



# Protecting Immunocompromised Canadians from COVID-19 and Beyond

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Canadian  
Immunocompromised  
Advocacy Network

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# EXECUTIVE SUMMARY

Since the summer of 2022, the Canadian Immunocompromised Advocacy Network (formerly the Immunocompromised Patient Action Group) has been meeting regularly to discuss the challenges faced by immunocompromised people in Canada as COVID-19 has moved into the endemic state. The findings and recommendations in this paper are drawn from the experiences of the group's members, a series of interviews with immunocompromised patients, and expert consultations. Additionally, a quantitative perspective was drawn from a survey, conducted in Spring 2023 by the Canadian Association of Retired Persons (CARP) and immunocompromised patient groups, with financial support from a research-based Canadian pharmaceutical company, completed by 2,945 respondents.

From all this, we have learned that COVID-19 continues to have a disproportionate burden on immunocompromised people[1]. 80% of immunocompromised respondents were still somewhat or very concerned about COVID-19, compared to only 64% of non-immunocompromised respondents. Similarly, twice as many immunocompromised respondents (40%) respond feeling anxious compared to non-immunocompromised respondents (20%) when it comes to COVID-19. Ultimately, this manifests in changes to daily living, with 65% of immunocompromised respondents report that COVID-19 is significantly impacting their day-to-day life as compared to 43% of non-immunocompromised respondents.

To improve the well-being of immunocompromised Canadians in the context of endemic COVID-19 and future pandemics, four calls to action have been identified:

- 1 Increased and ongoing knowledge generation and dissemination around COVID-19:**  
As COVID-19 continues to evolve (with new variants, varying incidence, different medications), knowing the ongoing risks faced by immunocompromised Canadians is critical for day-to-day decision making and well-being.
- 2 Greater alignment on definitions of immunocompromised across Canada:**  
This is critical to ensuring that even across jurisdictions, policy-makers and healthcare providers can identify who is immunocompromised and where targeted support and/or outreach is required.
- 3 Targeted infection control measures to protect immunocompromised patients:**  
While the use of broad societal public health measures is over, targeted measures such as masking in healthcare settings can go a long way in limiting the transmission of disease and protecting immunocompromised Canadians.

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[1] Singson JR, Kirley PD, Pham H, et al. Factors Associated with Severe Outcomes Among Immunocompromised Adults Hospitalized for COVID-19 — COVID-NET, 10 States, March 2020–February 2022. *MMWR Morb Mortal Wkly Rep* 2022;71:878–884. DOI: <http://dx.doi.org/10.15585/mmwr.mm7127a3>

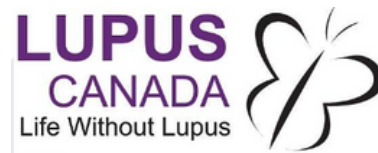
- 4 **Easier and more equitable access for prophylactic and therapeutic options for COVID-19 and other potential infectious diseases or pandemic pathogen:**  
 Prophylactics and therapeutics are even important at lowering patient risk and ensuring their equitable uptake and use (which requires optimizing approvals to education to rollout/administration) is key to protecting immunocompromised Canadians.

Ultimately, it is critical that governments, policy makers, and health authorities continue to support immunocompromised patients to keep them healthy and ensure they can attain the quality of life shared by the rest of society. These policies would support the ongoing risks posed by COVID-19 but also help prepare society in general, and immunocompromised people specifically, for the next pandemic.

## THE COALITION:

### Canadian Immunocompromised Advocacy Network (C.I.A.N)

In 2022, a coalition of immunocompromised individuals and representatives of immunocompromised patient advocacy groups across Canada united to form Canadian Immunocompromised Advocacy Network (C.I.A.N). Members of C.I.A.N. as of November 2023 include representatives of the following organizations (for most up-to-date membership list, please visit our website):



At its formation, the purpose of this coalition was to:

- Share strategies and create tools to help immunocompromised patients understand the risks posed by COVID-19, navigate the pandemic, and protect themselves.
- Unite and amplify the diverse voices of immunocompromised Canadians to increase awareness of their continued challenges and advocate for increased support in addressing their unmet needs.
- Develop strategies to increase awareness of and equitable access to COVID-19 preventative therapies, treatments, and vaccines.
- Create tools that can be used to disseminate learnings and recommendations to decision makers, media, and the broader public, thereby empowering immunocompromised patients to ensure their voices are heard in the decision-making process.

Now that the pandemic is past the emergency response phase, the focus of the coalition has shifted towards ensuring that all immunocompromised Canadians are protected from the ongoing risks of COVID-19, other infectious diseases, and even any future pandemics.

This position paper captures the experiences of the C.I.A.N membership and their patient communities (through both interviews and a national survey) and presents recommendations on how to achieve an equitable future state for immunocompromised Canadians.

## THE CURRENT REALITY FACING IMMUNOCOMPROMISED CANADIANS

### Who are immunocompromised Canadians in the context of COVID-19?

Immunocompromised Canadians include those who have a weakened immune system as a result of a medical condition or medications that suppress immune function. As a result, they are at higher risk of infection from an array of infectious diseases like COVID-19. Conditions that can make someone severely immunocompromised include cancers (solid organ and hematologic) and their treatment, primary immunodeficiencies, certain medications (e.g., B-cell depleting therapies), and more.

