2026

Canadian
Immunocompromised
Advocacy Network

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Advocating for the Health Equity of Immunocompromised Canadians

Canadian Immunocompromised Advocacy Network

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Executive Summary

Immunocompromised individuals across Canada continue to face disproportionate risks from infectious diseases, along with barriers in accessing timely and evidence-informed care. The Canadian Immunocompromised Advocacy Network (CIAN) developed this position paper to highlight the urgent and systemic gaps that affect the health, safety, and quality of life of people with varying immune function status. Grounded in the lived experience of its members and supported by emerging evidence, CIAN's mission is to advocate for equitable protection, informed decision-making, and stronger public health systems that recognize and take actionable steps toward addressing the unique needs of immunocompromised Canadians.

The findings and recommendations in this paper are drawn from the experiences of the group's 40+ members, including patient organizations, patient advocates, expert consultation and the learnings of the network since its inception, which have all contributed to four calls to action that guide the network in its work efforts:

Greater alignment on definitions of immunocompromised across Canada, to ensure there is a widely accepted, standardized definition and understanding across jurisdictions so policy makers and healthcare providers can identify who is vulnerable and where targeted support and/or outreach is required.

Increased and ongoing data generation and dissemination related to the immunocompromised community, including the efficacy, safety and duration profile of vaccines, monoclonal antibodies and other therapeutics. Understanding differences in the burden of disease compared to immunocompetent people and long-term implications of immune suppression/dysfunction in relation to disease progression and secondary co-morbidities.

Easier and more equitable access to prophylactic and therapeutic options for infectious diseases / pandemic pathogens. Increased awareness and education, for patients, caregivers, and healthcare providers, around the effectiveness of prophylactics and therapeutics on reducing risk in immunocompromised populations.

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 having a weakened immune state will always affect the well-being of immunocompromised Canadians.

Background

Immunocompromised Canadians include a diverse group of people who have a weakened immune system as a result of a medical condition or medications that suppress immune function. Immunocompromised individuals face significantly heightened vulnerability to infections such as influenza, RSV, and COVID-19, and are more likely to experience severe illness, hospitalization, longer recovery periods, long-term health complications or even death. This increased vulnerability is evident in national data showing that individuals aged 15 years and older with compromised immune systems comprise 14% of the Canadian population, yet they accounted for over 20% of COVID-19 hospitalizations. It is important to note, however, that these figures may not fully reflect the true size or diversity of the immunocompromised population, as clinical and research definitions of immune compromise vary and may not capture all individuals under their chosen definition. This context suggests that the burden observed in available data may be an underestimation. Even with these limitations, the available data point to a clear gap: those at high risk remain among the least protected by current health systems.

Despite their efforts to maintain wellness, immunocompromised Canadians continue to navigate a healthcare system that often overlooks their needs. The rollback of public health infrastructure and the rapidly shifting health system landscape in recent years have only widened these gaps. One of the most urgent challenges is the lack of accessible, consistent information and data that can inform clinical decisions, policy design, and individual choices. Without this foundation, patients, caregivers, and health systems are left ill-equipped to create equitable pathways to care.

In response to this gap, immunocompromised patients themselves have come together to take action. In 2022, an Immunocompromised Patient Action Group began meeting regularly to address these systemic challenges, and within a year, this work evolved into the launch of the Canadian Immunocompromised Advocacy Network (CIAN). CIAN's mission is clear: advocate for stronger health policies, equitable drug access, and recognition of the unique needs of this diverse and growing community. Our vision is a world in which the basic human rights of immunocompromised people are met, allowing them to thrive in safer, more inclusive communities.

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The Coalition

At its formation, the purpose of CIAN was to unite and amplify the voices of immunocompromised patients by sharing strategies and creating tools to support immunocompromised patients in understanding the risk posed by the COVID-19 pandemic and how to protect themselves while also advocating for equitable access to COVID-19 preventative therapies, treatments, and vaccines.

