



# 2020 REPORT CARD ON LYMPHOMAS

THE IMPACT OF COVID-19 ON CARE



# About Lymphoma Coalition

The Lymphoma Coalition (LC), a non-profit organisation, was formed in 2002 and incorporated in 2010 with the express purpose of facilitating lymphoma patient organisations around the world to form a community that could support one another's efforts in helping patients with lymphoma receive the best care and support. LC is currently made up of 83 patient organisations from 52 countries.

## VISION

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Equity in lymphoma outcomes across borders.

## MISSION

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Enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

## SPECIAL THANKS

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Special thanks to all patients and the LC member organisations who offered their insight and support as well as to the many other organisations, medical professionals, and individuals who generously shared their knowledge, resources and understanding for this report.

## REPORT TEAM

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## DISCLAIMER

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Lymphoma Coalition (LC) provides the 2020 Report Card on Lymphomas for general information related to topics relevant to lymphoma worldwide. While LC makes every effort to ensure accuracy, the information contained in the report is taken from various public and private sources. No responsibility can be assumed by LC for the accuracy or timeliness of this information.

## WARNING

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LC's 2020 Report Card on Lymphomas should not be used for the purpose of self-diagnosis, self-treatment or as an alternative to medical care. If you have any concerns arising out of the information contained in this report, you should consult your own physician or medical advisor. If you suspect you have lymphoma, seek professional attention immediately.

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## MESSAGE FROM

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# The Chair of the LC Medical Advisory Board

**Laurie H. Sehn, MD, MPH**

**Chair, BC Cancer Lymphoma Tumour Group**

**Clinical Professor, University of British Columbia, Vancouver, Canada**



2020 has been a year unlike any other in recent history. The breadth of the COVID-19 pandemic has brought with it significant challenges for everyone, along with high levels of pressure and stress. This is true for patients with lymphoma, worried about their COVID-risk while also facing their cancer alone due to safety protocols. It is also true for healthcare professionals, both in a professional and personal capacity, where the challenges have been many.

As haematologists and oncologists, we had to figure out how to best care for and treat patients with lymphoma, an immunocompromised group, while ensuring measures were in place to protect them from the novel COVID-19 infection. This was an evolving process and over the course of the year, guidance changed as we learned more about the virus and its impact on our patients. There is still much to learn. The true impact of the pandemic on cancer care will not be known for a while, until retrospective data is available.

Medical professionals had to cope with disruptions in our usual workflow. Treatment centres introduced necessary safety protocols. Patient consultations changed to telemedicine. Procedures used to collect diagnostic samples and their subsequent analysis were affected. Access to radiation therapy was impacted. Some clinics faced a shortage of medical supplies and medicines. Intensive care beds were reserved for patients with COVID-19. There were shortages of personal protective equipment (PPE) and increased work hours because of COVID-related staffing issues. On top of this, cancer care providers are at increased risk for COVID-19 infection due to their workplace setting. Many healthcare workers became ill or had to isolate after exposure. We lost people to the pandemic.

Lessons must be learned. **The pandemic has clearly highlighted the need for clear contingency plans for cancer care during healthcare emergencies.** Strategies must be developed to minimise interruptions to active cancer treatment, particularly in patients who are being treated with curative intent. It is crucial that these plans be implemented in a timely and proportionate manner, balancing risks, and protecting patients and healthcare professionals. Healthcare providers are a vital resource for patients with cancer, and attention must be paid to their wellbeing and sustainability during a healthcare crisis.

Together we can ensure the hard lessons learned in 2020 meaningfully change the future.

## MESSAGE FROM

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# The Chair of the LC Board of Directors

**Susan Thornton**  
**CEO, Cutaneous Lymphoma Foundation**



The COVID-19 pandemic has created negative psychosocial consequences for the general public due to social distancing, unemployment, home restriction, and constant exposure to stressful headline news. As a patient living with lymphoma, I fully understand the added stress that 2020 and the COVID-19 pandemic caused. As this virus spread across the globe, those of us who are immunocompromised looked on with fear and anxiety.

Many of us have had to isolate in the past due to compromised immune systems putting us at risk, but this was a new experience as we watched entire communities face restrictions. Patients had to figure out how to cope during quarantine and lockdowns. Those we could rely on in the past were limited or could no longer support us in practical ways. Friends and family who usually provided support during treatments and hospital visits were prohibited from being in the care centres due to safety measures. Many patients felt isolated and alone. Traveling to hospitals or clinics brought with it additional concerns about the risk of COVID-19 infection.

Communication with the healthcare providers we rely on changed. The use of telemedicine, with consultations by phone or video rather than in person, was new and technology sometimes challenging. Some patients had to see different doctors, sometimes in other treatment centres, as COVID-19 and new safety protocols impacted hospitals. For patients in active treatment, there were changes to the therapies used to ensure their immune systems were as functional as possible while also treating their cancer effectively. Others faced delays in treatments based on local COVID-19 infection rates and hospital capacity.

This is a significant amount of change. Cancer is hard enough already. Moving forward, let's ensure that those who require medical care can continue to access it, and specific measures are in place to ensure it is safe to do so. Additionally, improved psychosocial supports are required for patients with cancer, who have various worries surrounding their high risk of infection, delayed or altered care plans, and concerns about undergoing treatments or attending appointments alone.

**While the fear and anxiety patients experienced this year are understandable, it should not stand in the way of getting the care they need.** The possibility of contracting COVID-19 does not change the reality of cancer.

## MESSAGE FROM

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# The Chief Executive Officer

**Lorna Warwick**



Lymphoma Coalition is a worldwide network of patient groups who provide support to patients with lymphoma. **The Coalition is based on a deep-rooted belief in the value that patient organisations bring to a patient and their loved ones as they traverse an extremely difficult time in their lives.** We see first-hand the hard work of dedicated volunteers and staff doing their best to provide credible, current, easy-to-understand information and much needed support systems, while fighting for positive change to cancer care locally.

2020 has proven how deep the need is for patient organisations. During this year's pandemic, roughly 6 in 10 member organisations experienced an increase in the number of calls and emails, with an average increase of 44%. Seven in 10 organisations reported receiving calls relating to COVID-19, on average over one third of their total call volume. Patients and their family and friends reached out to trusted sources as they grappled with what the pandemic meant to their care and their quality of life.

Patient organisations responded and they did so quickly. Most organisations produced new COVID-19-related information. Half of member organisations moved existing services online, and a third developed new services to help ensure those affected by lymphoma had access to the support they needed.

They are having to sustain this new level of support while experiencing large decreases in income, and while managing the re-organisation of their structure and services. It comes as no surprise that when the economy falters, so do charitable contributions. When guidance comes forward about not gathering in large crowds, key fundraising events charities rely on cannot be held. Moving operations virtually meant unbudgeted expenses. Many volunteers and staff of charities are also patients, with their own concerns about COVID-19 and how it may impact them personally.

**Patient organisations played a key role this year, one that could not be filled by struggling, overwhelmed health systems.** During COVID-19 and future pandemics, it is important that funders continue to support patient organisations, even increasing support if possible and the value of patient organisations is recognised by the whole community. In ensuring that cancer treatment and services are not set back several years, it is also important for influential stakeholders to collaborate with patient organisations who can effectively articulate the impact on patients.

# Introduction

Words highlighted in **dark bold** are defined in the glossary at the end of the report.

## BACKGROUND ON COVID-19

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Coronavirus disease 2019 (COVID-19) is a novel (or new) coronavirus that was first detected in Wuhan, China in December 2019.<sup>1</sup> Coronaviruses are a family of viruses that can cause mild illness, like the common cold, to more severe diseases, like **Severe Acute Respiratory Syndrome (SARS)** and **Middle East Respiratory Syndrome (MERS)**.<sup>2</sup> The coronavirus that is responsible for the COVID-19 outbreak is named SARS-CoV-2 because it is related to the SARS-associated coronavirus (SARS-CoV).<sup>3</sup>

COVID-19 is characterised by rapid human-to-human transmission and was declared a pandemic by the World Health Organization (WHO) on 11 March 2020.<sup>4</sup> Globally, since the beginning of the outbreak, there have been more than 67 million confirmed cases of COVID-19, and over 1.5 million COVID-19 deaths recorded (as of 9 December 2020).<sup>5</sup> Incidence and mortality figures are changing every minute, and this alarming trend has forced many countries around the world into lockdown.<sup>1</sup> Although endeavours to create and deliver vaccines are beginning to yield results, until vaccines are widely available, or an effective treatment is identified, and because it is a new virus, there is presumably no pre-existing immunity in the population.<sup>3</sup> As such, widespread closures, physical and social distancing, handwashing, and personal protective equipment (e.g., masks) have been the main methods used to slow the spread of COVID-19 through 2020.<sup>2</sup>

COVID-19 has exhausted the capacity of many health systems around the world. This has major consequences for non-COVID-19 medical care, including specific impacts on cancer care.<sup>6</sup>

Throughout the COVID-19 pandemic, the medical community has faced numerous logistical, financial, and public health challenges in the delivery of optimal care for patients with cancer.<sup>4</sup> And in particular, for patients with **haematological malignancies** including lymphoma and chronic lymphocytic leukaemia (CLL).<sup>4</sup>



## ASSOCIATED RISKS OF COVID-19 FOR PATIENTS WITH CANCER

Cancer, including solid tumours and haematological malignancies, was responsible for 9.6 million annual deaths in 2018, and remains the second leading cause of death globally.<sup>7</sup> There are more than 18 million new cancer cases every year globally, and roughly 50,000 new patients are diagnosed and require treatment every day.<sup>7</sup>

The COVID-19 outbreak is having a profound effect on the entire oncology community and has altered healthcare delivery for a duration that cannot yet be estimated.<sup>7</sup>

With the WHO declaring the COVID-19 outbreak a pandemic, focus is needed on the impact of this virus on patients with cancer.

An increasing number of studies suggest that patients with cancer are at higher risk of contracting COVID-19 than individuals without cancer.<sup>8</sup> Patients with cancer are more susceptible to COVID-19 not only because of their **malignancy**, but also because of their anti-cancer therapies (e.g., **chemotherapy**, **targeted therapy**, **immunotherapy**) that result in a suppressed immune system.<sup>1,3,6,9-10</sup> Patients with haematological cancers appear to have specific risks relating to decreased bone marrow activity (myelosuppression) and low numbers of healthy **lymphocytes** (lymphodepletion).<sup>4</sup> Additionally, the hospital visits that are required for many cancer treatments may put patients at an increased risk for COVID-19 infection.<sup>6</sup>

Accumulating evidence also suggests that patients with cancer are at higher risk for a more severe course of COVID-19 once contracted. Several studies have shown that patients with cancer experience more complications, morbidities, and higher mortality rates due to COVID-19 than the general population, including studies that specifically highlight lymphomas and CLL.<sup>9-14</sup>

Please see **table 1** on page 10 for a summary of key studies examining the associated risks of COVID-19 for patients with cancer.