Severely immunocompromised patients bear the brunt of COVID-19. In a large US study, it was estimated that 12.2% of all hospitalized patients were immunocompromised, despite them representing

only ~3% the population[2]; even when vaccinated, hospitalized immunocompromised patients had higher odds of ICU admission (adjusted odds ratio = 1.40; 95% CI = 1.01–1.92) and death (adjusted odds ratio = 1.87; 95% CI = 1.28–2.75). Ultimately, immunocompromised Canadians are more likely to experience severe illness, require hospitalization and medical intervention, and/or die from COVID-19 than compared to those who are immune competent.

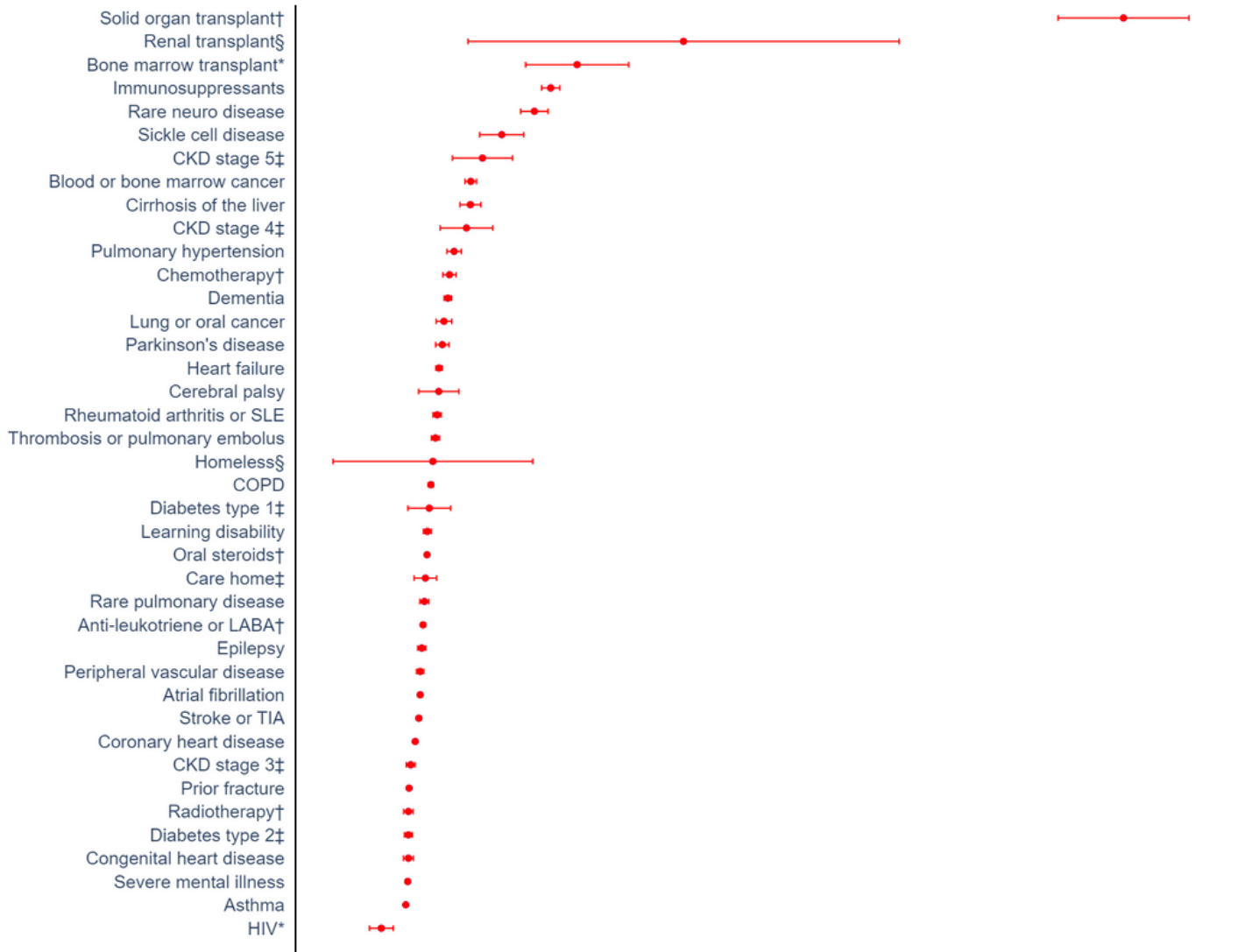
What makes immunocompromising conditions complex is they are a very diverse, heterogeneous set of conditions that leads to differential risk from COVID-19 and other infectious diseases. For instance, Figure 1 below highlights the relative risk of severe outcomes / death from COVID-19 among people who received a primary series and a booster who had different medical conditions compared to healthy individuals. There is a great deal of variation in the risk ranging from an almost 25x higher risk[3] of severe outcomes from COVID-19 in those with solid organ transplant compared to some chronic medical conditions, like asthma or diabetes, that only slightly increase the risk of severe outcomes. Furthermore, certain immunocompromising conditions such as hematologic malignancies, solid organ transplant, bone marrow / stem cell transplant, primary immunodeficiencies, and the use of anti-CD20 and B-cell depleting agents are known to be associated with a poor response to COVID-19 vaccines[4].