Since then, the organic growth of the network and understanding of the community's needs has evolved, and the focus of the network has broadened well beyond the original purpose of protecting the community from COVID-19. Now, CIAN focuses on supporting the overall health and well-being of immunocompromised patients across Canada, including protection from vaccine-preventable infectious diseases.

This position paper captures the experiences of CIAN members, their patient communities and presents recommendations on how to achieve an equitable future state for immunocompromised Canadians.

Greater Alignment on Definitions of Immunocompromised Across Canada

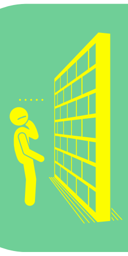
Greater alignment on definitions of immunocompromised across Canada, such that there is a widely accepted, standardized definition and understanding across jurisdictions so policy makers and healthcare providers can identify who is vulnerable and where targeted support and/or outreach is required.

Who Are Immunocompromised Canadians?

There is currently no universally accepted definition of what constitutes being immunocompromised. Immunocompromising conditions are highly complex and heterogeneous, encompassing a broad spectrum of underlying causes and levels of immune impairment. This diversity presents challenges for health policy, public health messaging, and clinical practice, underscoring the need for a more consistent and inclusive understanding of what it means to be immunocompromised.

CIAN currently defines immunocompromised individuals as those whose immune systems are weakened, limiting their ability to respond effectively to infections and immunizations. This reduced immune function may result from underlying health conditions (such as autoimmune diseases, transplants, or metabolic disorders), medical treatments (e.g., cancer treatments, immune suppressants and/or biologics[1]), infections (e.g., HIV/AIDS or Long COVID), or genetic conditions (such as CVID, Down syndrome, etc.). Due to this heightened vulnerability, immunocompromised people face, in comparison to immunocompetent individuals, an increased risk of severe illness, complications, hospitalizations, or death from otherwise common infections.

The lack of a universal definition of immunocompromised status has significant implications for research, patient care, and advocacy efforts. Without a consistent definition, there is a gap in data regarding the health burden and health outcomes experienced by immunocompromised individuals. Many patients do not realize they are immunocompromised, which adds a layer of complexity and delays preventive care. All together, these factors limit the ability of health systems to identify at-risk populations, allocate resources effectively, conduct research, and ultimately advocate for the health and well-being of immunocompromised individuals.



Advocate for
Health &
Wellbeing

Identify at-risk populations

Allocate Resources

Conduct Research

Establishing a clear and shared definition that is universally adopted would not only improve data collection and care, but it would also give patients, clinicians, and advocacy groups a unified voice to advocate for the needs of the immunocompromised community.

Impacts of Inconsistent Immunocompromised Definitions

Although Immunocompromised individuals account for a smaller portion of the population, they make up a disproportionately large amount of hospitalizations, ICU admissions, and deaths. The COVID-19 pandemic further exposed the severity of health disparities among immunocompromised Canadians, who were up to 16 times more likely to be hospitalized. This underscores the urgent need for a clearer, more consistent definition of who is considered immunocompromised in Canada, as current criteria are narrow, vague, and vary across provinces and territories. These inconsistencies contribute to significant provincial differences in eligibility for prophylactics and therapeutics, creating interprovincial inequities that cause distress and a sense of unfairness among patients, particularly during peak respiratory infection seasons.

"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 Lukemia 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."***

-Double Lung Transplant Patient

Why a Consistent Definition of Immunocompromised is Critical

Establishing a clear and consistent definition of immunocompromised at the national level, through organizations such as the National Advisory Committee on Immunization or the Canada's Drug Agency, would provide significant benefits. The current fragmentation of the definition of immunocompromised acts as a barrier for healthcare providers to easily identify patients, deliver targeted outreach, and ensure individuals are aware of their eligibility for specific prophylactics and therapeutics. Current non-specific definitions, which often encompass broad immunodeficiency states, leave patients uncertain about their status and eligibility. Greater alignment across Canada would create a clearer understanding across jurisdictions, enabling policy-makers and healthcare providers to identify who is at risk and direct targeted support where it is most needed.