**Table 1. Studies examining the associated risks of COVID-19 for patients with cancer**

Study	Country	Study Population	Key Results	Doi (link to article)
Yu et al. 2020 <sup>8</sup>	China	Medical records of 1524 patients with cancer (all types) treated at a single tertiary care hospital	Patients with cancer had a twofold increased risk of COVID-19 infection compared to general population.	<a href="https://doi.org/10.1001/jamaoncol.2020.0980">10.1001/jamaoncol.2020.0980</a>
Liang et al. 2020 <sup>9</sup>	China	Patients with cancer (all types) with confirmed COVID-19	Patients with cancer had a higher risk of developing severe events (ICU* admission, invasive ventilation, or death) due to COVID-19 compared with patients without cancer (39% vs 8%, p=0.003).	<a href="https://doi.org/10.1016/S1470-2045(20)30096-6">10.1016/S1470-2045(20)30096-6</a>
Mato et al. 2020 <sup>10</sup>	20 United States centres and 23 international centres in the European Union / United Kingdom and South America	Patients with CLL** diagnosed with symptomatic COVID-19	Hospital admission occurred in 90% of patients with CLL due to COVID-19. CLL patients admitted with COVID-19, regardless of disease phase or treatment status, were at a high risk of death.	<a href="https://doi.org/10.1182/blood.2020006965">10.1182/blood.2020006965</a>
Kuderer et al. 2020 <sup>11</sup>	United States, Canada, and Spain	Patients with active or previous cancer (all types) with confirmed COVID-19	30-day all-cause mortality due to COVID-19 was high and was associated with general risk factors and risk factors unique to patients with cancer.	<a href="https://doi.org/10.1016/S0140-6736(20)31187-9">10.1016/S0140-6736(20)31187-9</a>
Yigenoglu et al. 2020 <sup>12</sup>	Turkey	Patients with haematological malignancies with confirmed COVID-19	The rates of severe and critical disease, hospital and ICU admission, mechanical ventilation, and case fatality were higher for patients with haematological malignancies compared to COVID-19 patients without cancer.	<a href="https://doi.org/10.1002/jmv.26404">10.1002/jmv.26404</a>
Zhang et al. 2020 <sup>13</sup>	China	Patients with cancer (all types) with confirmed COVID-19	53.6% of patients in study had severe events and mortality rate was high (28.6%). Having an antitumour treatment within the last 14 days of contracting COVID-19 significantly increased the risk for developing severe events.	<a href="https://doi.org/10.1016/j.annonc.2020.03.296">10.1016/j.annonc.2020.03.296</a>
Dai et al. 2020 <sup>14</sup>	China	Patients with cancer (all types) with confirmed COVID-19	COVID-19 patients with cancer had higher risks in all severe outcomes compared to COVID-19 patients without cancer. Patients with haematologic cancer, lung cancer, or with <b>metastatic</b> cancer (stage IV) had the highest frequency of severe events. Patients who had surgery had higher risks of severe events.	<a href="https://doi.org/10.1158/2159-8290.CD-20-0422">10.1158/2159-8290.CD-20-0422</a>
Wise-Draper et al. 2020 <sup>15</sup>	United States, European Union, Argentina, Canada, Mexico, and United Kingdom	Patients with cancer (all types) with confirmed COVID-19	30-day mortality was highest amongst patients with cancer treated 1-3 months prior to COVID-19 diagnosis and those treated with <b>chemoimmunotherapy</b> . Mortality rate was particularly high (50%) in patients receiving anti-CD20 therapy 1-3 months prior to COVID-19 diagnosis.	<a href="https://doi.org/10.1016/j.annonc.2020.08.2312">10.1016/j.annonc.2020.08.2312</a>

\*ICU - intensive care unit; \*\*CLL - chronic lymphocytic leukaemia

## CONTEXT AND OUTLINE FOR THIS REPORT

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It is important that the challenges associated with managing patients with cancer during the COVID-19 pandemic be identified and mitigated for current and future pandemic preparedness, as well as ensuring the long-term impact of actions taken during the current pandemic are tracked and analysed.

**This report will point to various COVID-19-related impacts on patients with cancer, specific to lymphomas and CLL where possible, that have been identified through research. The specific areas of impact include:**

- Clinical care and practice
- Psychosocial effects, including data from the Lymphoma Coalition 2020 Global Patient Survey (LC 2020 GPS)
- Cancer research
- Patient organisations

Major gaps in care for patients with cancer will be identified and summarised, and recommendations for closing these gaps will be described.



# Impacts of COVID-19 on Patients with Cancer

## CLINICAL CARE AND PRACTICE

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Compared to the general population, current research shows that patients with cancer have a greater risk of COVID-19 infection. Additionally, patients with cancer have been shown to experience more severe events relating to the virus. Therefore, the first challenge faced by the oncology community is how to deliver effective, **curative treatments** to patients while avoiding exposing them, and their healthcare teams, to COVID-19.<sup>4</sup> Doctors are having to make increasingly complex treatment decisions in both patients who are COVID-19-negative and positive.<sup>4</sup>

Another challenge is completing the necessary diagnostic and staging studies in a timely manner. Among other factors, the availability of routine **molecular testing** is being affected because large-scale COVID-19 testing is consuming laboratory medicine.<sup>4</sup> Further, procedures are being deferred or consolidated to limit patients' exposure to healthcare settings.<sup>4</sup>

Lastly, cancer care consumes significant healthcare resources.<sup>16</sup> The rapid spread of COVID-19 can overwhelm primary and acute healthcare facilities, which may necessitate the reallocation of resources. This may be compounded by COVID-19 infection of medical personnel, quarantine requirements, and widespread closures (e.g., schools, offices). All these factors may affect staffing levels within healthcare settings and increase the stress of healthcare workers, which can in turn impact clinical care for patients with cancer.<sup>3</sup>

These challenges are described in further detail below.

## Diagnosis, Risk Assessment, and Initial Laboratory Evaluation

Acquiring diagnostic samples is a major factor impacting the diagnosis of haematological and other cancers. A recent international survey examining the global impact of COVID-19 on **nuclear medicine** departments found that respondents reported an average decline of 54% in diagnostic procedures.<sup>17</sup> **Positron emission tomography (PET)** and **computerised tomography (CT)** scans saw an average decrease of 36%, and **sentinel lymph node** procedures decreased by 45%.<sup>17</sup>

The procedures used to collect diagnostic samples have been affected. For example, performing diagnostic biopsies of lymph nodes or other suspicious masses for lymphoma. In many places, surgery has been restricted mostly to patients who require urgent, life-saving interventions. When this is the case, lymph node biopsy can be deferred, or **fine needle aspiration (FNA) biopsies** can be proposed as an alternative.<sup>4</sup> Because numerous clinical practice guidelines state that **excisional lymph node biopsy** is the gold standard for lymphoma diagnosis, it is not ideal for a diagnosis to be based on an FNA biopsy.<sup>18</sup> FNA biopsies may not remove enough of the sample to accurately diagnose lymphoma or determine the subtype.<sup>18</sup> Another challenge to accurate diagnosis during COVID-19 is that **bone marrow aspiration and biopsy**, which require qualified operators and assistants, may be avoided unless considered absolutely necessary at first sight. This eliminates the availability of important information.<sup>4</sup> Further, if clinics or medical practices are using outside laboratories to analyse their samples, the shipment of these samples may be delayed, which can delay diagnoses.<sup>4</sup>

The COVID-19 pandemic has affected the diagnostic facilities of clinical medicine and **pathology** laboratories. The activity of scientists and technicians has been reorganised to facilitate the development and deployment of reliable tests for COVID-19.<sup>4</sup> Additionally, numerous pathology departments at large institutions and academic centres have implemented autopsy programs for COVID-19 patients, which requires the allocation of internal resources and staff.<sup>4</sup> Finally, as it relates to healthcare personnel, the laboratory diagnosis of haematological and other cancers requires the intervention of certified **pathologists** or **cytopathologists**, clinical scientists, and technicians. Around the world, variable rates of COVID-19 infection among these personnel have directly impacted medical and diagnostic operations.<sup>4</sup>

Another challenge in the timely diagnosis of cancer during the COVID-19 pandemic has been the reluctance of some people towards attending in-person visits at healthcare facilities, even if they are symptomatic.<sup>19-21</sup> This reluctance could stem from a fear of contracting COVID-19, or from other concerns like further burdening an already stressed healthcare system.<sup>20-21</sup>

A poll by the National Health Service (NHS) England found that four in 10 people were not seeking help from their general practitioner (GP) because they were afraid to burden the NHS during the pandemic.<sup>20</sup>

Several early reports suggest that during the pandemic, there have been observed decreases in the level of routine clinical activity in general practice, as well as in the number of GP consultations.<sup>21</sup> This has obvious implications for the diagnosis of cancers, as patients cannot be diagnosed if they never make it to the doctor. A dataset that included 2.7 million patients in the United States (from 39 health systems) showed that appointments for cervical, colon, and breast cancer screening decreased by 86-95% in March 2020.<sup>21</sup> A dataset from the Netherlands showed that the number of new weekly diagnosis of all cancers (except skin) dropped to 73% of normal, and to 39% of normal for skin cancers.<sup>21</sup> A recent study examining population-based health records for adults in England and Northern Ireland found that compared to pre-pandemic levels, there was a 70-89% reduction in urgent referrals for early cancer diagnosis.<sup>22</sup>

Globally, because of the COVID-19 pandemic, it is likely that countless cancer diagnoses have been deferred or missed.

Evidence is not yet available to determine if deferral of diagnoses of cancers will correlate with more advanced stages of disease at presentation.<sup>4</sup> The diagnosis of patients with cancer should not be compromised during an infectious disease pandemic. Timely diagnosis may allow for cancers to be identified in a treatable stage and prevent further complications.<sup>3</sup> The management of the diagnosis process needs to be tailored to the best available resources during the COVID-19 and future pandemics.

## Treatment Decisions in Patients with Cancer

Cancer treatment often involves **immunosuppressive therapy**, tumour removal, and inpatient treatment.<sup>19</sup> In patients with cancer, the type of treatment used must be weighed against the risk for COVID-19 exposure in a healthcare setting.<sup>16</sup> The fact that cancer treatments may increase a patient's vulnerability not only to COVID-19 infection, but also to experiencing more adverse outcomes after contracting COVID-19, must be considered.<sup>16</sup>

While many solid tumours and some haematologic cancers require immediate diagnosis and treatment, other common early-stage cancers may not. This is true for many indolent lymphomas where **active surveillance** or watch-and-wait is a common approach to care. There is not a 'one-size-fits-all' model that applies to all patients. As such, oncologists are being asked to exercise their best judgement in deciding which patients need to initiate or continue treatment, and which patients can tolerate a delay.<sup>16</sup> Numerous consensus recommendations<sup>1,3-4,7,23</sup> have been developed throughout the pandemic to help providers make effective triage decisions, but these recommendations are subject to change based on changing levels of risk relating to the virus.<sup>16</sup>

Based on recommendations, oncologists are having to revise treatment protocols to minimise the number of inpatient visits required, as well as to reduce the level of **immunosuppression**.<sup>19</sup> For example, maintenance therapy for low-grade lymphomas may not be recommended because it requires an office visit, increases immunosuppression, and improves progression-free but not overall survival.<sup>19</sup> The length of time between treatments may be stretched out using medications, or the start of treatment may be delayed.<sup>2</sup> In some cases, delaying treatments for supportive care (e.g., bone strengthening treatments, intravenous iron supplementation) may be suggested.<sup>2</sup> As much as possible, appointments have been switched to telemedicine, where patients are able to speak with their doctor using video conferencing on computers or phones.<sup>2</sup>

Findings from a nationwide survey in the Netherlands indicated that 30% of patients with cancer reported that the COVID-19 pandemic had consequences for their oncological treatment or follow-up.<sup>6</sup> The most frequently reported consequence was conversion from hospital visit to consultation by phone or video.<sup>6</sup> The majority of patients with curable disease continued their treatment without changes, while treatment was more frequently postponed in patients with incurable disease. The most frequently adjusted treatments were chemotherapy (30%) and immunotherapy (32%).<sup>6</sup>

The suspension or delay of certain aspects of cancer care may have particularly grave consequences for certain subgroups of patients with lymphoma.

For example, patients requiring **stem cell transplants**, or patients for whom **chimeric antigen receptor T-cell (CAR-T) therapy** may be the best treatment option.<sup>19</sup> Both of these patient groups are at high risk for infection and may require care in intensive care units (ICU), and there is concern about proceeding with care options that may add pressure to ICUs in an already resource-constrained system.<sup>19</sup> Another patient subgroup includes those with **refractory disease** who are nearing end-of-life, but for whom an experimental targeted therapy may provide another option. These patients would normally be offered an early phase clinical trial, but some clinical trials have been paused, and future enrolment concerns exist surrounding potential needs for ICU care.<sup>19</sup>

### Care for COVID-19 Negative Patients with Cancer

The COVID-19 pandemic focuses medical attention on treating infected patients and protecting others from infection; however, it is important that patients with non-COVID-19-related disease continue to receive optimal levels of care.<sup>19</sup> For patients with cancer, new risks have necessitated the reconsideration of usual standards of care.

Recommendations have been developed to guide outpatient and inpatient cancer care settings in protecting their COVID-negative patients against infection. Some of these recommendations are summarised in **table 2** below.