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[2] Singson JR, Kirley PD, Pham H, et al. Factors Associated with Severe Outcomes Among Immunocompromised Adults Hospitalized for COVID-19 — COVID-NET, 10 States, March 2020–February 2022. *MMWR Morb Mortal Wkly Rep* 2022;71:878–884. DOI: <http://dx.doi.org/10.15585/mmwr.mm7127a3>

[3] Agrawal U, Bedston S, McCowan C, et al. Severe COVID-19 outcomes after full vaccination of primary schedule and initial boosters: pooled analysis of national prospective cohort studies of 30 million individuals in England, Northern Ireland, Scotland, and Wales. *Lancet*. 2022 Oct 15;400(10360):1305–1320. DOI: 10.1016/S0140-6736(22)01656-7. PMID: 36244382; PMCID: PMC9560746.

[4] Antinori A, Bausch-Jurken M. The Burden of COVID-19 in the Immunocompromised Patient: Implications for Vaccination and Needs for the Future. *J Infect Dis*. 2023 Aug 4;228(Suppl 1):S4–S12. doi: 10.1093/infdis/jiad181. PMID: 37539764; PMCID: PMC10401620.



**Figure 1:** Pooled analyses of rate ratios for specific clinical risk factors associated with COVID-19 related hospitalization or death among individuals who received booster doses of mRNA vaccine

## Immunocompromised people feel left behind as the pandemic has evolved

The initial response to COVID-19 across Canada was swift, with governments, public health authorities, and individual communities implementing broad measures to limit the transmission of the virus. There was a heightened sense of urgency and willingness to make sacrifices in order to protect the most vulnerable in society. This was evidenced by the prioritization of the elderly and the immunocompromised in the initial rollout of vaccines, the implementation of mandates for both vaccines and masks, a general societal willingness to follow challenging public health guidelines like limiting social gatherings, social distancing, and more.

As the pandemic continued, there was a gradual relaxing of public health measures and an understandable desire for society to re-open. By early 2022, most jurisdictions in Canada were relaxing public health measures including vaccine requirements, limitations on social gatherings and mask mandates. By the summer of 2022, much of society was returning to what it was like before the pandemic and, as of today, there are essentially no COVID-19 restrictions. In May 2023, the WHO formally determined that COVID-19 no longer constituted a public health emergency of international concern[5]. The removal of broad public health measures has disproportionately affected those who are already at the greatest risk. For example, the removal of mask mandates in health care settings is particularly impactful for immunocompromised individuals who cannot avoid these spaces and are at higher risk for severe outcomes[6].

In addition to the relaxing of public health measures in 2022, there was a broad societal apathy towards COVID-19, and at times, even an antipathy. This apathy has manifested itself in very low rates of COVID-19 booster vaccination, despite the fact that COVID-19 remains a leading cause of hospitalization across the country. For instance, uptake of the primary series in those 5 and older was over 84% in Canada, only slightly more than half have received even one booster dose, with fewer yet receiving multiple boosters[7]. Additionally, the general public's willingness to prevent the spread of COVID-19 through behaviours such as mask wearing or isolating when sick all but disappeared, with groups emerging that strongly opposed any vaccination mandates, masking mandates, or even the idea of masking itself.

Due to these pressures, decision-makers are unwilling to implement broad protective measures for society. Therefore, targeted measures, designed to protect the most vulnerable, are critical.

## The burden of risk

As many immunocompromised individuals are unable to mount an immune response to COVID-19, even when fully up-to-date with vaccines, they are at a far higher risk of negative outcomes if they become infected[8]. This places a disproportionate burden of risk on immunocompromised Canadians compared to those who are immune competent. Immunocompromised people are left with difficult choices between remaining relatively isolated, with its high social and mental costs, or exposing themselves to the risk of infection, severe illness, hospitalization, or death.



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[5] World Health Organization. Statement on the fifteenth meeting of the IHR Emergency Committee on the COVID-19 pandemic. May 5, 2023.

[6] Why mask mandates are lifting in hospitals cross Canada. CBC. Apr 15, 2023.

[7] Government of Canada. COVID-19 vaccination: Vaccination coverage. Available at: <https://health-infobase.canada.ca/covid-19/vaccination-coverage/>

[8] Lee ARYB, Wong SY, Chai LYA et al. Efficacy of covid-19 vaccines in immunocompromised patients: systematic review and meta-analysis. BMJ. 2022 Mar 2;376:e068632. doi: 10.1136/bmj-2021-068632. PMID: 35236664; PMCID: PMC8889026.



When there were public health restrictions earlier in the pandemic, everyone was making such trade-offs (e.g., do I attend a social gathering and face a higher risk of contracting COVID-19? do I travel? etc.) but now this decision-making is generally limited to immunocompromised individuals who are concerned about the risk they continue to face from COVID-19 on a daily basis.

All-in-all, these changes have left many immunocompromised Canadians feeling abandoned and vulnerable. Protecting themselves may mean choosing to avoid receiving the health care or medications they require or remaining in relative isolation away from important social networks and connections. With fewer preventative options and no broad societal protections, they face more restrictions in navigating their lives at a time when the rest of society is increasingly unrestricted.

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**“As much as [the general public has] moved on - back to the way life was back in 2019, there are many others that can't.** I think that we need to show a little bit more humanity, a little bit more empathy, and a little bit more compassion for those that are immunocompromised. We all have to respect the rights of the people who want personal choice. Well, what about our rights? **It is what I would call the forgotten pandemic. We've been marginalized as a population.”**

**- Double Lung Transplant Recipient**

“I wish we could've held onto that a little bit longer, that sense of - we are a society that cares about one another, **and you're only as strong as the weakest member of society or maybe the most vulnerable member of society.”**

**- Hematologic Cancer Patient Advocate**

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“Pulling from my experience of people I've spoken to in the donation and transplant community, I wish there were more resources along the pathway. I felt like a lot of them were left to navigate the system on their own... They had nowhere to turn. So, in general more resources need to be made available to them tailored to what they need.”