While this is challenging, given the way provincial health data structures are set up, having the ability to identify and contact 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.

Increased and Ongoing Data Generation & Dissemination

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Increased and ongoing data generation and dissemination related to the immunocompromised community including the efficacy, safety and duration profile of vaccines, monoclonal antibodies and other therapeutics. Understanding differences in the burden of disease compared to immunocompetent people and long-term implications of immune suppression/dysfunction in relation to disease progression and secondary co-morbidities.

Implications of Minimal Data Generation

Critical need for data that reflects the clinic and real-world experiences of immunocompromised patients

Although research on immunocompromised populations increased during the COVID-19 pandemic, both pre-pandemic and subsequent data that has emerged have been highly fragmented, limited, and insufficient to equitably guide long-term, evidence-based decision making. Limited and irregular research acts as a barrier to fully understand disease burden, vaccine and therapeutic effectiveness, and the diverse clinical outcomes faced by people with varying degrees of immunocompromised status. This reinforces an ongoing and critical need for data that accurately reflects the clinic and real-world experiences of immunocompromised patients that can effectively inform policymakers, regulatory bodies, public health, pharmaceutical manufacturers, immunocompromised people, and the general public about the community's unique needs. Without coordinated data collection and transparent knowledge dissemination, these gaps continue to negatively impact evidence-based planning, reinforce health disparities, and limit the development of effective prevention and treatment strategies for the immunocompromised population.

Data Gaps Due to Lack of Standard Definition of "Immunocompromised"

The lack of a widely accepted, standardized definition of "immunocompromised" acts as a barrier to effective data generation, surveillance, and health system planning. Without an agreed upon definition, researchers, institutions, policy makers, pharmaceutical companies, healthcare providers, and the general public have no reliable way to identify or track immunocompromised individuals across care settings or within research.

This gap forces those working with immunocompromised populations to exercise their due diligence to determine whether studies are truly referring to immunocompromised individuals or to groups of individuals with an underlying health condition. Although immunocompromised individuals often do have underlying health conditions, it is important to provide patients with the empowerment and autonomy to determine their own level of risk and if they believe they are immunocompromised. With the limited availability of research data, many resort to using data on people with underlying health conditions as a proxy, which can lead to inaccurate estimates and misrepresentation of the unique risks and outcomes faced by immunocompromised populations. Furthermore, immunocompromised patients are often misdiagnosed, resulting in further health complications for this population. A result of this fragmentation is the difficulty in comparing data, which ultimately undermines burden of disease estimates, evaluation of vaccines and therapeutics, and skews the true needs of this diverse community.

Inclusion of Immunocompromised Individuals in Clinical Trials

The lack of data on immunocompromised individuals can be attributed to their underrepresentation in clinical trials. This serves as a barrier to understanding and improving outcomes for immunocompromised populations. Many clinical trials for vaccines, therapeutics, and other interventions exclude individuals with compromised immune systems. This was evident during the early development of novel COVID-19 vaccines, monoclonal antibodies, and antiviral drugs, where a majority of trials did not include immunocompromised participants. Adding to this challenge is the inherent heterogeneity of immunocompromised patients, which often leads to some of the subgroups being excluded from many clinical trials. The lack of inclusion limits the availability of evidence and acts as a barrier to guiding clinical decisions and forces clinicians and patients to make health-related decisions with insufficient information. Immunocompromised individuals are at a significant disadvantage, where treatment plans and preventative strategies may be less effective due to the underestimation of the unique risks faced by the immunocompromised community.

Many clinical trials for vaccines, therapeutics, and other interventions exclude individuals with compromised immune systems.