**Table 2. Recommendations for reducing COVID-19 transmission risk in outpatient and inpatient cancer care settings**

Outpatient Settings <sup>3</sup>	Inpatient/Hospital Settings <sup>3,7</sup>
<ul style="list-style-type: none"><li>• Clear communication and education about hand hygiene, infection control measures, COVID-19 signs and symptoms, high-risk travel or exposure, and importance of reporting new symptoms to healthcare workers</li><li>• One or no visitors with the patient</li><li>• Limited entry/exit points with personnel to supervise</li><li>• Clinics should develop and employ strict screening algorithms or questionnaires</li><li>• Consider switching IV chemotherapy to acceptable alternative oral anti-cancer drugs on a case-by-case basis</li><li>• To reduce risk at pharmacy departments, consider drive-through medicine collection facilities, alerting patients by telephone when medicine is ready, or some hospitals may choose a courier service and deliver medications to a patient's home</li></ul>	<ul style="list-style-type: none"><li>• Avoid moving patients into hospitals unless necessary</li><li>• Patients and healthcare professionals should wear protective masks, use <b>hydroalcoholic solutions</b>, and/or wash hands before and after patient-to-professional contacts</li><li>• Avoid any mixing of COVID-19 positive or suspected patients with COVID-19 negative patients</li><li>• Patients with suspected or confirmed COVID-19 must be hospitalised in specifically separated COVID-19 units. Where possible, it is advisable to dedicate healthcare practitioners to the care of COVID-19 to avoid transmission to unaffected patients</li><li>• Consider systemically testing patients with a new cancer diagnosis or in need of cancer treatment for COVID-19 infection, even in asymptomatic patients</li></ul>

### Care for COVID-19 Positive Patients with Cancer

For patients with cancer who have tested positive for COVID-19, it is recommended that any scheduled surgery or treatment with **radiotherapy** and/or medical oncology therapy, including high-dose therapy with autologous stem cell transplant, **allograft**, or CAR-T cell infusion, should be postponed until a negative COVID-19 test is achieved.<sup>2,7,24</sup>

While most COVID-19 infections seem to be controlled within two weeks, some patients may test positive for COVID-19 for up to four weeks, suggesting that it might be necessary to postpone anti-cancer therapies for at least two to four weeks.<sup>7</sup> However, patients may continue to test positive for COVID-19 even after all symptoms have resolved. In those cases, if all clinical and radiological signs of COVID-19 have disappeared, the healthcare team will consider the risks and benefits of resuming treatment despite the positive test.<sup>2,7</sup> Some treatments may be able to continue (e.g., those that do not impair the immune system), especially if patients test positive for COVID-19 but are asymptomatic or only have mild symptoms.<sup>2</sup>

When a patient has recovered from COVID-19, therapeutic management of their cancer should resume as soon as possible to reduce the risk of cancer-related death.<sup>7</sup>

## Resource Management for Cancer Care During COVID-19

As has been highlighted throughout this section, a primary challenge for cancer care throughout the COVID-19 pandemic has been resource allocation and management.

**Significant healthcare resources are required for cancer care, which in certain cases, may directly conflict with care delivery for those with COVID-19.<sup>16</sup>**

For example, beyond staff, a cancer ward may use intensive care unit beds, ventilators, pharmaceuticals, blood products, and basic medical supplies that are also required for COVID-19 care.<sup>16</sup> In these cases, difficult decisions and trade-offs must be made.

**The COVID-19 pandemic has put a lot of stress on the healthcare systems and personnel involved in cancer care. Healthcare providers are vital resource for patients with cancer, and attention must be paid to their wellbeing and sustainability during a healthcare crisis.**

Cancer care providers are at increased risk for COVID-19 infection due to their workplace setting.<sup>1</sup> Because of this, cancer care providers must consider their own exposure risk, and how an exposure would limit their ability to care for future patients.<sup>19</sup> This complex decision-making was, and continues to be compounded by shortages of personal protective equipment (PPE) and increased work hours because of COVID-related staffing issues.<sup>1,19</sup> Additionally, oncologists are being asked to make difficult treatment decisions for their patients based on new recommendations and standards of care, some of which were changing rapidly as the pandemic unfolded and new learnings were implemented. Cancer care providers are working under extreme circumstances, with high levels of pressure and stress. Managing the mental health and psychosocial wellbeing of healthcare professionals during COVID-19 and future pandemics is equally as important as managing their physical health.<sup>1</sup>

**Additionally, to prepare for increased care demands and resource use during pandemics, strategies must be developed to minimise interruptions to active cancer treatment, particularly in patients who are being treated with curative intent.<sup>3</sup>**

For example, in many cases, radiation therapy (RT) is regarded as essential in the clinical treatment of patients with haematological malignancies.<sup>25</sup> However, during the COVID-19 pandemic, limitations in resources (e.g., space, equipment, staff), when compounded by new protocols (e.g., increased sanitation measures) were seen to reduce RT capacity.<sup>25</sup> The International Lymphoma Radiation Oncology Group (ILROG) has made recommendations for alternative radiation schemes during COVID-19 that could be adapted for future pandemics.<sup>25</sup>

Something that must be considered is the possibility of shortages in medical supplies. During the COVID-19 pandemic, on top of the shortages of PPE available to healthcare providers and patients, there was a large shortage of ventilators and ICU beds in many countries during the first wave of the virus. This created disastrous situations for some countries (e.g., Italy); because not all patients could receive ICU care or access ventilators, doctors were having to make moral decisions similar to those made in wartime triage (e.g., based on patients' overall health, comorbidities, age, number of 'life-years').<sup>26</sup>



Shortages of medications, including chemotherapy and narcotics, can also negatively impact the delivery of cancer care.<sup>3</sup> Many pharmaceutical companies do stockpile ingredients or supplies to protect against unexpected stoppages, and so drug shortages may not manifest immediately.<sup>3</sup> However, COVID-19 affected medical product supply chains, and some countries began to report shortages during the first wave of the pandemic. For example, as of 21 March 2020, the U.S. Food and Drug Administration (FDA) Drug Shortages list included 26 oncology medications.<sup>3</sup> Drug shortages can be life-threatening when certain therapy regimens are preferred, or there are no alternative medicines. This includes customised treatments like CAR-T therapy, which provides a treatment option for patients whose lymphoma has not responded to other forms of treatment. The COVID-19 pandemic has created logistical, administrative, distribution, and patient care challenges that have significantly impacted the delivery of **cellular therapeutics**, including CAR-T.<sup>27</sup> Transparency and communication between suppliers, stakeholders, and health organisations is essential in the successful implementation of strategies that help anticipate and manage drug shortages.<sup>3</sup>

Lessons from the COVID-19 pandemic have highlighted the need for clear contingency plans for cancer care during infectious disease pandemics and other healthcare emergencies.

The policies and procedures that have been developed during COVID-19 will serve as a guide for addressing the next similar crisis. In the future, it is crucial that these plans be implemented in a timely and proportionate manner.<sup>3,16</sup> These plans must balance risks and protect patients with cancer and healthcare professionals. Strong leadership and clear communication within oncology teams nationally and locally will be required for successful implementation of consensus recommendations and guidelines.<sup>3</sup>

## PSYCHOSOCIAL IMPACTS

The COVID-19 pandemic is creating negative psychosocial consequences for the general public due to social distancing, unemployment, home restriction, and constant exposure to stressful headline news.<sup>7</sup> Beyond managing these stressors, patients with cancer are having to face the uncertainties of their diagnosis and treatment, while also being told they are high risk for COVID-19 infection and severe complications.<sup>7</sup> This new situation increases psychological distress for patients with cancer.

First, despite being high risk for COVID-19, many patients still must travel to hospitals or outpatient clinics to receive treatment, which can lead to fears surrounding contracting the disease.<sup>28</sup> Additionally, in many cases, patients have been made to attend treatments and other in-person procedures alone, unless a caregiver is specifically required.<sup>28</sup> This could lead to increased stress and anxiety for patients. Another potential consequence is the increased risk for misunderstandings. In interactions with the healthcare system, it is often helpful for patients to have someone with them to help in asking questions, taking notes, and providing general support.

**Studies suggest that patients with cancer also have numerous fears about how COVID-19 will delay or otherwise negatively impact their cancer care.<sup>6,28</sup>**

Additionally, the widespread switch to telemedicine for patient appointments and follow-ups can have unintentional negative consequences. For example, for meetings that happen over the phone, the doctor cannot pick up on visual cues that might signal that a patient is overwhelmed or confused.<sup>19</sup> Even when video conferencing is available, the lack of actual in-person interaction, when compounded by the unavailability of typical support systems, can make it harder for patients to emotionally cope with their diagnosis and care plan.<sup>19</sup>

To illustrate these themes, a study examining psychological distress in outpatients with lymphoma in Italy during the COVID-19 pandemic found that 75% of patients had increased worries during the pandemic.<sup>28</sup> Their greatest concerns were the risk of COVID-19 infection at the hospital (33%), the risk of delaying treatment (21%), social distancing from their loved ones (13%), financial difficulties (5%), and potential difficulties in contacting the doctor if needed (4%).<sup>28</sup> Further, 36% of patients reported anxiety, 31% reported depression, and 35% fulfilled the diagnostic criteria for post-traumatic-stress disorder (PTSD).<sup>28</sup> The need for online psychological support was expressed by 25% of patients.<sup>28</sup>

Findings from a nationwide survey of patients with cancer in the Netherlands found that 47% of patients were very concerned about being infected with COVID-19.<sup>6</sup> Compared to patients in follow-up, patients in active treatment were more often very concerned about COVID-19 infection.<sup>6</sup> Among patients whose oncological treatments or follow-ups had not experienced any COVID-related consequences yet, 24% were very concerned about the potential consequences for their treatment or follow-ups.<sup>6</sup> 55% of patients who experienced treatment delay were concerned about it, and 62% who experienced discontinuation of treatment were concerned about it.<sup>6</sup>

Evidently, patients with cancer could benefit from more psycho-oncological support and information during the COVID-19 and future pandemics. The fact that patients with cancer are high-risk for COVID-19 infection has been well-communicated, and this has resulted in a high fear of infection among patients with cancer, especially those in active treatment. As such, it is important for there to be equally effective communication surrounding the safety of hospitals and cancer care centres, including what specific measures are being taken to keep patients with cancer safe during their visits.

**Public messaging regarding COVID-19 has focused on the need for vigilance about viral transmission; however, this messaging cannot detract from the message that patients who require medical care should continue to access healthcare, and that it is safe to do so.**

Additionally, efforts must be made to provide more psychosocial support to patients when they are undergoing treatments or attending appointments alone (e.g., without a caregiver or family member/friend).

It is also important that supports are in place in cancer care facilities to screen patients for emotional and distress conditions, and then intervene with appropriate and accessible psychological support to the best of available resources.<sup>3</sup> Further, using telemedicine, careful follow-up should be conducted with cancer patients who are confined at home. Through these follow-ups, recommendations can be made to mental health professionals who patients can access from home.<sup>7</sup>

## RELEVANT LYMPHOMA COALITION 2020 GLOBAL PATIENT SURVEY RESULTS

The Lymphoma Coalition 2020 Global Patient Survey (LC 2020 GPS) was published and made live on 13 January 2020 and was hosted online until 13 March 2020. The survey timing was close to the COVID-19 pandemic, mainly the outbreak in Asia was happening during survey fieldwork. Because of this crossover, it is possible to conduct some analysis regarding the impacts of COVID-19 on different subgroups of patients with lymphoma.

While the virus was present in the rest of the world already during survey fieldwork, it was not being tested for or publicly acknowledged like it was in Asia. Nor were there any large-scale COVID-19-related restrictions being implemented outside of Asia. Therefore, for this analysis, patients with lymphoma who reported living in Asia were examined.

This patient group would have been experiencing COVID-19-related restrictions both prior to and during the time of the survey. Patients who were diagnosed within the last six months (n=291) were compared against patients who were diagnosed more than six months ago (n=1206). The intent was to examine any compounding effects of COVID-19 on patients who were newly diagnosed and/or managing treatments during the pandemic. The 'diagnosed within the last six months' subgrouping aimed to capture as many of these patients as possible.