**- Kidney Transplant Recipient and Patient Educator/Advocate**

“Every time I step out of our door to go anywhere, I still put on my mask. And the rest of the world is like, what's wrong with you? You know, this is all gone. **And the World Health Organization's saying that the pandemic is over - I don't think that did anybody any favours, because it's just like saying the cold and flu season is over. But that doesn't mean you can't get a cold or a flu any time of the year.** This is just what the world is like now. Everybody's forgotten that COVID ever happened, but it's never going to go away for me. **Because even with all of these shots, I still don't feel safe. I don't feel comfortable.** There's no evidence, no hard science saying that because you got seven shots, that's the magic number, then you are as protected as you can be.”



- Heart and Kidney Transplant Recipient and Patient Advocate

## Information gaps continue to make individual decision-making challenging

A further challenge facing immunocompromised people is the **lack of, or diminished, information that would inform decision-making** around COVID-19. Critical information that is needed for immunocompromised individuals to make informed decisions includes:

- Information to understand specific risks for specific populations, including:
  - **The relative risk for severe outcomes from COVID-19** (e.g., risk of hospitalization, ICU admission, death) given a particular immune compromising condition (or conditions) along with the necessary medications; and,
  - **Effectiveness of vaccines, monoclonal antibodies, and treatments given a particular immune compromising condition(s)**
- Information to understand the general spread and overall risk from COVID-19, including:
  - Overall COVID-19 prevalence, which has diminished significantly since broader testing was stopped;
  - Levels of hospitalizations and ICU admissions in specific jurisdictions, along with demographics of patients being hospitalized and admitted to the ICU for COVID-19;
  - Diminished wastewater surveillance data which, in the absence of testing, is a reasonable proxy for overall levels of infection; and
  - Circulating variants and their relative infectiousness, immune-evasiveness, and severity (e.g., the XBB family of variants including EG.5, BA.2.86, etc.).

Compared to the height of the pandemic, this information is either more difficult to obtain or unavailable. The rapid evolution of new variants makes it challenging to understand unique risks facing different immunocompromising conditions.

Not only is this information difficult to access publicly, but many healthcare workers (e.g., family physicians, specialists) are less apprised of this information, making it even more challenging for immunocompromised patients to find the right information. With the existing diversity of immunocompromising conditions, the challenges and resources required by patients, such as special access, coverage, and drug-drug interactions, can vary widely.

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“Right now we make these decisions, but we're not really informed. We're just guessing. It's trial and error basically.”

- **Chronic Lymphocytic Leukemia Patient and Patient Advocate**

“We're not given current information on the number of hospitalizations that pertain to COVID. It's difficult to even get to the wastewater level information. There's zero information coming from the transplant team on COVID. **You're on your own.**”

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- **Double Lung Transplant Recipient**

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“**From a COVID perspective, our GPs know very little about post-transplant health.** And even what medications you're allowed to take. They know very little. **There is just no support for patients. If your medications need to be updated or renewed, or anything, people are really falling through the cracks.**”

- **Kidney Transplant Recipient and Transplant Patient Ambassador**

The relative dearth of information makes it particularly challenging for immunocompromised people to make informed decisions about their health and well-being, and adds to their anxieties and fears around COVID-19. Challenges with Canada's generally fractured COVID-19 data infrastructure was cited as an area of improvement in a recent paper analyzing Canada's response to the pandemic[9].

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[9] Bubela T, Flood C M, McGrail K, Straus S E, Mishra S. How Canada's decentralised covid-19 response affected public health data and decision making BMJ 2023; 382 :e075665 doi:10.1136/bmj-2023-075665

Ultimately, ensuring the effective generation and dissemination of information is critical for the management of any future pandemic and it is particularly important to ensure that clinically vulnerable populations like immunocompromised Canadians have access to the right information. The pandemic highlighted the vulnerability of immunocompromised patients and the ongoing need to support these patient populations. It is critical that we take the lessons learned from the pandemic and provide ongoing longitudinal support for vulnerable patients, with timely access to quality information and ongoing access to knowledgeable providers/therapies.



## CONTINUING IMPACTS OF THE PANDEMIC ON IMMUNOCOMPROMISED CANADIANS

While there are many anecdotes of immunocompromised patients feeling confused, anxious, and feeling left behind as COVID-19 has entered the endemic state, it is important to quantify some of these sentiments. As a result, in the spring of 2023, a survey was developed by the Canadian Association of Retired Persons (CARP), and immunocompromised patient groups (with financial support from a research-based Canadian pharmaceutical company) to assess views and attitudes around COVID-19. This provided an opportunity to explore how attitudes and perceptions of COVID-19 were changing and how they differed between immunocompromised and immunocompetent Canadians. Several survey questions were specific to immunocompromised populations. This survey was shared via CARP's opt-in e-newsletter along with different immunocompromised patient groups' distribution channels.

2,945 respondents completed the survey. The majority (64%) of respondents were from Ontario but there were respondents from across the country. The majority of respondents (88%) were 65 and older. Among the 2,945 respondents, 778 (26%) reported being immunocompromised in some way with the most common disease states being autoimmune / B-cell depleting therapy (15% of immunocompromised respondents), solid organ tumor (14%), and dialysis/chronic kidney disease (9%).