Having readily accessible clinical trial data specific to immunocompromised people is essential for informed and ethical decision-making. Without reliable information on the efficacy and safety of vaccines, therapeutics, and other interventions, it becomes increasingly difficult to understand the short and long-term implications of immune suppression, the risk of secondary co-morbidities, or even the basic burden of severe disease, hospitalization, and death from vaccine-preventable infections. This lack of clinical evidence can also lead to immunocompromised individuals being excluded from eligibility criteria, thereby limiting their access to life-saving tools. It also prevents public health officials, physicians, and specialists from guiding their patients. In some cases, this lack of information has led to immunocompromised individuals resorting to self-isolation to protect themselves. Without data to make informed decisions about their health, some individuals may opt to avoid risks at all cost, at the expense of their employment, social, and mental well-being.

An active effort to ensure existing data is readily accessible to policymakers, healthcare professionals, and the community is at the forefront of CIAN's call to action. For patients to be able to make educated decisions in the best interest of their well-being, accurate and reliable 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 infectious diseases in immunocompromised people and the efficacy of potential prophylactic and therapeutic supports. Secondly, this information must be made broadly available to and understandable by immunocompromised Canadians and their physicians. CIAN advocates for the consistent inclusion of immunocompromised people in clinical trials and rare disease registries as it is a vital step toward generating comprehensive, up-to-date, generalizable data that can be used to inform individualized care and support equitable health outcomes across this diverse population.

Improving Knowledge Dissemination: What COVID-19 Taught Us

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, be it research data or educational materials. The pandemic highlighted the vulnerability of immunocompromised patients and the ongoing need to support these patient populations. We must take the lessons learned from the pandemic and provide ongoing longitudinal support for vulnerable patients, timely access to quality information, ongoing access to knowledgeable providers/therapies, and immunocompromised populations must be included in clinical trials to inform the safety and efficacy of immunizations and other therapeutics for the community.

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. 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 infectious diseases (e.g., risk of hospitalization, ICU admission, death) given a particular immune-compromising condition (or conditions) along with the necessary medications;
- The bidirectional and interconnected risks between conditions and immune functions (e.g., a persistent HPV infection would not make someone immunocompromised but could lead to different cancers over time; and sepsis, which occurs more frequently in immunocompromised individuals and can itself cause long-term immune system damage);
- Effectiveness and safety of vaccines, monoclonal antibodies, and treatments, taking into consideration the unique nuances of immunocompromising conditions; and
- The long-term health implications of prolonged immune system suppression or damage.

De-identified data to understand the general spread and overall risk to immunocompromised populations, including:

- Overall prevalence of any pathogen of concern, which has diminished significantly since wastewater surveillance programs that were instated during the COVID-19 pandemic and were a reasonable proxy for overall levels of infection, were scaled back or discontinued entirely
- Levels of hospitalizations and ICU admissions in specific jurisdictions, along with demographics of patients being hospitalized and admitted to the ICU;
- Circulating pathogens and their relative infectiousness, immune-evasiveness, and severity.

Equitable Access to Prophylactics and Therapeutics

[1]

Easier and more equitable access for prophylactic and therapeutic options for infectious diseases / pandemic pathogens. Increased awareness and education, for both patients and healthcare providers, around the effectiveness of prophylactics and therapeutics on reducing risk in immunocompromised populations.

Challenges With Access to Prophylactics and Therapeutics

In the face of any pathogen of concern, immunocompromised Canadians have more contraindications, potentially leading to limited preventative options. Targeted strategies are required to protect immunocompromised Canadians from the elevated risk posed by infectious diseases.

During 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, wherein 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, which 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.

