Canadian
Immunocompromised
Advocacy Network

July 17, 2024

Re: Greater COVID-19 Education and Expanded COVID-19 Vaccine Choices for all Canadians

Dear Prime Minister Trudeau, Minister Holland, Dr. Sharma, Dr. Tam, Minister Duclos, Dr. Tunis, Dr. Harrison, and Heather Jeffrey,

Executive Summary

We are writing to you as concerned stakeholders advocating for broader access to diverse COVID-19 vaccine options for Canadians, particularly those beyond the mRNA vaccines currently dominating the public offering. We urge the Public Health Agency of Canada (PHAC), all the provinces/territories and immunization providers to address the pressing need for enhanced COVID-19 awareness and education, this includes increased availability and access to protein-based vaccines, such as Novavax, which are currently limited in distribution.

Key issues highlighted include:

1. **Access Issues**: Many Canadians face significant challenges in accessing the Novavax COVID-19 vaccine due to systemic barriers, long travel distances, and inconsistent information from government and healthcare providers.
2. **Educational and Awareness Gaps**: There is a significant lack of public awareness regarding the need for ongoing COVID-19 vaccination, particularly additional (booster) doses.
3. **Communication Breakdown**: Effective communication between healthcare providers, public health officials, and the public is crucial. Reports of conflicting advice and misinformation from healthcare providers diminish public trust and impede vaccination efforts.
4. **Trust-Building**: Public skepticism towards vaccines, fueled by mixed messages and perceived politicization, must be addressed through transparent communication and community engagement.

We recommend enhancing vaccine access, supporting data generation, boosting education and awareness, strengthening communication, and building public trust with real world experience examples and suggestions below. We are open to further discussion and collaboration with all stakeholders to enhance the effectiveness of COVID-19 vaccination campaigns. We look forward to advancing public health in Canada through immunization and to hearing from you regarding our recommendations and questions.

1. Access Issues

Many Canadians face significant challenges in accessing the Novavax COVID-19 vaccine. Reports from various regions, including Quebec, New Brunswick, British Columbia, and Ontario (see below), highlight systemic barriers, long travel distances, and inconsistent information from government and healthcare providers. These obstacles underscore the geographical and logistical disparities that hinder equitable vaccine access for healthy as well as vulnerable high-risk populations.

Patient Experience Highlights from Roundtable Discussion (June 17, 2024):

- **Linda Wilhelm of New Brunswick:** Linda, a patient with rheumatoid arthritis experienced worsening flares after each subsequent mRNA vaccine (up to 6 doses received of both Moderna and Pfizer), requiring additional treatment. They had to travel over 1.5 hours to access Novavax. Her last dose of the Novavax COVID-19 vaccine resulted in no flare, highlighting the importance of accessible alternatives.
- **Dr. Christine Guptill of Ontario:** Despite having a centralized provincial booking system for COVID-19 vaccine appointments for mRNA based vaccines, families could not easily find the Novavax vaccine as it was not available through the provincial system. People needed to know that a protein-based vaccine was available (in some cases, it was the only way family members would consider getting vaccinated because it had been reported to have had fewer side effects) and could only get it through booking special appointments with their local Public Health Unit using a completely different system for each Public Health Unit.
- **Lisa Petsinis of Ontario**: Parent faced significant obstacles and delays in securing the Novavax COVID-19 vaccine for her high-risk teen, while elderly parents encountered similar challenges obtaining their spring booster.
- **Annie-Danielle of Quebec:** An immunocompromised individual struggled to locate a vaccination clinic providing Novavax, facing systemic barriers despite their urgent need.
- **Anonymous of British Columbia:** S.M. reported difficulties in booking COVID-19 vaccine appointments of the Novavax COVID-19 vaccine for their family, while other vaccines were readily available at local pharmacies, underscoring the need for simplified access to all COVID-19 vaccines.
- **Anonymous of Ontario:** A patient with Rheumatoid Arthritis in Ottawa who experienced worsening flares with each mRNA vaccine gave up trying to access Novavax, opted for another mRNA and a worsening disease flare because of the fear of contracting COVID-19 and ending up in hospital before she could navigate all the barriers to accessing Novavax.

To better understand Canada's commitment to ensuring Canadians have access to a protein-based COVID-19 vaccine option, we request confirmation of the number of doses that will be publicly available for the Fall 2024 immunization season, and what the relative distribution will be for each Canadian province and territory.

2. Educational and Awareness Gaps

There is a significant lack of public awareness regarding the need for ongoing COVID-19 vaccination, particularly additional (booster) doses. Public health campaigns must emphasize the importance of vaccination, especially for high-risk groups, and clarify the availability of alternatives like Novavax. Furthermore, misinformation among healthcare providers about non-mRNA vaccines exacerbates hesitancy and confusion.

3. Communication Breakdown

Effective communication between healthcare providers, public health officials, and the public is crucial. Reports of conflicting advice and misinformation from healthcare providers diminish public trust and impede vaccination efforts. Consistent, transparent messaging about all COVID-19 vaccine options is essential to build confidence and encourage informed vaccine choices.

4. Trust-Building

Public skepticism towards vaccines, fueled by mixed messages and perceived politicization, must be addressed through transparent communication and community engagement. Involving trusted figures and community leaders in advocacy efforts can significantly bolster public confidence in vaccines.