Some key findings from the survey include:

- **Overall concern around COVID-19 has fallen but remains high:**
  - 80% of immunocompromised respondents were somewhat or very concerned about COVID-19, compared to 64% of the non-immunocompromised respondents.
  - 63% of non-immunocompromised respondents had significant or somewhat decreased concerns about COVID-19 as compared to a year ago, while a smaller proportion (53%) of immunocompromised respondents had significant or somewhat decreased concerns. Among those who did not report decreased concern, some of the key reasons were more societal apathy, loss of protective measures, and new variants.
- **Most respondents believe that more protection is needed for immunocompromised patients:**
  - 76% of immunocompromised respondents were aware that COVID-19 vaccinations did not provide the same protection to the immunocompromised compared to the general public; this compared to 69% of non-immunocompromised respondents.
  - Similarly, 76% of immunocompromised respondents felt it was very important (9 or 10 on a 10 point scale) for immunocompromised Canadians to have additional protection/support in dealing with COVID-19, as compared to 65% of non-immunocompromised Canadians.
- **Immunocompromised Canadians are continuing to modify their behaviours because of COVID-19:**
  - 72% of immunocompromised Canadians are still sometimes, often, or always maintaining some shielding behaviour when it comes to COVID-19, including (1) minimizing contact with others by staying home, (2) minimizing non-essential travel outside of the home, (3) avoiding visitors at home, (4) avoiding social gatherings with >2 people, or (5) maintaining a 2m distance from others outside of home.
  - This is affecting the quality of life of caregivers/partners, with 31% of caregivers and/or partners' saying that their quality of life was affected either 'a great deal' or 'a lot' by the shielding behaviours.
- **Feelings of anxiety and restriction are common among immunocompromised respondents:**
  - Twice as many immunocompromised respondents (40%) respond feeling anxious compared to non-immunocompromised respondents (20%) when it comes to COVID-19.
  - Similarly, more than twice as many immunocompromised respondents (18%) respond feeling restricted compared to non-immunocompromised respondents (8%).
  - Positively, the most common emotion is actually 'hopeful', with 52% of non-immunocompromised respondents and 42% of immunocompromised respondents feeling hopeful about the current COVID-19 situation.
- **Ultimately, COVID-19 is continuing to impact the daily lives of immunocompromised respondents:**
  - 65% of immunocompromised respondents report that COVID-19 is significantly impacting their day-to-day life as compared to 43% of non-immunocompromised respondents.

- **What immunocompromised Canadians would like to see to make things better:**
  - When it comes to improving quality of life and lessening the burden from COVID-19, the top requests from immunocompromised patients include:
    - Continued information on COVID-19 as they pertain to immunocompromised people (30% of respondents).
    - Access to new preventive/therapeutic options for COVID-19 (28%).
    - Additional protective measures, such as masking in clinical environments (17%).

These findings reflect many of the comments we are hearing from immunocompromised patients about how COVID-19 is continuing to affect people's lives.



"Life as an immunocompromised person means that, **on a daily basis, you need to think about and pre-plan every single thing that you do when you leave the house.** So it's challenging today, because **immunocompromised people are not on a level playing field with the immune-competent people.**"

- Double Lung Transplant Recipient

"There are those who are still fully isolated. **Like, we're talking fully isolated. Some of these people have lost jobs** because their employers expect them to be in person."

- Acute Promyelocytic Leukemia Survivor and Patient Advocate



"I've heard the experiences of dialysis patients who, a lot of them I will say, are not in very good positions. **A lot of them really rely on things like public transit to get to their medical appointments. So, what happens now when you're not supposed to be around people? You're supposed to stay home.** You have no way to get to dialysis.

**COVID really messed up the donation system - like donations and transplants stopped, my programs stopped working.** Specifically with donations and transplants - the amount of surgeries across Canada that were just shut down, the number of deceased donors who weren't able to donate because there wasn't capacity to have those surgeries or living donors whose planned donation was postponed.

**I think for the donation transplant community, it really affected them in many multiple ways."**

- Kidney Transplant Recipient and Patient Educator/Advocate



“Cancer patients under chemo become immunosuppressed, but they have to go to the cancer center to receive their chemo infusion. **So they continue to be exposed to more risk.**”

- **Bone Marrow Transplant Recipient, Hematologic Cancer Patient and Advocate**



## CHALLENGES WITH THE ROLLOUT OF PROPHYLACTICS AND THERAPEUTICS

Canada responded to COVID-19 by implementing a broad, population health approach to protect the general public, with vaccination programs and public health mandates. However, the approach to protecting immunocompromised individuals has been far more limited and reactive. Targeted strategies are required to protect immunocompromised Canadians, who have fewer preventative options and are still facing elevated risk posed by COVID-19.

An immense effort was made to ensure the effective rollout of the primary series of vaccines in Canada. Doing so required adapting or developing new delivery systems, a significant amount of healthcare worker education, and a great deal of public education and confidence-building. These efforts meant that a very high uptake of the primary series of the COVID-19 vaccine was ultimately achieved. Some of the key enabling factors for the successful initial rollout of vaccines included the following:

- **Strong procurement** of vaccinations at the federal level - Canada was able to source a variety of vaccines, including mRNA vaccines and viral vector vaccines, relatively quickly compared to most peer countries.
- **Multimodal access points** for vaccines - this included the use of public health, pharmacies, primary care, and community-based clinics to deliver vaccines in most jurisdictions in Canada, leading to relatively easy access for patients to obtain vaccines.