In contrast, immunocompromised individuals who may not respond to vaccines had to rely on non-vaccine prophylactics (e.g., Evusheld) and antivirals (e.g., Sotrovimab, Remdesivir, Paxlovid) for prevention and treatment. The rollout of these prophylactics and treatments was far less consistent and less successful, leaving many immunocompromised Canadians unaware of their availability. Several systemic issues contributed to this gap:

Variation in Eligibility Across Provinces and Jurisdictions

A large barrier to implementing vaccines and therapeutics is the inconsistent eligibility criteria, which often vary across jurisdictions. Throughout the COVID-19 pandemic we saw access to therapeutics like Evusheld and Paxlovid vary across provinces and recommendations changed. The differences in eligibility and access can create significant inequities for certain populations and lead to misinformation and frustration.

> *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**

Drug Procurement and Approval Process

Canada's procurement and approval of prophylactics and therapeutics were fairly successful during the pandemic, with products being sourced and authorized relatively quickly compared to other countries. However, procurement pathways have largely reverted to pre-pandemic processes. This shift has resulted in reduced access to a range of vaccine and therapeutic options, with some products becoming unavailable altogether.

This limitation has particular consequences for immunocompromised individuals. If provinces offer only mRNA vaccines, which may be ineffective or even harmful for some immunocompromised individuals, uptake is likely to be low and protection inadequate. This not only limits protection but also exacerbates the problem by providing options that do not meet the needs of this population. To address this, procurement strategies must prioritize interventions that are safe and effective for the IC community, ensuring they have the tools necessary to prevent or mitigate infection and reduce their disproportionate risk.

With Evusheld, by the time we got our act together in Canada, the virus had out moved us. It had mutated beyond. So, the virus was moving faster than we were capable of responding to it, yet we had the tools.

What prevents Health Canada from just picking up EU or FDA approvals and doing approvals post market access? There is a process existing to do that. We just didn't use it. Health Canada should not be delaying these things."

-Vasculitis Patient and Patient Advocate

Low Healthcare Worker and Patient Awareness

Low awareness among both healthcare workers and patients continues to undermine effective protection for immunocompromised people. Canada lacks consistent approaches to identifying immune function status, and there is no coordinated data collection system to support clinical decision-making. This is compounded by significant research gaps regarding vaccine tolerance, safety, and efficacy in immunocompromised populations. As a result, many general practitioners and even some specialists do not have clear, evidence-based guidance on which vaccines or protective measures to recommend, nor do they have the information needed to confidently address patient questions.

"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

Variation in Access and Provider Responsibility

Throughout COVID-19, access to different interventions was inconsistent. Vaccines were widely available through public health clinics and pharmacies, while monoclonal antibodies were often restricted to specialist centers (e.g., cancer or transplant clinics). Even for broadly recommended interventions like the influenza vaccines, patients frequently needed to visit multiple sites to complete their immunizations. With masking mandates relaxed, each additional visit to a healthcare facility increased exposure risk, particularly for immunocompromised individuals.

These challenges persist as we enter new respiratory seasons. Some provinces now require registration for COVID-19 vaccination, limit eligibility to people with moderate to severe immunocompromise (excluding family members, close contacts, or caregivers), and have reduced access points by removing vaccines from pharmacies. In Alberta, publicly funded COVID-19 vaccines are restricted to older adults, healthcare workers, supportive-living residents, and immunocompromised individuals. All others must pay out of pocket, creating a significant barrier to equitable access.

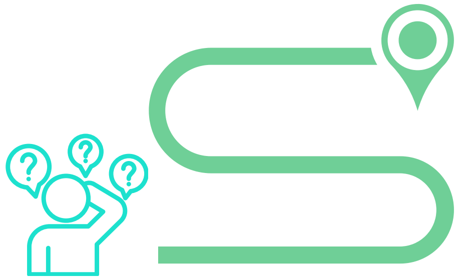
> *When COVID started, there was very limited information that I would be able to access unless I went online. Even from my transplant center specifically, there wasn't a whole lot of information that they were providing. And even now, I don't think there's a lot of information related to COVID. I relied 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**

Lack of Patient Identification and Contact

Coordinated efforts by health authorities to identify high-risk patients during the pandemic were effective in vaccinating vulnerable patients. The proactive identification of eligible patients could have significantly enhanced uptake of all diseases. However, most provinces and territories do not have the capacity to systematically identify subsets of patients (e.g., immunocompromised patients). As a result, proactive patient identification is not sustainable, leading to greater health risks for high-risk populations and higher transmission of infectious diseases.