Patients in the diagnosed in the last six months subgroup were selected if they were unsure of their treatment options, were in watch-and-wait, or were in treatment (**table 3**). Patients in the diagnosed more than six months ago subgroup were selected if they had finished treatment and were in maintenance therapy, if they were in remission, or if they were not having or stopped treatment (**table 3**). It was hypothesised that because newly diagnosed patients (i.e., less than six months ago) are facing many uncertainties and require more interaction with the healthcare system (e.g., diagnostic tests, treatments, follow-ups), there is increased potential for more COVID-related distress in this population.

Where possible, comparisons were made between the newly diagnosed subgroup and a group of matched controls (n=815) from the LC 2018 GPS. The 2018 control group was matched based on stage of patient experience (newly diagnosed, watch-and-wait, in treatment), and the group was restricted to include only patients living in the Asian countries that were represented in the 2020 newly diagnosed subgroup.

**Table 3. Stage breakdown of patient subgroups**

Patients Diagnosed Within Last 6 Months			Patients Diagnosed More than 6 Months Ago		
Stage	n=1	%	Stage	n=1	%
Newly diagnosed & unsure of treatment options	17	6	Finished treatment & on maintenance therapy	442	37
Treatment not yet needed (watch-and-wait)	31	11	In remission	287	24
Had treatment now back in watch-and-wait	18	6	Not having or stopped treatment	404	33
Currently receiving treatment	225	77	Other	73	6
Total	291	100	Total	1206	100

From this point on, the subgroup of patients diagnosed within the last six months will be referred to as 'newly diagnosed', and the subgroup of patients diagnosed more than six months ago will be referred to as '+6 months ago'.

## Demographics

The newly diagnosed subgroup (n=291) had representation from patients in five countries in Asia, with the top three countries by response being China (84%), South Korea (11%), and the Philippines (2%). The +6 months ago subgroup (n=1206) had representation from patients in eight countries in Asia, with the top three countries by response being China (84%), Japan (10%), and South Korea (5%). The COVID-19 outbreak was occurring in China during the time of survey as well in the months leading up to it. Given that patients from China represent the largest proportion of patients in each subgroup, it increases the likelihood that the experiences of patients with lymphoma during the pandemic have been captured.

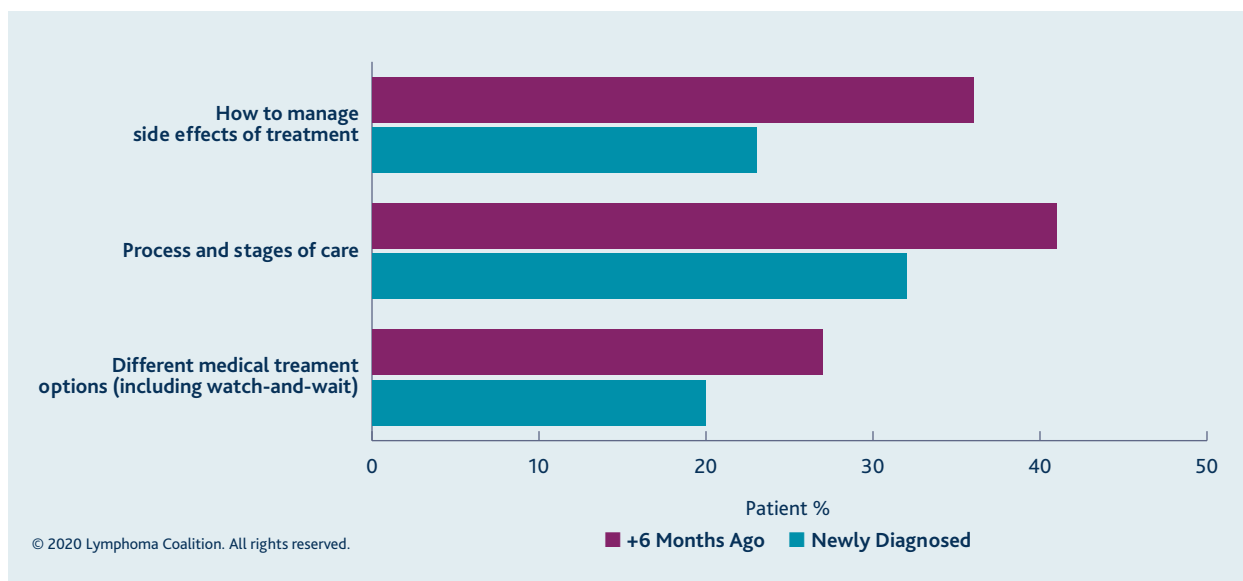
The majority of patients in the newly diagnosed group were between 30-39 years old (35%), while the majority of patients in the +6 months ago group were between 40-59 years old (48%). The rest of the demographics were similar for both subgroups. There was a fairly equal male to female ratio in both groups, and most patients in both subgroups were married or living in a partnership with children, had full-time employment, lived in urban areas, and had a post-secondary education. The top three lymphoma subtypes reported in both subgroups were diffuse large B-cell lymphoma (DLBCL) (27% newly diagnosed, 35% +6 months ago), follicular lymphoma (21% newly diagnosed, 22% +6 months ago), and Hodgkin's lymphoma (16% newly diagnosed, 13% +6 months ago).

Demographic information for the subgroup of newly diagnosed patients from the LC 2018 GPS can be found in [appendix 1](#).

## Information, Guidance, and Support

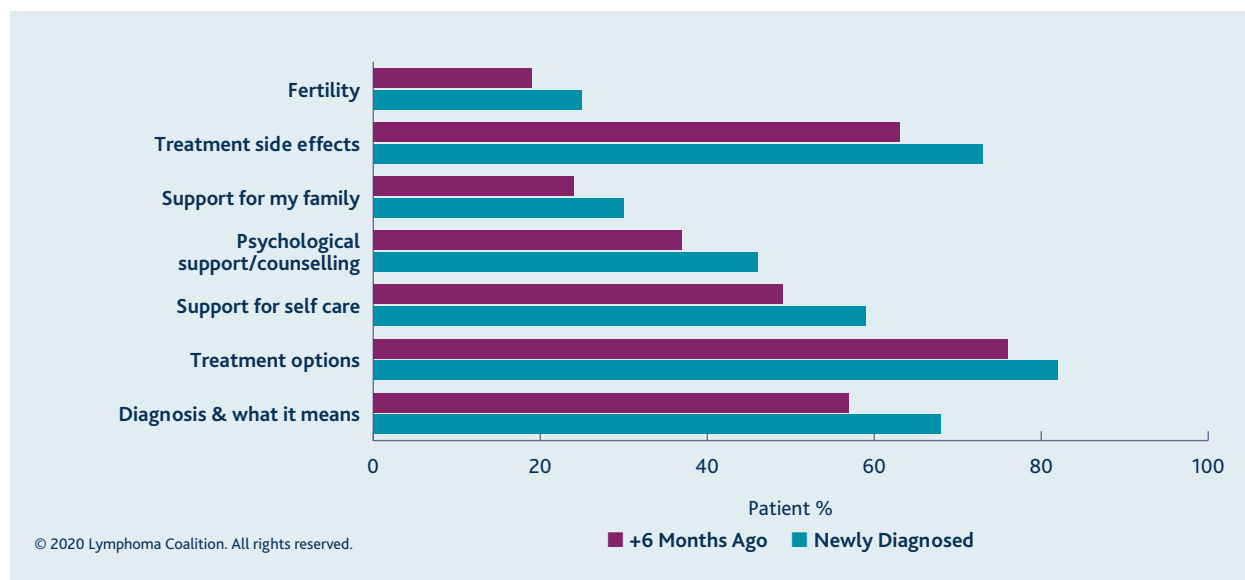
Patients who were diagnosed anytime in the last two years were asked questions about their initial diagnosis experience. Information provision and understanding around the time of initial diagnosis differed between the subgroups. While most patients in both subgroups were told their lymphoma subtype at diagnosis (72% newly diagnosed, 78% +6 months ago), fewer patients in the newly diagnosed group reported receiving information on and completely understanding different topics relating to their diagnosis and treatment ([figure 1](#)).

**Figure 1. Patients who, at diagnosis, received information on and completely understood different topics relating to their disease and care**



Compared to patients in the +6 months ago group (30%), fewer newly diagnosed patients (25%) reported receiving the right amount of information at diagnosis. Additionally, more newly diagnosed patients (63%) reported not receiving enough information at diagnosis compared to the +6 months ago group (55%). Both subgroups reported needing more information within the first month following diagnosis. Patients were asked to select which types of information they needed more of. Compared to the +6 months ago group, a greater proportion of patients in the newly diagnosed group needed more information about each topic (figure 2).

**Figure 2. Patients who indicated they needed more information about listed topics**



Patients were asked to rank their top three information sources from 1 to 3. The top three information sources (ranked 1) for both subgroups were 1] doctors (75% newly diagnosed, 74% +6 months ago), 2] websites (14% newly diagnosed, 15% +6 months ago), and 3] patient organisations (9% newly diagnosed, 8% +6 months ago).

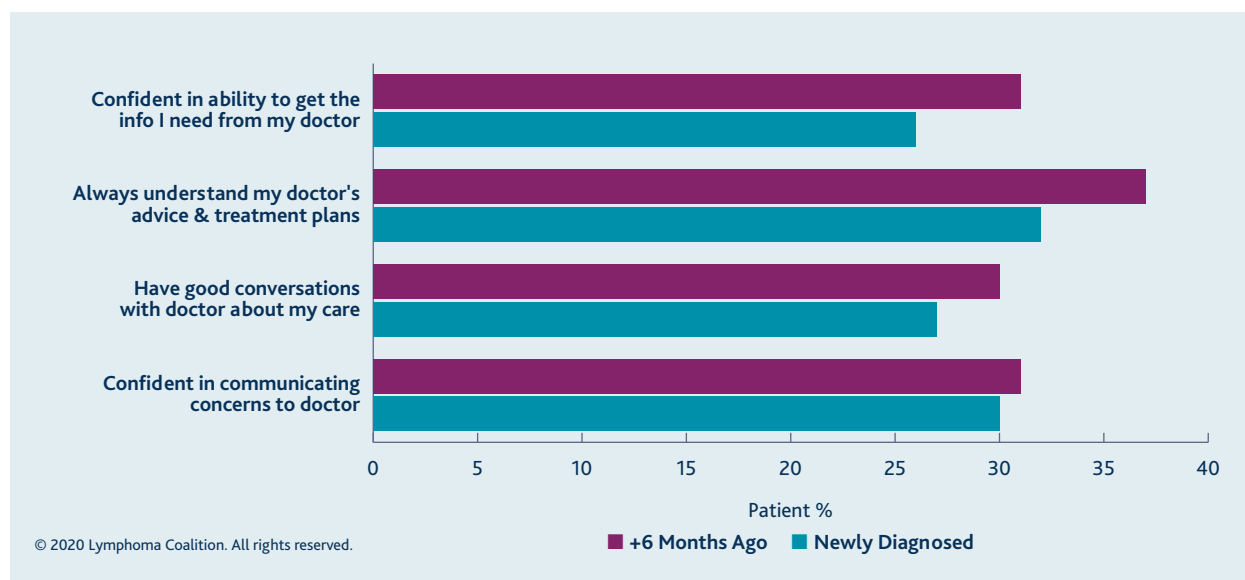
**In both subgroups, patient organisations were the top reported information source for the rank 2 (36% newly diagnosed, 32% +6 months ago) and rank 3 (42% newly diagnosed, 43% +6 months ago) categories.**

In the LC 2018 GPS, patients were asked to select all the primary information sources they use rather than to rank their top three information sources. The top three information sources for newly diagnosed patients in 2018 were doctors (57%), websites (56%), and patient organisations (54%). Using the 2020 data, if only the total number of patients who reported using each information source is considered, the top three information sources for newly diagnosed patients would be doctors (92%), patient organisations (79%), and websites (67%).