- **High healthcare worker awareness** and engagement in the immunization process, including a great interest in providing patient education and supporting vaccine delivery efforts.
- **High patient awareness and broad society-wide mobilization** that lead to high levels of vaccine demand and multiple venues for vaccine education coming not only from traditional sources like public health but also NGOs, large employers, etc. Additionally, there was a strong, coordinated effort from health authorities to identify and notify high-risk patients, including those who are immunocompromised, through analysis of patient data (e.g., drug databases, specialist provider patient data, etc.).

However, immunocompromised individuals, who may not respond to vaccines, had to rely on non-vaccine prophylactics (e.g., Evusheld) for prevention and antivirals or monoclonal antibodies (e.g., Sotrovimab, Remdesivir, Paxlovid) for treatment. **Unfortunately, the rollout of these prophylactics and treatments was significantly different and less successful than the rollout of the vaccines.** In fact, many Canadians were not even aware of the availability of these specialized options. Issues with this rollout included:

- **Drug Procurement / Approvals:** Generally speaking, Canada's procurement and approvals of prophylactics and therapeutics was fairly successful, and we procured and sourced these products relatively quickly compared to other countries. Low uptake was driven more by some of the other factors listed below. However, it is important that the Government continues to implement an approach to managing COVID-19 that emphasizes access to COVID-19 prophylactics and medicines in a timely manner, particularly as new variants continue to emerge, as emphasized in a May 5, 2023 communication from PHAC[10].
- **Disjointed rollout process once approved,** as manifest in a number of areas outlined below.
  - **Inconsistent eligibility:** one of the greatest challenges with the rollout of non-vaccine modalities was the inconsistent patient eligibility across provinces/territories. For example, Evusheld was available to a fairly broad subset of patients in Alberta but was virtually unavailable next door in British Columbia. These differences in eligibility created significant inequities in access and also led to healthcare worker and patient confusion, and frustration.
  - **Low healthcare worker and patient awareness:** Overall awareness among healthcare workers for non-vaccine modalities was much lower than for vaccines. This meant that most general practitioners and even some specialists were not as aware of options such as Evusheld and Paxlovid, meaning they could not recommend it to potential patients nor answer patient questions. Similarly, there was also limited patient awareness of these products. In the Spring 2023 survey referenced above, only 40% of immunocompromised respondents and 34% of non-immunocompromised respondents were aware that there were monoclonal antibodies available to boost the response in

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[10] Government of Canada. Update on the COVID-19 situation in Canada – May 5, 2023. Available at: <https://www.canada.ca/en/public-health/news/2023/05/update-on-the-covid-19-situation-in-canada--may-5-2023.html>



those who might not respond to vaccines, despite them being available for one year by the time the survey was fielded.



**“There were a lot of inconsistencies across the different provinces, which made it challenging and a headache to figure out.** I was definitely trying to keep up to date and make sure that I had information to help the community that I supported. **But even I had to accidentally stumble upon it.** So again, just showing that there was a lot of confusion.”

“Each province was deciding - are we offering all of Evusheld, Paxlovid, and Remdesivir? I called PEI Health and asked, ‘Are you guys giving this out?’ And they said, ‘I don't know what that is, but we're giving out this other one.”

“At the beginning information was really good in terms of who's eligible, how you can sign up to get your vaccine. I know here in Nova Scotia, at first I thought they did a really good job. It was really clear. They had to make decisions on who they should prioritize. **But that really started to lessen as we moved from second doses to the boosters to where we're at now. I found that it was really hard to get information and that they would release things, but it would be almost like a whisper.”**

- Hematologic Cancer Patient Advocate

“With Paxlovid and Evusheld, first of all you have to find out that these things exist. Then you have to figure out if they're available. **Then you have to figure out from the website or from your doctor, if he's aware of it, how to access it. And even accessing your doctor these days is not easy.** Sometimes it can be not easy to find it if you don't know what to look for on a website. **And depending on the province, you've got all sorts of hoops to jump through to obtain treatment.”**



- Chronic Lymphocytic Leukemia Patient and Patient Advocate

- **Confusing and difficult points of access:** These products were often limited to specialist centers (e.g., cancer, transplant sites), in contrast to the vaccines which were available at thousands of points of access. The role of the spectrum of healthcare providers (e.g., pharmacists, public health) was not always clear and they were not as involved as they could have potentially been - certainly not as much as they were doing the vaccine rollout where many types of providers played key roles. Furthermore, there were often delays in developing access pathways for these products. Over time, the number of access points gradually increased, but this occurred too late to significantly impact uptake.



“I only go to the transplant center twice a year, at six-month intervals, just for my check-ups. So, I said next time I go down there, I'm going to get it... because I want to do everything I can to keep myself protected. **So I went for my checkup, and I asked [the staff at the transplant center] ‘Hey, you know, I heard about this Evusheld. Can I still get that shot?’ And they said ‘We don't know.’** And then I saw a sign getting off the elevator going to the clinic room, and it said ‘Evusheld Clinic’ with an arrow. And so, I walked around to the other side and asked, and they said, ‘No, we don't know what you're talking about. Why don't you try the pharmacy?’ So, then I went to the pharmacy on the first floor of the hospital, and they said, ‘I don't know about this kind of thing.’ **So, I left that day feeling very frustrated, thinking ‘Come on, you guys say this is important for us, and nobody knows what's happening.’**”

- Heart and Kidney transplant recipient, Patient Advocate

“When COVID started, there was very limited information that I would be able to access unless I went online. **Even from my transplant center specifically, there wasn't a whole lot of information that they were providing.** And even now, I don't think there's a lot of information related to COVID. I relied heavily on the Kidney Foundation, who did a pretty decent job with updating the website on COVID-related information.”



