rollout. By addressing concerns about safety and efficacy, providing accurate information, and targeting messaging to specific populations, healthcare providers and public health officials can help to improve vaccine uptake and prevent the spread of infectious diseases. Additionally, it is important to consider the root causes of vaccine hesitancy and the importance of equity in vaccine distribution for addressing this public health challenge in the future.

THE COST OF INACTION (ON CANCER)

Amongst the many lessons learned during the pandemic, perhaps the most significant takeaway is the inextricable link between health and the economy. The Canadian healthcare system has demonstrated agility and innovativeness in its response to the COVID19 crisis, a departure from the traditional inertia observed in healthcare. The lack of a clear economic argument for a range of healthcare interventions, including those aimed at reducing the burden of cancer in this country, only increases healthcare spending and inefficiency.

According to a recent report by Canadian Health Policy, patented oncology drugs were only 1.3% of overall national health expenditure in 2021; and declined as a percentage of the economic burden of cancer, from 18.4% in 2012 to 15.9% in 2021. New cancer drugs defined as high cost by the Patented Medicines Pharmaceutical Pricing Review Board (PMPRB) accounted for only about one-tenth of one percent (0.12%) of national health expenditure. On average in Canada only 11% of new cancer drugs approved for marketing from 2016 to 2020 in at least one of three jurisdictions (EU, US, CA) were listed on a public formulary as of December 2021. The corresponding percentage for the European Union was 73% and for the United States 90%. Canada was a low priority for new cancer drug launches; approved fewer new oncology drugs; listed fewer new cancer medicines on public formularies. This has resulted in *Canadian oncology patients waiting on average 1,835 days from first new drug application across the EU, US, CA to listing on a public formulary versus 788 days for Europeans, and 486 days for Americans.*⁵⁷ Advancements in technology and new discoveries in medicine have led to breakthroughs that will shape and improve the future of cancer care. However, in order to fully realize the potential of these technologies, it is essential that they become available to patients. To do so requires us to consider the broader economic and societal impacts of their implementation, reevaluating the way we think about and plan healthcare in this country. This shift in thinking is required to fully embrace this new era of healthcare, looking at the impact beyond health expenditure and considering the direct and indirect costs associated with new technologies.

Traditionally, healthcare has been viewed as a cost centre by policy makers and other stakeholders. The focus has been on how much it costs to provide healthcare, rather than on the benefits that investment in an individual's healthcare can provide in terms of quality of life and economic growth for both the individual and society as a whole. This limited perspective has led to underinvestment in healthcare and a lack of focus on the long term benefits of healthcare technologies and interventions.

By reframing the discussion to focus on an investment strategy rather than a pricing strategy, we can begin to view healthcare as a building block of an overall economic investment strategy aimed at ensuring citizens have access to proven technologies. This changing paradigm requires combining the therapeutic value of technology and interventions with their economic and social value, looking at the impact beyond health expenditure, taking into consideration the direct costs of their implementation, but also the indirect costs and benefits that result. For example, a new cancer drug may have a high initial cost, but the long term benefits in terms of improved quality of life (QoL) and increased economic productivity may far outweigh that initial cost.

Considering these broader impacts, we can move beyond the traditional view of healthcare as a cost center and instead see it as a driver of economic growth and social progress. By doing so, we can move towards a more holistic approach to healthcare that recognizes the interdependence of different sectors of the economy and the importance of healthcare as a driver of overall economic growth and social progress. Within these new parameters, the commonly used economic prioritization tools (cost effectiveness analysis, cost benefit analysis, etc.) can no longer be expected to lead to appropriate priority setting for cancer control. Reframing how we define investment and cost, by applying Marshallian efficiency to healthcare, allows payors to spend a little more, if the final results represent incredible advantages, in terms of QoL, GDP, workforce participation (especially for women) economically and socially. This would allow health technology assessments to think about how much it would cost to not reimburse an intervention instead of how much an intervention costs, and healthcare decision makers to think in terms of efficiency vs inefficiency and prioritization in healthcare, and more specifically in cancer care.