**Compared to 2018, newly diagnosed patients in 2020 were not only relying more on patient organisations than websites, but a greater proportion of these patients reported using each of these top three information sources.**

Now returning to the comparison of the newly diagnosed and +6 months ago subgroups. While most patients in both subgroups reported receiving enough support from their doctor throughout their experience (83% newly diagnosed, 88% +6 months ago), fewer patients in the newly diagnosed group strongly agreed with positive statements about patient-doctor communication (figure 3).

**Figure 3. Patients who strongly agreed with statements about patient-doctor communication**



Some other differences observed between the subgroups include an increased number of newly diagnosed patients who sought a second opinion about their most recent treatment (44% newly diagnosed, 24% +6 months ago). Additionally, 59% of newly diagnosed patients agreed or strongly agreed to feeling overwhelmed by managing their health and condition, compared to 53% of those in the +6 months ago group. A similar proportion in both subgroups reported agreeing or strongly agreeing that they wait until health issues can no longer be ignored before seeking help (43% newly diagnosed, 40% +6 months ago).

There are several ways the overlapping timing of the COVID-19 pandemic could have contributed to the trends observed in the newly diagnosed subgroup. Regarding information provision at diagnosis, the newly diagnosed subgroup reported less understanding than the +6 months ago subgroup. The newly diagnosed group also required more information about every topic and relied more heavily on various information sources than was reported in 2018. On top of information about their diagnosis and treatment, patients in the newly diagnosed subgroup may have been processing additional information relating to their COVID-19 risk and associated adjustments to their care plan. Additionally, relating to patient-doctor communication, patients in the newly diagnosed subgroup may have experienced decreased contact with their cancer care teams due to emerging protocols. Their appointments may have been delayed, consolidated, switched to telemedicine, or they may have been switched to another centre for care. This can impact the efficacy of patient-doctor communication and have implications for patient understanding.

More than 40% of newly diagnosed patients reported waiting until health issues could no longer be ignored before seeking help.

Patients with cancer are at high risk for COVID-19 infection, therefore they may avoid healthcare settings unless urgently necessary.

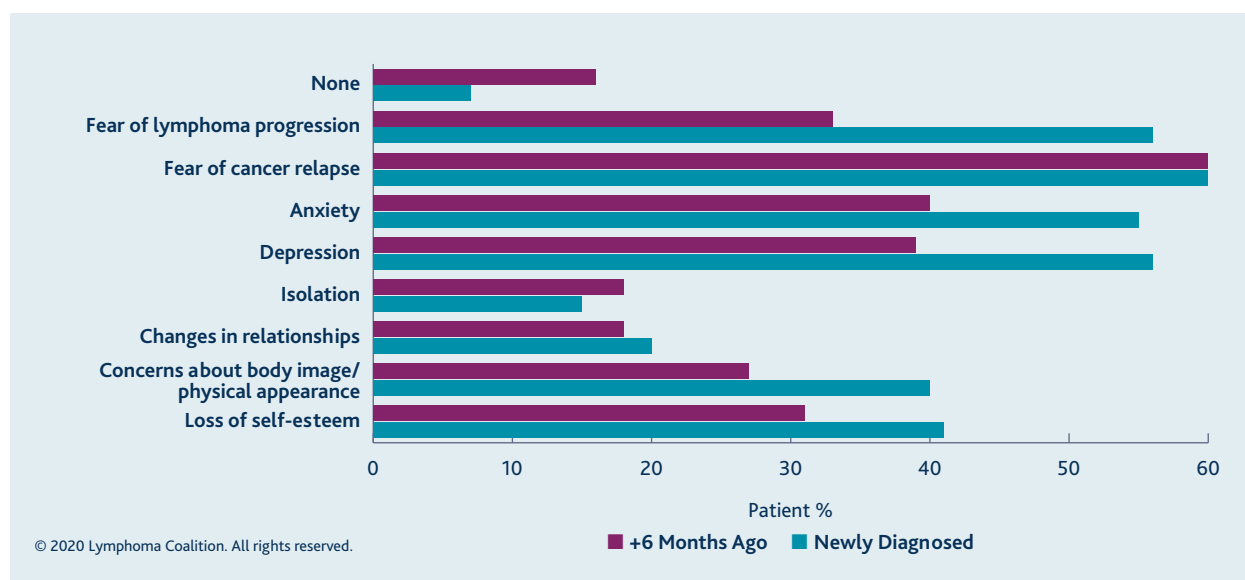
Additionally, they might have less regular access to appointments with their care team where these issues could be brought forth. Finally, more than half of newly diagnosed patients were overwhelmed by managing their health and condition.

Managing a cancer diagnosis and treatment during a global pandemic, in the absence of typical medical and social support systems, is undoubtedly overwhelming.

## Psychosocial Issues

Patients were asked if they had experienced any psychosocial issues in the last 12 months because of their diagnosis. Compared to the +6 months ago subgroup, except for isolation, a greater proportion of patients in the newly diagnosed group reported experiencing each issue (figure 4). Additionally, compared to the +6 months ago subgroup, a lesser proportion of patients in the newly diagnosed group reported experiencing no psychosocial issues ('none').

**Figure 4. Psychosocial issues that patients reported experiencing in the last 12 months due to their diagnosis**



It is logical that the newly diagnosed subgroup reported more psychosocial issues than those in the +6 months ago subgroup. Those in the +6 months ago group had more time to process their diagnosis, and many patients in this group had already finished treatment and were in remission. Therefore, the newly diagnosed subgroup was compared to the control group of newly diagnosed patients from the LC 2018 GPS. This was to determine if the 2020 COVID-19 time period may have played a role in increasing the psychosocial issues for newly diagnosed patients, versus the usual distress associated with a new cancer diagnosis.

In the LC 2018 GPS, patients were asked to indicate if they had experienced psychosocial issues before, during, or after treatment. Patients could select more than one time period for each psychosocial issue.

To account for these time periods, two separate comparisons were conducted between the 2020 newly diagnosed and the 2018 newly diagnosed subgroups. Only psychosocial issues that were listed in both years were analysed.

For the 'before treatment' period, the reporting of psychosocial issues was compared between patients in the 2018 and 2020 newly diagnosed subgroups who had not yet received treatment (n=130 2018, n=48 2020) (**figure 5**).

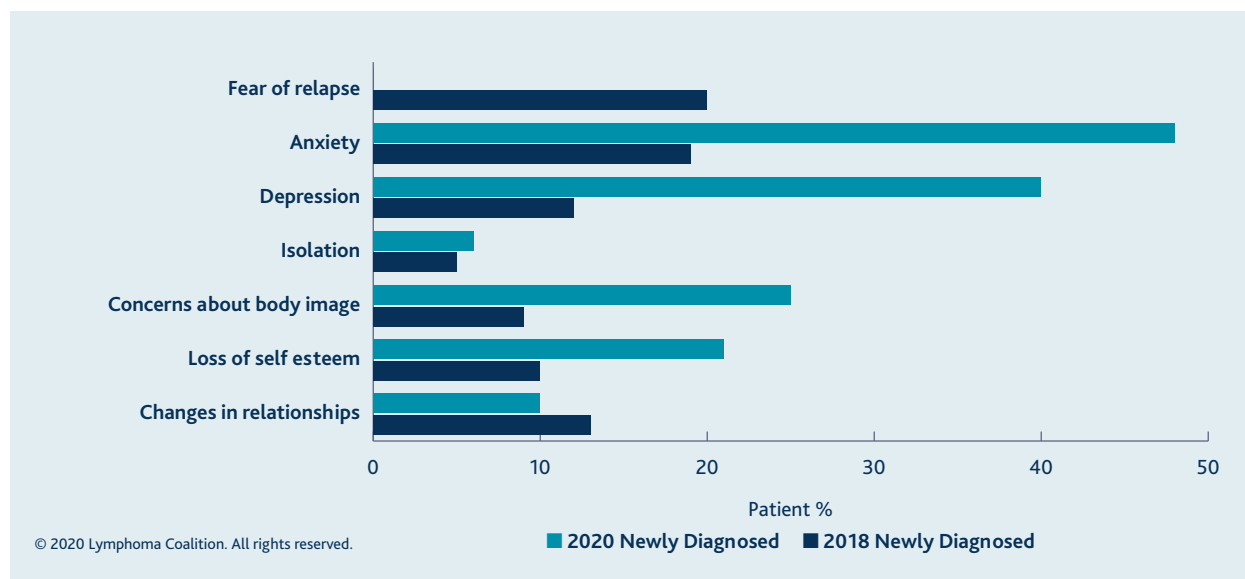
For the 'during treatment' period, the reporting of psychosocial issues was compared between patients in the 2018 and 2020 newly diagnosed subgroups who were in treatment, or who had treatment and were now back in watch-and-wait (n=685 2018, n=243 2020) (**figure 6**). Across both comparisons, a greater proportion of patients in the 2020 newly diagnosed subgroup reported experiencing the majority of the psychosocial issues.

**Cancer diagnosis and treatment, when compounded by being high risk for COVID-19 infection and complications, can create high levels of psychological distress for patients.**

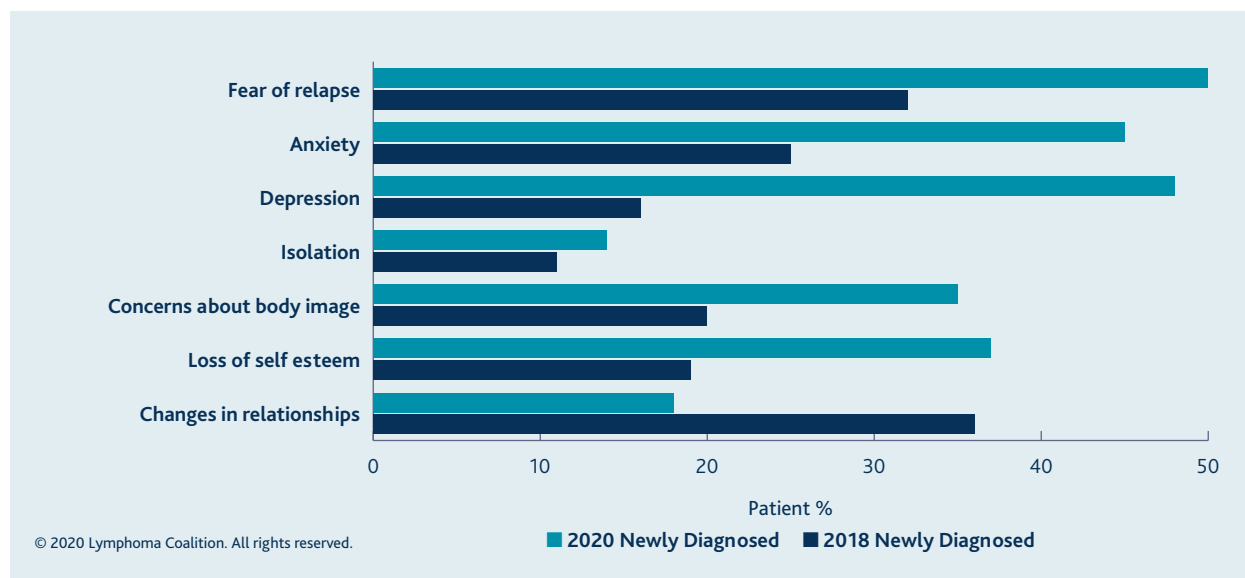
Additionally, patients with cancer during COVID-19 must manage stress related to less frequent touchpoints with their care team, potential treatment changes and/or delays, and the absence of traditional support systems due to social distancing protocols. It was observed that 2020 patients who were newly diagnosed experienced high levels of anxiety (55%) and depression (56%). It was also observed that 2020 patients who were newly diagnosed reported higher levels of most all psychosocial issues compared to both the +6 months ago subgroup (2020) and the 2018 newly diagnosed control group. While it is possible the distress stemmed from the actual cancer diagnosis and related implications, the differences observed suggest that COVID-19 played a role in the greater reporting of psychosocial issues for newly diagnosed patients in 2020.