> *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, "Yes, 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**

Taken together, these challenges continue to suppress uptake of both vaccine and non-vaccine prophylactic options. As responsibility for procurement and program design shifted from federal to provincial and territorial governments, these gaps have widened rather than narrowed. The result is predictable: immunocompromised Canadians face reduced protection, and health systems face escalating inefficiencies.



Current State:
Uninformed patients limit the impact and utilization of procured supply.

Despite provinces successfully securing substantial quantities of COVID-19 vaccines, including Nuvaxovid and mRNA products like SPIKEVAX and COMIRNATY, only a fraction of doses have been used. Patients often remain unaware of when or where to be vaccinated or which products are available, undermining the value of the supply that is procured. The consequences of this disconnect are already visible. In Alberta, after the federal withdrawal from vaccine supply, the province assumed responsibility for funding and managing its own inventory. During the 2024-25 respiratory season, approximately 401,000 doses–60% of the provincial order–were unused and discarded, representing over $44 million in wasted publicly funded products. In 2025-26, the province produced 485,000 doses for a more narrowly targeted program, reflecting an increasingly cautious and restrictive approach driven by sustainability concerns.

These patterns point to a critical systems issue: without clear eligibility, coherent access pathways, strong provider guidance, and effective public communication, provinces risk repeating costly cycles of low uptake and high waste. More importantly, immunocompromised Canadians will continue to face preventable gaps in protection, especially as decisions for procurement continue to exclude their needs. A coordinated national strategy that supports consistent eligibility criteria, streamlined access to therapeutics, proactive provider education, and reliable information for patients is essential to avoid further erosion of uptake and to ensure that available tools are used effectively, equitably, and responsibly.

Targeted Infection Control Measures to Protect Immunocompromised Patients

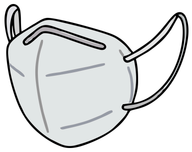
Targeted infection control measures to protect immunocompromised patients, including targeted masking mandates in clinical settings and greater understanding and empathy from society in general, recognizing that having a weakened immune state will always affect the well-being of immunocompromised Canadians.

Immunocompromised individuals in Canada continue to experience significant gaps in protection, resources, and public health support within a rapidly evolving health landscape. The early stages of the pandemic prompted swift, coordinated action to safeguard vulnerable populations. Immunocompromised individuals were recognized as being at heightened risk, and policies such as prioritized vaccine access and broad public health interventions provided critical layers of protection. These measures reflected a collective willingness to adapt behaviours and systems to safeguard those who are vulnerable. Over time, however, many of these protections have been reduced or withdrawn.

Masking Mandates

The removal of mask mandates in health care settings has re-exposed immunocompromised individuals to long-standing risks, despite their reliance on these environments for essential medical care. Combined with reductions in access to prophylactic treatments, antivirals, and other protective tools, these policy shifts disproportionately affect those who cannot rely solely on standard immunization strategies to protect themselves.

Ongoing circulation of infectious diseases such as COVID-19, influenza, RSV, and pneumococcal disease underscores the need for updated infection control measures in healthcare settings. Immunocompromised individuals, who often require more frequent medical appointments, face increased exposure risks in these environments.



Research consistently demonstrates that respirators (e.g., N95s) provide significantly greater protection against airborne transmission than surgical masks.

Consistent two-way masking in healthcare settings, where disease transmission risk is likely, would substantially reduce viral spread, protecting immunocompromised patients, healthcare workers, and the broader public. Some hospitals, including the University Health Network in Toronto, as well as facilities in New Brunswick and Prince Edward Island, have reintroduced masking requirements in clinical areas to reduce respiratory illnesses, demonstrating the continued value of these measures in protecting vulnerable populations. Complementary public health education reinforcing basic prevention practices, such as staying home when ill and regular handwashing, would further mitigate transmission.