- Kidney Transplant Recipient and Patient Educator/Advocate

- **Challenges with patient identification and contact:** Coordinated efforts by health authorities to identify high-risk patients, as seen during the rollout of vaccines, were missing during the rollout of therapeutics. The proactive identification of eligible patients could have significantly enhanced uptake of products, like Evusheld and Paxlovid, that are only meant to be available to a specific subset of the population. Unfortunately, most provinces/territories do not have the data systems to systematically identify subsets of patients (e.g., immunocompromised patients eligible for Evusheld). As a result, patient identification and contact generally did not occur or was left to individual sites (e.g., a transplant site).

Ultimately, all of the above factors led to a much lower uptake of non-vaccine products than initially anticipated by provincial/territorial governments and, while Canada actually procured a sizable amount of products like Evusheld and Paxlovid, we were only able to use a fraction of what we obtained due to these issues. Many potential patients were not even aware of the existence of these options and those who were faced immense difficulty in accessing them.



# LESSONS LEARNED AND CALLS FOR ACTION – COVID-19 AND BEYOND

For many immunocompromised patients, navigating their daily lives in light of the ongoing health risks presented by COVID-19 remains an immense challenge. Protecting themselves from this risk may mean choosing to avoid receiving the health care or medications they require, or remaining in relative isolation away from important social networks and connections.

**It is critical that governments, policy makers, and health authorities continue to support immunocompromised patients to keep them healthy and ensure they can attain the quality of life shared by the rest of society.** These policies would support the ongoing threat posed by COVID-19 but also help prepare society in general, and immunocompromised people specifically, for the next pandemic.

Through regular meetings of the Canadian Immunocompromised Advocacy Network, a series of interviews with immunocompromised patients, a national survey, and expert consultation, four calls to action have been identified:

- 1** **Increased and ongoing knowledge generation and dissemination** around COVID-19 and its prevalence and epidemiology; how it affects different immunocompromised populations differently; and the effectiveness of different prophylactics and therapeutics on reducing risk in immunocompromised populations.
- 2** **Greater alignment on definitions of immunocompromised across Canada** such that there is clearer understanding across jurisdictions so policy-makers and healthcare providers can identify who is most vulnerable and where targeted support and/or outreach is required.
- 3** **Targeted infection control measures to protect immunocompromised patients**, including targeted masking mandates for high-risk clinical settings and greater understanding and empathy from society in general, recognizing that COVID-19 is still significantly affecting the well-being of immunocompromised Canadians.
- 4** **Easier and more equitable access for prophylactic and therapeutic options** for COVID-19 and other potential infectious diseases / pandemic pathogens. This includes everything from approvals to patient and healthcare provider education to the actual rollout and administration of these medications.



## Increased and Ongoing Knowledge Generation and Dissemination Around COVID-19

From our patient survey, the top ‘ask’ of immunocompromised patients is to continue to receive information on COVID-19, namely its risks and potential harms to different immunocompromised patients, its prevalence, circulating variants, and how effective different vaccines, prophylactics, and treatments continue to be.

Why is this information so critical? The ‘shielding’ behaviour we saw in the survey is a direct result of the absence of any broad societal measures or efforts to prevent the spread of COVID-19, as well as the absence of accurate information on the resulting risks still posed by COVID-19 on those who are immunocompromised. Information on the actual risks of COVID-19 and other infectious diseases will allow immunocompromised people to make important decisions about their day-to-day lives and lead to a reduction of this ‘shielding’ behaviour. Moreover, information is power and having a good understanding of the risks they are facing will alleviate the uncertainty, anxiety, and fear around the ongoing risks of COVID-19.

For patients to have the right information on COVID-19, this information must actually exist and be readily disseminated to patients and those in their “circle of care”. There needs to be ongoing research and evidence generation on the risks of COVID-19 and other infectious diseases on immunocompromised people. Secondly, this information must broadly be made available to and understandable by immunocompromised Canadians.

## Greater Alignment on The Definition Of Immunocompromised Across Canada

There is a pressing need to improve the definition of who is considered immunocompromised in Canada, as the current definitions are narrow, vague, and inconsistent across provinces and territories. As a result of the inconsistent definitions across Canada, we saw provincial variation in eligibility for prophylactics, like Evusheld and therapeutics like Paxlovid. These interprovincial inequities caused a significant amount of distress and a sense of unfairness among the immunocompromised patients.