**Figure 5. Psychosocial issues experienced 'before treatment' by newly diagnosed patients in 2018 and 2020 who had not yet received treatment**



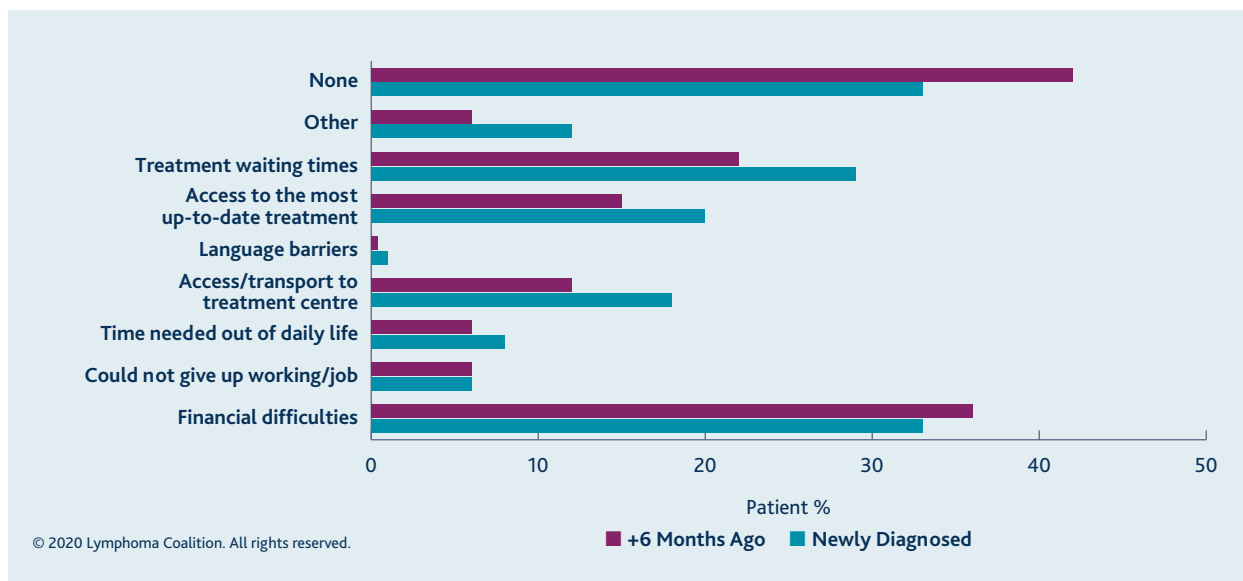
**Figure 6. Psychosocial issues experienced 'during treatment' by newly diagnosed patients in 2018 and 2020 who were in treatment, or who had treatment and were back in watch-and-wait**



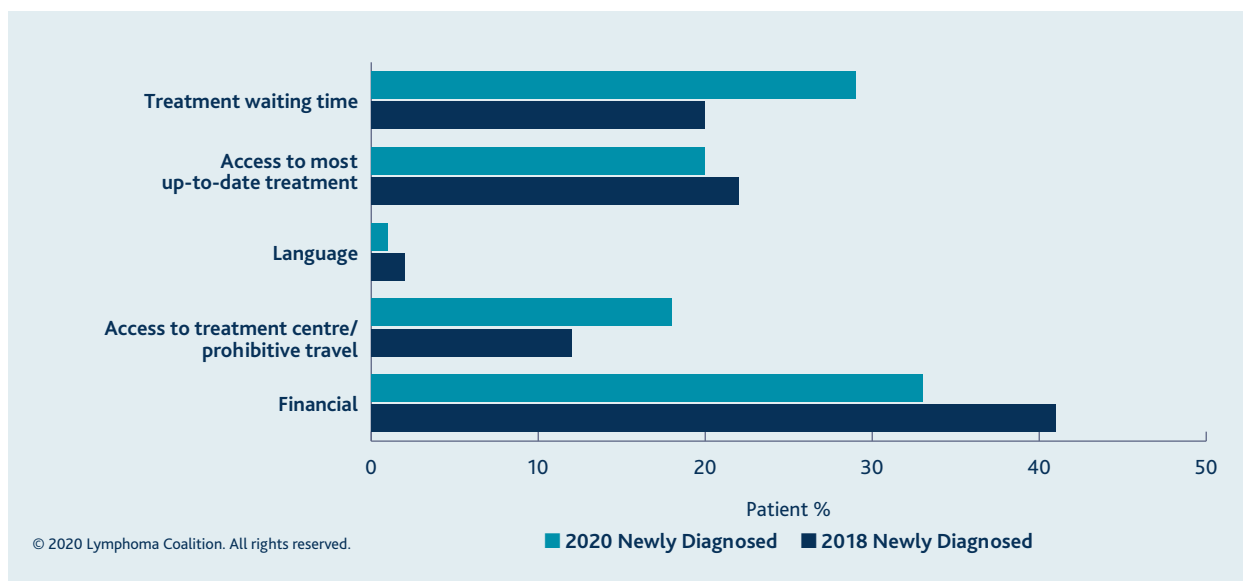
## Barriers to Treatment

Patients who were currently receiving treatment, or who had received treatment in the past, were asked if any barriers had prevented them from receiving treatment. Compared to the +6 months ago subgroup, with the exception of financial difficulties, a greater proportion of patients in the newly diagnosed subgroup reported each barrier to treatment (figure 7). Additionally, compared to the +6 months ago subgroup, fewer patients in the newly diagnosed subgroup reported experiencing no barriers to treatment ('none').

**Figure 7. Reported barriers to treatment that patients experienced**



**Figure 8. Barriers to treatment reported by the 2018 and 2020 subgroups of newly diagnosed patients**



Barriers to treatment reported by the newly diagnosed group were also compared against the barriers reported by the 2018 newly diagnosed subgroup (**figure 8**). Only barriers that were listed in both years were analysed. Compared to the 2018 newly diagnosed subgroup, a lesser proportion of patients in the 2020 newly diagnosed subgroup reported finances, language, or access to up-to-date treatments as barriers. However, compared to the 2018 newly diagnosed subgroup, a greater proportion of patients in the 2020 newly diagnosed subgroup reported treatment waiting times and access to treatment centres as barriers.

The COVID-19 pandemic caused widespread closures and necessitated the creation of new guidelines for healthcare systems relating to social distancing and sanitation. As such, it is possible that COVID-19 created additional barriers to treatment for those in the newly diagnosed group. 'Financial difficulties' was the largest barrier for both patient groups; however, LC does not have the evidence to understand what the underlying causes were, or if the causes were different.

A top reported barrier for newly diagnosed patients was 'treatment waiting times'. Patients with cancer are high risk for COVID-19 infection and complications. Therefore, in certain cases, patients are facing treatment delays or discontinuation based on new risk assessment protocols. 'Access/transport to treatment centre' was also a top reported barrier for newly diagnosed patients. Cancer care facilities are attempting to reduce traffic to decrease the spread of infection, which may impact patient access. Additionally, if patients take public transit to their treatment centre, they may be reluctant to do so because of their infection risk, and/or public transit may not be available in places with severe restrictions.

## Limitations

While certain questions were matched to the 2018 survey for comparison of the newly diagnosed subgroups, this was not possible for all questions. Due to the absence of a true baseline, it cannot be ascertained that trends observed in the 2020 newly diagnosed subgroup are attributable to the timing of the COVID-19 pandemic versus their actual cancer diagnosis and care.

# IMPACT OF THE COVID-19 PANDEMIC ON CANCER RESEARCH

The COVID-19 pandemic has affected clinical and basic cancer research. In some cases, strict COVID-19-related public health measures have slowed the pace of clinical trial initiation, enrolment, and progress.<sup>4</sup>

## **This is due to several factors relating to both patients with cancer and the healthcare system, including:**

- The activity of personnel at research centres is being reorganised according to social distancing and/or quarantining measures, which may require staff to work in shifts. This may create a shortage of human resources to screen or include new patients in clinical trials exploring anti-cancer agents.<sup>7</sup>
- There are restrictions on visits to healthcare facilities required for vulnerable populations, including some clinical trial participants.<sup>4</sup>
- Clinics may only be allowing essential or critical visits or may be refusing to take part in clinical trials.<sup>4</sup>
- Recruited patients may drop out of clinical trials due to their level of risk.<sup>4</sup>
- A clinical trial may require participants to undergo laboratory tests, imaging, or other diagnostic tests, which may not be accessible.<sup>4</sup>
- A clinical trial design may require access to acute care beds or ICU beds, which may not be available during COVID-19.<sup>19</sup>

All these factors may lead to clinical trial protocol deviations and/or violations for missed or delayed patient visits. These deviations and violations can lead to countless queries.<sup>3</sup> This may force research teams to devote time and resources to these tasks, rather than to accelerating the clinical investigation to make up for lost time.<sup>3</sup>

Some resources in the cancer research sector are also being shifted away from investigating anti-cancer agents, and towards exploring the different clinical impacts of COVID-19 on patients with cancer. For example, the effect of anti-cancer therapy on patients with COVID-19, the outcomes of patients with cancer with COVID-19 infection, and the epidemiological, clinical, pathological, and radiographic features of patients with cancer with COVID-19 infection.<sup>7,29</sup> In some cases, cancer laboratories are even pivoting their experiments towards exploring therapeutic options for COVID-19 infection.<sup>29</sup>

As the pandemic has continued, many cancer research centres have attempted to make changes to their programs in order to adapt to the evolving situation without interrupting their activity.<sup>29</sup> Several health authorities (e.g., FDA, European Medicines Agency, Swissmedics) have attempted to aid in this by issuing guidelines for handling the effects of COVID-19 on clinical trials.<sup>4</sup> These guidelines contain recommendations for increasing flexibility in protocols while maintaining the integrity of clinical trials.<sup>29</sup> For example, remotifying communication with patients for follow-up, making changes and exceptions to trial protocols, and reducing multiple hospital visits through reduced testing and/or allowing for testing in community health settings, rather than mandating testing in clinical trial hospitals.<sup>29</sup>

## **Experimental research is critical in providing the best care for patients with cancer and suspending or slowing this research can have particularly grave consequences for certain patient groups.<sup>3</sup>**

For example, for patients with relapsed or refractory cancers who are reliant on clinical trials for treatment because available therapies have failed. During the COVID-19 and future pandemics, it is important to protect the clinical cancer research process while ensuring the safety of clinical trial staff, as well as the rights, safety, and wellbeing of trial participants.<sup>4</sup>

## THE IMPACT OF COVID-19 ON CANCER PATIENT ORGANISATIONS

Patient organisations are a key point of contact for patients with cancer around the world. Beyond advocating for patients, these organisations are uniquely positioned to educate and improve patient care and experience. They also provide essential funds for research and provide insight into the patient experience.<sup>30</sup>

During the COVID-19 pandemic, patient organisations have remained a vital source of information for patients with cancer. Because patients with cancer are high risk for COVID-19 infection and complications, patient organisations are managing questions and concerns relating to disruptions in diagnosis, surgery, treatments, trials, and follow-ups.<sup>31</sup> They are also supporting patients with psychosocial issues, such as anxiety and isolation, that stem from new protocols like social distancing.<sup>31</sup> This is in addition to continuing to provide their regular support in cancer diagnosis and care.

Patients organisations are having to sustain this new level of support while experiencing large decreases in income, and while managing the reallocation of staff and volunteers, the development of new services, and the acquisition of new tools and skillsets (e.g., online learning).<sup>31</sup>

### Survey on the Impact of COVID-19 on Patient Organisations

In May 2020, a survey about the impact of COVID-19 on patient organisations was launched. This survey was developed by the World Ovarian Cancer Coalition, the World Pancreatic Cancer Coalition, the Lymphoma Coalition, the Advanced Breast Cancer Global Alliance, and the World Bladder Cancer Patient Coalition. Together, these five global coalitions represent around 400 organisations.<sup>31</sup> In total, 157 patient organisations from 56 countries took part in the survey. The participating organisations support over 350,000 people living with different cancers.<sup>31</sup>

The survey showed that all patient organisations, regardless of their location, size, or the types of patients they support, had been significantly affected by the COVID-19 pandemic. Key findings are summarised in **table 4** on page 30.