Despite clear evidence of a historically large and growing cancer burden, cancer services have generally not been prioritized. The consequences of inadequate investment and delayed interventions in cancer care are profound, both for individual patients and for society as a whole. What more is needed to make the case for investing in cancer control, including the necessity of reducing cancer deaths, the leading cause of death in Canada, but an understanding that the cost of doing nothing has far greater consequences than the cost of any technological or clinical intervention. Decisions are being made behind closed doors without consideration of the human cost

INNOVATION IS A VIRTUOUS CYCLE THAT REQUIRES COMMITMENT, INVESTMENT, AND VISION

The costs of cancer care are not only challenges for governments but are increasingly placing a financial burden on patients. From a societal perspective, cancer related costs were CAD 26.2 billion in Canada in 2021, with 30% of costs borne by patients and their families.⁵⁸ When considering healthcare costs, traditionally the area of greatest focus has been the perspective of the institutional payer such as governments or insurance companies, this approach only covers one component of the total economic burden of cancer. How the values, needs, and preferences of patients have been meaningfully incorporated into value assessments is becoming an increasingly important consideration in value calculations. A standard definition of value and patient centricity in healthcare remains unsettled, yet incorporating patient perspectives into such assessments requires collaborative and consistent efforts. Neglecting this crucial aspect will only result in sporadic and superficial conversations with patients, failing to capture meaningful data that can foster a healthcare system which truly places them at the centre. Data, analysis, and a real world understanding of the covered population is imperative to really bring value to healthcare. Old practices that have created data silos, minimized the role of patients, fostered the wrong kind of competition instead of the right kind of collaboration have hindered progress in healthcare, resulting in slower development of new treatments, interventions and policies that have ultimately delayed the delivery of better care to patients.

MAKING CANCER A POLITICAL PRIORITY

While COVID19 was a deadly and important event, the lessons learned during the pandemic offer solutions to prioritizing cancer (and healthcare) in Canada. Since the onset of the pandemic, social attitudes have shifted and healthcare has increasingly become a priority for Canadians. Forcing decision makers to not only reimagine approaches to healthcare delivery but their role in steering an effective response to the growing burden of cancer in Canada. Using this as an opportunity to make meaningful change, in much the same way that governments and stakeholders have adapted to plagues and pandemics of the past.

The COVID19 pandemic has not only demonstrated the importance of political leadership in managing a public health crisis, but the vital connection between health and the economy. Despite this mutually beneficial relationship, governments, decision makers and payors take a less positive view of health systems expenditure. The enormous pressures exerted on health systems and the healthcare workforce during the COVID19 pandemic has exacerbated the inadequate investment in healthcare and the fragmented silos we work in. Despite these challenges, the response to COVID19 was rapid, effective, nimble, and evolving with the evidence.

COVID19 can serve as a blueprint, taking the lessons learned and applying them to create a cancer system that is responsive, effective, equitable, innovative, and agile. What we learned is when there is sustained political will and commitment, innovation can happen quickly, and transformation can occur rapidly. Governments must prioritize cancer in their policy agendas, allocate resources and funding (research, treatment, prevention, data, digital health, etc.), work collaboratively with healthcare providers, patients, communities, and industry to develop effective health, industrial, pharmaceutical, and human resource policies, and strategies, while redefining value in cancer care.

Public health issues are no longer merely a health concern, no longer can ministries of health work in silos to address the growing burden of cancer, but an all hands on deck approach must be utilized with ministries and ministers of health working in conjunction with ministries and ministers of science and innovation, finance, economy and labour, ministries and ministers coordinating senior's health, as well as those responsible for women's health must understand the intricate links and work across silos in order to tackle the challenges of cancer care in Canada. By working together, governments can make meaningful progress towards improving outcomes for cancer patients and ensuring that cancer care is a priority within Canada's healthcare system.

This increased awareness and importance of healthcare has created a window of opportunity to prioritize cancer in Canada. Despite the enormous human, social and economic costs, claiming millions of lives worldwide and placing enormous pressure on faltering health systems, the pandemic, by contrast, has also shown us what is possible when the situation necessitates it. The decisive speed and extent of the responses, challenging decision makers to move away from a *can't do to must do* mentality, providing a blueprint to strengthen our cancer systems. The pandemic has shown us that when the political will is there, a more robust and adaptable healthcare

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system is possible, and we must adapt these possibilities into cancer care. We know we can create a stronger, more resilient healthcare system, one that is better prepared to face the challenges of the future, including the growing burden of cancer, but only if our politicians are dedicated to this change. Cancer is not a tomorrow problem, and it requires attention and action today. By applying these lessons to cancer care, we can create a system that is more patient centered and equitable, that is focused on improving patient outcomes, and enhancing the quality of life for Canadians diagnosed and living with cancer and aligned with social benefit.

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