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There is a general lack of understanding of who makes up that population. So, we're kind of back to square one, right? Who are these people? **If there is a lack of understanding of who these people are, there is gonna be no understanding or care to accommodate.**”

- Acute Promyelocytic Leukemia Survivor and Patient Advocate

**“There was still a lot of confusion around, ‘Am I eligible, being in that sort of special immunocompromised class, or not?’ I remember talking to a lot of people that were caring for someone with CLL or themselves had it, and they were just so frustrated that they weren’t being acknowledged properly.”**

**- Hematologic Cancer Patient Advocate**

**“**

**“Often cancer patients are only considered immunocompromised while under treatment, but it’s really, before, during, and after. It’s all periods.”**

**- Hematologic Cancer Patient Advocate**

Having a national organization like the National Advisory Committee on Immunization or the Canadian Agency for Drugs and Technologies in Health create common definitions of who is considered immunocompromised would be helpful. A more consistent, specific and precise list of conditions would make for easier patient identification and outreach in providing information on COVID-19 and other diseases and in letting patients know they are eligible for certain prophylactics and therapeutics. Non-specific definitions encompassing broad immunodeficiency states leave patients wondering about their eligibility.

While this is challenging, given the way provincial health data structures are set up, having the ability to identify and contact different immunocompromised patients, such as with the identification of Clinically Extremely Vulnerable (CEV) populations in British Columbia (other jurisdictions had similar definitions) while the initial supply of the primary series of vaccines was still limited, would go a long way in increasing Canada’s preparedness for any future pandemics or even other disease states.

**“I would make sure that their immunocompromised status was in their medical records. So that the next time that immunocompromised people are eligible for X, Y, Z, all the pharmacist has to do is look up in the medical record and say, ‘Yep, it says they’re immunocompromised.’ I was aware of the Evusheld and Paxlovid because of my involvement with CLL Canada, but if you’re not hooked into the patient organization world at all, how do you find out?”**

**- Chronic Lymphocytic Leukemia Patient and Patient Advocate**

## Targeted Infection Control Measures To Protect Immunocompromised Patients

Although we are past the era of society-wide measures and mandates for COVID-19 and other infectious diseases, reinstating reasonable and targeted measures can help form a critical layer of protection for the immunocompromised population. For example, requiring masking in medical clinics, lab facilities, and pharmacies - spaces rife with risk that immunocompromised patients cannot avoid - would be an easy-to-implement and high yield measure. A renewed push for public health education, seen earlier in the pandemic, on the importance of avoiding public places when sick or hand washing would also bring the idea of protecting those who are more vulnerable back to top of mind for the general public.

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“I definitely felt, especially early on when they were getting rid of masks, that **there are a lot of community spaces that immunocompromised people can't avoid**, like the drugstore. I was like, "Oh my god, just wear it in the drugstore, right? That's where us sick people are.”

- Hematologic Cancer Patient Advocate

“The last statistic that I saw said that the make-up of high-risk people in Canada is 15% of the population. 15% of the Canadian population are at high risk of developing severe illness. And to me, that seems like a fairly high number. **Wouldn't we want to be taking minimally invasive or minimally offensive measures to protect that percentage of the entire country's population?**”

- Acute Promyelocytic Leukemia Survivor and Patient Advocate

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## Easier and More Equitable Access to Prophylactic And Therapeutic Options

Vaccines, prophylactics, and therapeutics form a critically important protective layer when it comes to ensuring the health and well-being of the most vulnerable Canadians. Ensuring that immunocompromised people, along with their caregivers and members of their homes, have the best possible access to prophylactic and therapeutic options for COVID-19 and other infectious diseases will be helpful today and help us be prepared for the next pandemic.

Improving access and ensuring equitable access means optimizing everything from drug approvals to procurement, to patient and healthcare worker education and awareness, to rollout and points of access for the patient. Health Canada approvals for prophylactics and therapeutics for COVID-19 for immunocompromised patients must be done as quickly as possible. Efforts need to be put into educating both providers and patients about these products to maximize uptake. Finally, the rollout and administration of these products, including factors like patient eligibility and where patients can actually receive products should be optimized in such a way that improves ease and access for patients. Immunocompromised Canadians cannot afford to experience the same levels of confusion, lack of coordination, lack of communication etc. as they did during the COVID-19 pandemic again.

When the next public health crisis occurs, we must ensure that a response plan is in place, with clear lines of communication and roles/responsibilities are established amongst all stakeholders including policymakers at all levels, health care providers (GPs, specialists, pharmacists) and patients. This is particularly important for specialty products that require more guidance on medication interactions (e.g., Paxlovid) where engaging a range of educated healthcare providers will be key to ensuring patient awareness and healthcare worker access.



"You had to get an appointment with your doctor, **which is almost impossible within that window**. And then your doctor had to email this line to see if you're eligible. **It felt very convoluted and also very much like, if you have five days to do this, we're not gonna make it.**"

- Hematologic Cancer Patient Advocate



# LOOKING TO THE FUTURE - PREPARING FOR THE NEXT PANDEMIC

While much of society has moved on from the pandemic, as COVID-19 continues to evolve, immunocompromised Canadians continue to be at higher risk from the disease and carry a disproportionately large burden. These individuals continue to modulate their lives around the disease and have a lower quality of life than they could potentially have.

The Canadian Immunocompromised Advocacy Network (C.I.A.N) is calling on all stakeholders including regulatory agency, decision makers, health care providers, and society at large to ensure that this population is protected from the current risks of COVID-19 and from any future pandemics. C.I.A.N will continue to pursue its goals by:

- Amplifying the diverse voices of immunocompromised patients and patient advocacy groups and identifying/pursuing a unified advocacy goal.
- Supporting the educational needs of immunocompromised Canadians and healthcare professionals.
- Advocating for increased understanding, compassion, and support from the general public.
- Engaging with decision makers to ensure the voices of immunocompromised patients are being heard.







Canadian  
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