These interventions could have tremendous benefits to the Canadian health care system by limiting the number of severe illnesses and hospitalizations among vulnerable populations, unnecessary use of finite healthcare resources, and a positive economic impact by reducing work absences and disability claims.

“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

Wastewater Monitoring

Wastewater surveillance has become an increasingly important tool for public health authorities as a means of detecting and tracking infectious diseases at the population level. By analyzing traces of viruses and other pathogens shed into community wastewater, surveillance teams can identify changes in infection trends, often before clinical testing data becomes available. This early-warning capacity proved especially valuable during the COVID-19 pandemic.

Despite its demonstrated utility, wastewater monitoring programs have been scaled back or discontinued in some jurisdictions, such as Ontario. This reduction in capacity limits the ability of public health systems to identify rising transmission early enough to implement targeted actions that protect high-risk groups, including immunocompromised people.

Wastewater data also has significant, yet often underutilized, potential as a public-facing risk communication tool. Public reporting of wastewater findings remains inconsistent across Canada, even though research shows that people adjust their protective behaviours, such as masking, limited exposures, or seeking vaccination, when they perceive community infection levels to be rising. As such, sharing wastewater trends with the public could play an important role in reducing transmission as well as supporting informed decision-making and reinforcing trust in public health messaging.

Herd Immunity

Herd immunity refers to the indirect protection that arises when a large share of a population has immunity to an infectious disease, either through vaccination or prior infection and recovery. When immunity reaches a high enough level, transmission becomes less efficient, reducing the likelihood that the pathogen will reach people who remain vulnerable, such as those who cannot be vaccinated or who have compromised immune systems.

For the immunocompromised community, the effects of herd immunity could look like:

- Reduced chance of exposure
- Protection when vaccines are less effective, delayed, or contraindicated
- Greater ability to participate in daily life safely, without relying solely on individual-level precautions; and
- Reduced burden on healthcare systems, especially during surges

Achieving and maintaining herd immunity, however, is increasingly challenging in the context of pandemic fatigue. Over time, people grow weary of repeated vaccination campaigns, masking recommendations, and ongoing public health guidance. This fatigue can lead to lower vaccine uptake, reduced adherence to preventative measures, and uneven protection across the community. At the same time, inconsistent public messaging, fragmented provincial policies, and misinformation further undermine collective immunity. Balancing these realities requires targeted strategies that recognize social and behavioural constraints while prioritizing protections for those most at risk.

Ultimately, sustaining layered protections, including targeted infection control in healthcare settings, robust surveillance mechanisms, and strong community immunity, is critical to reducing exposure and severe outcomes. By prioritizing these measures, we can ensure that the healthcare system protects those most at risk, strengthens overall resilience, and addresses inequities in access to protection and care.

Conclusions: Immunocompromised People Feel Unsupported in a Rapidly Changing Health Environment

Canada’s capacity to detect and respond to infectious threats has also been weakened by the rollback of public health infrastructure. Access to key pharmaceutical interventions, like monoclonal antibodies, protein-based vaccines, and antiviral medications, such as Paxlovid, have been reduced. Collectively, these responses leave both immunocompromised Canadians more vulnerable to future health threats.

The risks facing immunocompromised individuals extend beyond a single pathogen. For example, the resurgence of measles in communities with suboptimal vaccination coverage highlights ongoing vulnerabilities. Individuals who cannot receive the MMR vaccine due to its live attenuated formulation rely heavily on herd immunity for protection. Declining vaccination rates undermine this protective barrier, increasing the likelihood of severe outcomes among those who remain unprotected.