**Table 4. Key findings showing how different aspects of the work of patient organisations have been affected**

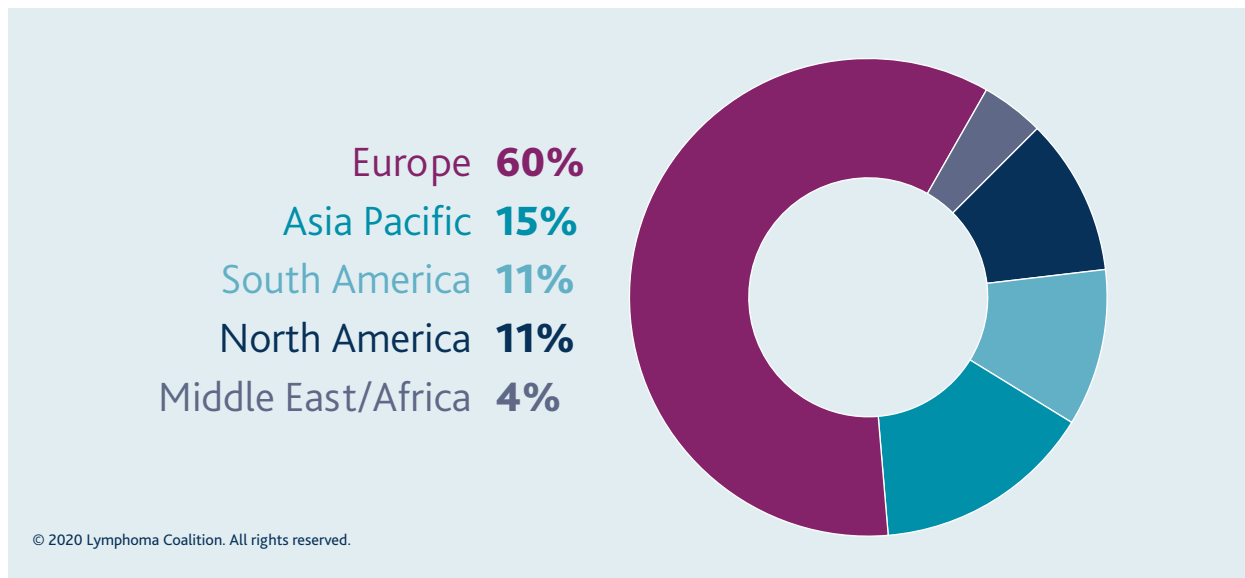
Support Services	Fundraising
<ul style="list-style-type: none"> <li>Nearly all organisations (89%) had altered their services for patients with cancer</li> <li>Roughly 6 in 10 organisations experienced an increase in the number of calls and emails, with an average increase of 44%</li> <li>7 in 10 organisations reported receiving calls relating to COVID-19, on average 35% of their total call volume</li> <li>Most organisations (63%) had produced new COVID-19-related information, half (49%) moved existing services online, and 33% developed new services</li> </ul>	<ul style="list-style-type: none"> <li>Nearly all organisations reported that they use fundraising to support their activity</li> <li>All fundraising types were reported to be affected, including grants, major donors, mail, online donations, and community events</li> <li>Only 5% were confident in their financial position at the time of the survey</li> <li>8 in 10 organisations predicted a fall in income over the next year, with an average decrease of 46% expected</li> <li>1 in 5 organisations reported that income drops were affecting their current viability, and 45% reported their viability may be affected in the future</li> </ul>
Awareness, Education & Advocacy	Organisation of Services
<ul style="list-style-type: none"> <li>Half of the organisations had to alter their awareness initiatives, cancelling or postponing events, and/or adjusting messaging</li> <li>68% of organisations who are involved in health professional education activities had to alter services, move services online, or pause programs because healthcare professionals were redeployed</li> <li>Two thirds of organisations had to delay or alter their activities and messaging relating to influencing or lobbying</li> </ul>	<ul style="list-style-type: none"> <li>1 in 10 organisations had made cuts in staffing, and roughly the same proportion had used government schemes to support staff wages (i.e., 'furloughed')</li> <li>A third of organisations had to source technology and equipment to move working environments into homes, and to develop new services</li> <li>Organisations reported concerns about staff burnout, and about the lack of direct contact with colleagues and patients</li> </ul>
Research	Impact on Cancer Care & Diagnosis
<ul style="list-style-type: none"> <li>Half of the organisations were involved in funding or conducting research, and only a quarter of these activities remained unaffected at the time of the survey</li> <li>A third of organisations were concerned about the viability of their current projects</li> <li>3 in 10 organisations expect to reduce the amount of funding they can supply to research, or the amount of research they undertake in the future</li> </ul>	<ul style="list-style-type: none"> <li>Organisations reported that every aspect of cancer diagnosis, treatment, follow-up, clinical trials, and support had been affected</li> <li>While guidelines for cancer care during COVID-19 have been established for countries or local areas, it was reported that guidelines can differ by region, or even by hospital</li> <li>Organisations reported that COVID-19 cancer care guidelines are not always being implemented, which can make messaging to patients with cancer more confusing</li> <li>Organisations reported observing a considerable level of anxiety among patients</li> </ul>

Findings taken from the 2020 survey report by the World Ovarian Cancer Coalition, the World Pancreatic Cancer Coalition, the Lymphoma Coalition, the Advanced Breast Cancer Global Alliance, and the World Bladder Cancer Patient Coalition.<sup>31</sup>

## Results Specific to Lymphoma and CLL Patient Organisations

Of the 157 responses to the survey, 45 were from organisations who belong to the Lymphoma Coalition (LC). Together, these organisations were in touch with over 200,000 patients with lymphoma and CLL.<sup>31</sup> The greatest proportion of LC member responses came from organisations in Europe (figure 9).

**Figure 9. Geographic breakdown of LC member responses to the May 2020 survey on the impact of COVID-19 on patient organisations**

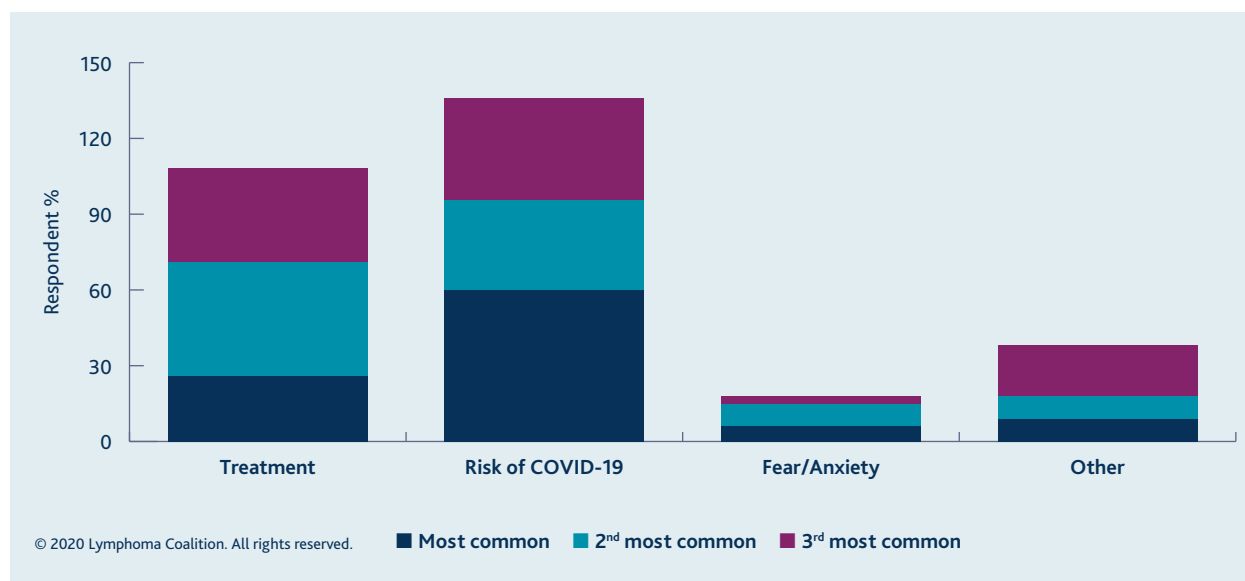


In terms of organisational structure, 38% of LC members reported that they have no paid staff, and 40% reported that they have more than five full time equivalent staff. Many LC members rely on volunteers to deliver their services. In total, 3400 such people are supporting the work of the 45 LC member organisations represented in this survey. Before the outbreak of COVID-19, LC members described their working arrangements as follows: 32% reported that they always or mainly worked from offices, and 56% always or mainly worked from home.<sup>31</sup>

As of May 2020 (when the survey was completed), 71% of LC members saw an increase in the number of calls and emails they were receiving, with an average increase of 49%.

83% of LC members reported receiving calls relating to COVID-19, representing on average 44% of their total call volume. Organisations were asked to list the three most common questions raised by people with cancer. LC members reported that questions about the risks of contracting COVID-19, and questions about cancer treatments during the pandemic were the most common (figure 10).<sup>31</sup>

**Figure 10. Most common questions raised by patients with lymphoma and CLL during the COVID-19 pandemic**



**Nearly all LC members (99%) reported having to adjust their services.**

Most have produced new information relating to COVID-19 (74%), half moved existing services online (52%), and 37% developed new services. In terms of changes to LC member activities, of the 73% who undertake advocacy activities, 63% have delayed these activities, and 20% have altered the messaging. Of the 67% who undertake symptom awareness activities, 41% reported altering these activities. An even higher proportion of those providing healthcare professional education activities (45%) have had to alter their services (68%), mainly by finding online solutions.<sup>31</sup>

50% of LC members involved in research are concerned about the viability of their current projects. While 50% of LC members involved in research do expect to resume conducting and/or funding research, 29% also reported that they expect to reduce the amount of funding they provide, and/or the amount of research they undertake. A key issue is falling income; costs have continued (e.g., paying research staff), but projects are being delayed or halted (e.g., labs closed). Some clinical trials have been closed, and some labs have been repurposed into COVID-19 testing centres. This is concerning as it may impact progress relating to treatments. Additionally, many patient organisations conduct research relating to the patient experience, insights from which are vital in improving patient care.<sup>31</sup>

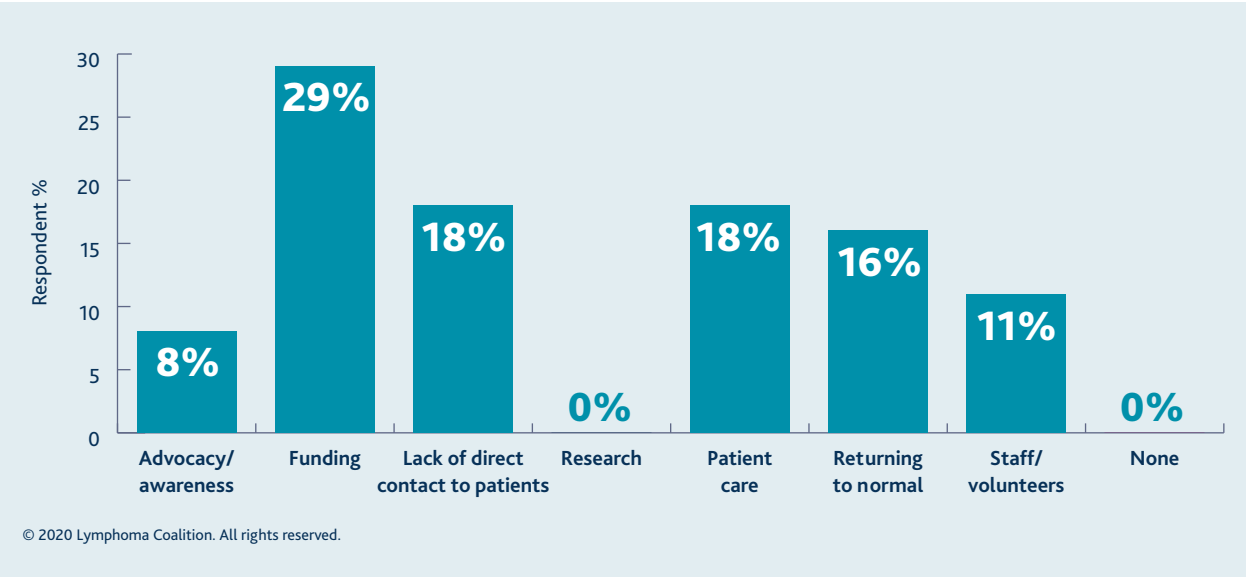
**Most LC members (84%) reported that they fundraise to support their activities. A staggering 76% of LC members predicted a fall in income over the next 12 months, with the average expected drop in income being 43%. Only 7% of LC members were confident of their financial stability at the time of the survey. Every type of fundraising was reported to be affected by the COVID-19 pandemic.<sup>31</sup>**



54% of LC members reported that they are trying to find new ways of fundraising. Some of these new initiatives include emergency appeals, virtual happy hour webinars, online celebrity auctions, virtual concerts by leading performers, virtual fundraising galas, and virtual running/walking races. Because the pandemic has widely imposed financial hardship across the general public, some LC members reported being hesitant to ask for donations, when they know that patients in their community are also facing dire personal financial circumstances. However, others reported that it is important to keep in touch and offer more options, so patients know you are there for them, even if the new offerings are not large money raisers. Moving fundraising initiatives and services online can be costly, especially if new technological infrastructure must be implemented. 40% of LC members reported having to spend more on technology and equipment for new services, but also for moving to home-based work. Those who were wholly or mainly office-based were most likely to have to spend money on technology and equipment.<sup>31</sup>

Organisations were asked to state what their biggest concern was in relation to their work and the COVID-19 pandemic. As displayed in **figure 11** below, issues relating to funding were most prominent, followed by concerns relating to patient care and lack of direct access with patients.<sup>31</sup>

**Figure 11. Biggest concerns for patient organisations relating to their work during the COVID-19 pandemic**



## Moving Forward

Patient organisations have continued to provide vital services for patients with cancer during the COVID-19 pandemic.

They are adapting to new ways of working, experiencing increases in their levels of activity, and having to develop new services and/or move services online. This is all during a time when their finances are severely challenged. Learnings from the survey suggest that patient organisations should embrace new technologies now, starting small if necessary.<sup>31</sup> Organisations are encouraged to review their plans boldly, and to collaborate, share ideas, and engage with other patient organisations and relevant stakeholders.<sup>31</sup>

It is evident that COVID-19 has caused significant financial strain on patient organisations. During COVID-19 and future pandemics, it is important that funders continue to support patient organisations, even increasing support if possible. The support of those who can assist organisations in developing technological solutions and collaborative working models is vital to opening up access to patients and helping organisations to survive and thrive.<sup>31</sup> Moving forward, it is important to analyse and learn from what has worked well for patient organisations during the COVID-19 pandemic. However, it is also important to understand where elements of cancer care and support have been threatened, and where progress has been slowed.

In ensuring that cancer treatment and services are not set back several years, it is important for influential stakeholders in that space to collaborate with patient organisations who can effectively articulate the impact on patients. Cooperation will be crucial in mitigating negative impacts and enabling progress.<sup>31</sup>

# Conclusions

The COVID-19 pandemic has brought forth new risks and challenges for patients with cancer and the systems they rely on for their care and support.

Emerging protocols and evolving healthcare needs have impacted healthcare systems and staff involved in cancer care. Managing patients with cancer during COVID-19 has necessitated the reconsideration of usual standards of care. New COVID-19-related gaps in cancer care have emerged, which must be addressed, mitigated, and learned from for future pandemic preparedness.

The accurate and timely diagnosis of patients with cancer during COVID-19 has been challenging due to various procedural, logistical, and resource-related limitations. Additionally, there is a reluctance among some patients to seek medical attention for symptoms because they fear contracting COVID-19 in healthcare settings, among other factors.

## Recommendations for Clinical Care, Practice, and Research

- Moving forward, **observed decreases in the level of routine clinical activity must be tracked and considered in planning for future healthcare needs** (e.g., potential later stage presentations of cancer and other diseases). Efforts must also be made to avoid these decreases through improved communication about the importance of accessing medical care if required.
- **Healthcare facilities must have a plan ready to put in place outlining specific safety precautions to keep patients safe** and, once in place, a communication plan to ensure patients are aware of these precautions so they feel safe entering the premises.
- The diagnosis of patients with cancer cannot be compromised during an infectious disease pandemic. **Lessons learned from the COVID-19 pandemic must be applied toward developing strategies to manage the diagnosis process, tailored to the best available resources, in future healthcare emergencies.**
- To prepare for increased care demands and resource use during pandemics, **strategies must be developed to minimise interruptions to active cancer treatment, particularly in patients who are being treated with curative intent.** The suspension or delay of certain aspects of cancer care and research may have particularly grave consequences for certain subgroups of patients with lymphoma, for example those who may benefit from customised treatments (e.g., CAR-T therapy) or from clinical trials.
- **Efforts must be made to anticipate for and manage shortages in medical supplies and resources** (e.g., ICU and acute care beds, PPE, drugs, equipment, staff) to maintain the viability of all cancer treatment options during future healthcare emergencies.

## Recommendations for Psychosocial Support

- Relating to treatment, **improved psychosocial supports must be designed and implemented for oncologists and allied healthcare professionals**, who are working and making complex treatment decisions under extreme circumstances.
- **Improved psychosocial supports are also required for patients with cancer**, who have various worries surrounding their high risk of infection, delayed or altered care plans, and concerns about having to undergo treatments or attend appointments alone. Results from the LC 2020 GPS analysis specific to Asia confirmed that patients who were newly diagnosed and/or undergoing treatment during the COVID-19 pandemic experienced high levels of psychosocial distress.
- These patients (newly diagnosed in Asia during the COVID-19 pandemic) reported a lesser understanding of different topics relating to their diagnosis and treatment, less positive communication with their doctors, and greater overall information needs. Because of emerging protocols, many patients with cancer may have had their appointments delayed, consolidated, switched to telemedicine, or they may have been switched to another centre for care. This can impact the efficacy of patient-doctor communication and have implications for patient understanding. **Lessons learned from communication strategies during COVID-19 must be applied towards developing effective means of communication and information provision during future healthcare emergencies.**

## Recommendations for Patient Organisations

- Lastly, **patient organisations have remained a vital source of information for patients with cancer during the COVID-19 pandemic.** Patient organisations have helped patients with cancer not only to navigate their diagnoses and care plans but have also provided information and support relating to their risk of COVID-19 infection and disruptions in care. They are also supporting patients with psychosocial issues, such as anxiety and isolation, that stem from new protocols like social distancing. Patient organisations are having to sustain this new level of support while experiencing large decreases in income, and while managing the re-organisation of their structure and services. **During COVID-19 and future pandemics, it is important that funders continue to support patient organisations, even increasing support if possible.**
- Additionally, in ensuring that cancer treatment and services are not set back several years, it will be crucial for influential stakeholders in that space to **collaborate with patient organisations who can effectively articulate the impact on patients.**

# Appendix

## Demographic information for the subgroup of newly diagnosed patients from the LC 2018 GPS

Country of residence	n=1	%
China	767	94.1
Japan	28	3.4
Malaysia	1	0.1
Philippines	2	0.2
South Korea	17	2.1
Total	815	100

Area	n=1	%
Rural	202	25
Urban	499	62
Suburban	111	14
Total	812	100

Age	n=1	%
18-29	113	14
30-39	166	21
40-59	305	38
60 -69	168	21
70+	51	6
Total	803	100

Sex	n=1	%
Male	453	56
Female	358	44
Prefer not to answer	4	1
Total	815	100

Top Three Subtypes	n=1	%
Diffuse large B-cell lymphoma	259	33
Follicular lymphoma	116	14
Hodgkin	97	12

# Glossary

## **Active surveillance**

A treatment plan where a patient's condition is closely watched, and treatment is not administered unless there are changes in test results that indicate the condition is getting worse. Also called watch-and-wait.

## **Allograft**

The transplant of an organ, tissue, or cells from one individual to another individual of the same species (who is not an identical twin).

## **Bone marrow aspiration and biopsy**

A bone marrow biopsy removes a small amount of bone as well as a small amount of fluid and cells from inside the bone (bone marrow). A bone marrow aspiration removes only bone marrow.

## **Cellular therapeutics**

The transfer of intact, live cells into a patient to help reduce or cure a disease. The cells can originate from the patient (autologous cells) or from a donor (allogeneic cells).

## **Chemoimmunotherapy**

A treatment regimen that combines chemotherapy with immunotherapy.

## **Chemotherapy**

Treatment that uses drugs to stop the growth of cancer cells, either by stopping the cells from dividing, or by killing the cells.

## **Chimeric antigen receptor T-cell therapy (CAR-T)**

A treatment that modifies a patient's own immune cells (T cells) to express a receptor on their surface. The receptor recognises and binds to specific structures (antigens) on the surface of cancer cells, and once bound, the T cell is stimulated to attack the cancer cell.

## **Computerised tomography (CT) scan**

A procedure that uses an x-ray machine linked to a computer to make a series of detailed pictures of specific areas inside the body. These pictures are used to produce three dimensional views of tissues and organs.

## **Curative treatment**

Treating patients with the intent of curing their disease, as opposed to reducing the number of cancer cells and alleviating symptoms.

## **Cytopathologists**

A pathologist (doctor) who is trained in diagnosing human disease through studying cells that are obtained from body secretions and fluids.

## **Excisional lymph node biopsy**

The removal of an entire lymph node. A pathologist will view the tissue under a microscope to look for cancer cells.

## **Fine needle aspiration (FNA) biopsies**

A procedure that uses a very thin needle and syringe to remove a sample of cells, tissue, or fluid from an abnormal area or lump in the body.

## **Haematological malignancy**

Cancer that begins in blood forming tissue (e.g., bone marrow) or in cells of the immune system. Also called blood cancer.

## **Hydroalcoholic solutions**

A solution in which the solvent is a mixture of water and alcohol (e.g., hand sanitiser).

## **Immunosuppression**

Suppression of the body's immune system, which lowers its ability to fight infections and other diseases.

## **Immunosuppressive therapy**

Treatment that lowers the activity of the body's immune system.

## **Immunotherapy**

Treatment that uses certain parts of a person's immune system to fight diseases such as cancer.

## **Lymphocyte(s)**

An immune cell that is made in the bone marrow and is found in the lymph tissue and in the blood. There are two main types of lymphocytes, which include B lymphocytes and T lymphocytes.

**Malignancy**

Disease where abnormal cells divide uncontrollably and can invade nearby tissues. Malignant cells can travel to other parts of the body through the blood and lymph systems. Also called cancer.

**Metastatic**

Cancer cells that spread from the place where they originally formed to another part of the body.

**Middle East Respiratory Syndrome (MERS)**

A viral respiratory disease that is caused by a coronavirus. Most patients with MERS develop severe respiratory illness with symptoms of fever, cough, and shortness of breath.

**Molecular testing**

A laboratory test that checks for certain genes, proteins, or other molecules in a sample (e.g., tissue, blood, body fluid).

**Nuclear medicine**

A specialised area of radiology that uses small amounts of radioactive substances to examine organ structure and function. Radioactive substances may be used in both the diagnosis and treatment of cancers.

**Pathologists**

A doctor who is specially trained in the identification of diseases through studying cells and tissues under a microscope.

**Pathology**

A branch of medical science involving the study and diagnosis of disease through the examination of surgically removed tissues, organs, bodily fluids, and sometimes the entire body (e.g., autopsy).

**Positron emission tomography (PET) scan**

A procedure where radioactive glucose (sugar) is injected into a vein, and a scanner is used to make computerised, detailed pictures of specific areas inside the body where the glucose is taken up.

**Radiotherapy**

The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumours.

**Refractory disease**

Cancer that does not respond to treatment.

**Sentinel lymph node**

The first lymph node where cancer is likely to spread to from the primary tumour.

**Severe Acute Respiratory Syndrome (SARS)**

A viral respiratory disease that is caused by a SARS-associated coronavirus. It is an airborne virus that spreads through small droplets of saliva. In general, SARS begins with a high fever.

**Stem cell transplants**

A procedure where a patient receives healthy stem cells (blood-forming cells) to replace their own stem cells that have been destroyed. The healthy stem cells can come from the blood or bone marrow of the patient, or from a related or unrelated donor. Formerly known as bone marrow transplants.

**Targeted therapy**

Treatment that uses drugs or other substances to locate and attack specific types of cancer cells with less harm to normal cells.

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