It has become clear to the Canadian Immunocompromised Advocacy Network that many immunocompromised Canadians were suffering in silence long before the global pandemic, with limited options to self-protect. The disproportionate risks posed by infectious diseases have forced many to seek support, bringing greater awareness to the urgent need for specialized resources and attention for this population. Today, immunocompromised people continue to seek clarity about how their health conditions affect their immune function, as well as tools to support their overall well-being.

While individual groups within the community — including but not limited to those with cancers, autoimmune conditions, organ transplants, and primary immune deficiencies — have long advocated for their specific needs, it is the collective voice of these groups that defines the broader immunocompromised community. Together, they now articulate an acute need for a comprehensive suite of supports to help achieve true health equity.

Scientific advances, including the rapid development of mRNA vaccines, present important opportunities to strengthen protection for immunocompromised individuals. However, many immunocompromised individuals are unable to elicit adequate immune responses to standard vaccination protocols or may face contraindications. Ensuring equitable protection, therefore, requires expanded access to alternative immunization options and the meaningful inclusion of immunocompromised individuals in clinical trials and rare disease registries to generate evidence-based strategies tailored to their needs.

Individually or compounded, these heightened risks can also lead to further health complications and worsening health and well-being, which places a disproportionate burden of risk on immunocompromised Canadians compared to those who are immunocompetent. 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.

These challenges are intensified by limited vaccine options, frequent exclusion from clinical trials that could generate evidence for tailored protections, and broader public apathy when standard vaccines do not work for them. When immunocompromised people take all available measures to protect themselves, they can face ridicule, harassment, invalidation, or social ostracism. Even at a minimum, the loneliness and isolation that result from being surrounded by people who do not recognize or respect the vulnerabilities faced by IC populations is emotionally and psychologically harmful. All together these factors reinforce inequities and leave immunocompromised Canadians without the same level of protection or support as the general population.

During COVID-19, at the time that health restrictions were at an all time high, immunocompromised people became acutely aware of the supports that could exist to help them achieve health equity and when restrictions were lifted, and then an onslaught of additional pathogens of concern began to surface, some after decades of near or complete eradication, the community could not put that acute awareness of their personal vulnerability or the lack of help, back in the box. Today, there are still many questions about how to gain access to vaccines, when to take which vaccines, what measure of non-therapeutic interventions immunocompromised people should adopt to self-protect, and equally important, how much of that burden could be lifted by having reasonable public health measures in place.

All-in-all, those in the greatest risk category, which is not always consistent with the provincial and territorial breakdown of risk categories, are left 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 inadequate preventative options, they continue to face disproportionate risk in navigating their lives at a time when the rest of society is unrestricted.

*"**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

*"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

CIAN Members

Members of CIAN include:

Immunocompromised Patient Advocates

- Derek Clark
- Charles Cook
- Yuan Lew
- Annie-Danielle Grenier
- Jenna Kedy
- Harjeet Kaur
- Emily Foucault

Immunocompromised Patient Organizations & Allies

IPANE
Immunocompromised People Are Not Expendable

LEUKEMIA & LYMPHOMA SOCIETY OF CANADA

Immunodeficiency Canada
Immunodéficience Canada

CLL CANADA

LUPUS CANADA
Life Without Lupus

NavigatingHealthcare.ca

SOCIÉTÉ CANADIENNE DE LA COVID
CANADIAN COVID SOCIETY

CAPA
Canadian Arthritis Patient Alliance

Coalition Priorité Cancer au Québec

immunity canada

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CARP

CANADIAN SOCIETY FOR IMMUNOLOGY

TRANSPLANT AMBASSADOR PROGRAM
TAP
Give & Gain

CCRAN
Colorectal Cancer Resource & Action Network

obesity canada

CORD
Canadian Organization for Rare Disorders

Asthma.ca
Asthma Canada

hpv global action

LUPUS ONTARIO
Life Without Lupus

Kidney Patient and Donor Alliance Canada

CANADIAN CANCER SURVIVOR NETWORK

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