Recommendations

To address these challenges and improve vaccine access and public health outcomes, we respectfully urge PHAC, all provinces/territories and all organizations and stakeholders involved in the administration of COVID-19 vaccines to consider the following recommendations:

1. **Enhance Vaccine Access:**
    - Procure sufficient doses for all Canadians who want or need access to a protein based COVID-19 vaccine.
    - Increase distribution points for Novavax, ensuring availability through all channels where mRNA vaccines are offered, across Canada as well as underserved and remote areas.
    - Simplify the process for booking and obtaining vaccines, reducing bureaucratic barriers and wait times.
2. **Data Generation:**
    - Support the generation and dissemination of information about the importance and benefits of protein-based vaccines compared to mRNA vaccines to improve knowledge of and access for patients who need an alternative option.
3. **Boost Education and Awareness:**
    - Launch comprehensive public health campaigns to educate the public on the importance of COVID-19 vaccination and the availability of non-mRNA options like Novavax.
    - Provide updated training and resources for healthcare providers to ensure they have accurate information about all available vaccines.

4. **Strengthen Communication:**
    - Develop clear, consistent public health messaging to address common concerns and misconceptions about COVID-19 vaccines.
    - Foster better communication channels between public health officials, healthcare providers, and the public to ensure timely and accurate dissemination of information.
5. **Build Public Trust:**
    - Engage community leaders and trusted figures to advocate for vaccination and address vaccine hesitancy.
    - Ensure transparency in the decision-making process regarding vaccine recommendations and availability, involving community input and feedback.

Conclusion

Addressing these issues requires coordinated efforts from public health officials, healthcare providers, patient organizations and the community to ensure equitable vaccine access and improve public confidence in the vaccination process. We are open to further discussion and collaboration with all stakeholders to enhance the effectiveness of COVID-19 vaccination campaigns. Please contact us at capa.arthritis@gmail.com to coordinate an introductory call.

We look forward to advancing public health in Canada through immunization and to hearing from you regarding our recommendations and questions above.

Thank you for considering our concerns and recommendations.

Sincerely,

Linda Wilhelm
President, Canadian Arthritis Patient Alliance (CAPA)

Michelle Burleigh
Founder, Immunocompromised People Are Not Expendable
Co-Chair, Canadian Immunocompromised Advocacy Network

Mary Jo Nabuurs
Director, Ontario School Safety

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COVID-STOP

Dr. Vivien Brown
Assistant Professor, Department of Family & Community Medicine,
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Dr. Jeff Gilchrist
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Associate Professor, Rehabilitation Sciences
University of Ottawa

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Developmental Biologist, Researcher
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Annie-Danielle Grenier
Founder, Ma vie de zèbre
Rare Disease Advocate and Patient Partner
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Kathleen Gadd, MLIS
Health sciences librarian
Member of POPNB and Canadian Aerosol Transmission Coalition
New Brunswick
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COVID-STOP

ONTARIO SCHOOL SAFETY

SOCIÉTÉ CANADIENNE DE LA COVID

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APPENDIX A

Novavax access difficulties in Ottawa, Ontario

First of all, the process to get a Novavax vaccine in Ottawa has been inconsistent for some time: No pharmacies stocked them, it wasn't advertised as being available through Ottawa Public Health, and the person had to know they wanted Novavax and dig on the OPH website to find out how to get one. The documentation on the website indicated for quite some time that it was not a recommended vaccine, and if someone wanted one, they had to fill out a form that essentially discouraged them from it, because it was meant to be used only for people who could not, or would not, accept an mRNA vaccine.

I received my first dose in Australia in 2022, where I was visiting from September until the end of December. I was prepared to feel poorly afterwards but had zero side effects. My husband is a little bit shy, and doesn't like doing things that are not recommended; so he and my two teenage daughters received mRNA vaccines prior to traveling to Australia in early December.

The first Novavax my husband and I received in Ontario was in April 2023 at an OPH Health Hub; we filled out the documentation on the OPH website in advance. The nurse did ask if we understood that Novavax was not the recommended vaccine, and we said that we did. Both my husband and I had zero side effects from the vaccine.

In summer 2023, I took my younger daughter (who was 14) to get Novavax in New York City, where we were visiting. The pediatric vaccine had been approved as a first dose in the US for quite some time, but despite my advocacy efforts with PHAC, my MP, and my MPP, it had still not received approval in Ontario. We lied and told the pharmacist that my younger daughter had never received a vaccine before, because that was the only way to get it. My daughter had zero side effects. We would normally have vaccinated both our daughters at that time, but unfortunately, while I was waiting for access to the vaccine we wanted, my older daughter caught COVID for the second time in early June 2023, very nearly disrupting her grade 11 exams and resulting in missed classes and poorer grade outcomes.

In fall 2023, I again advocated strongly with federal, provincial and local health authorities to make Novavax available in time for the fall vaccines. It became clear that we weren't going to get access in time, so all 4 of us had mRNA vaccines in fall.

In April 2024, I booked all of us through the OPH website for Novavax. There was a rumour that Ontario was not going to allow people who were not immune compromised or otherwise considered vulnerable to get a spring vaccine, so we went two weeks earlier than 6 months. We were informed that it was not 'recommended' by the province that we get a second vaccine that year, and one of the nurses in particular was quite disapproving and negative about it, telling us that it wasn't recommended; but we insisted. None of us had any side effects from Novavax.

At this point, I have had 2 original and 1 updated Novavax, my husband and younger daughter have had 1 original and 1 updated, and my eldest has had 1 updated. I prefer this vaccine because it has no side effects. I intend to continue seeking it out every 6 months until a sterilizing vaccine becomes available.

Christine Guptill, PhD, OT Reg. (Ont.)
Associate Professor, Rehabilitation Sciences
University of Ottawa.

Novavax access difficulties in Montréal, Québec

Last March my spouse and I wanted to get a COVID vaccine, as it had been over a year since our last booster. We hoped to get the updated booster in the fall of 2023 (of any type), but couldn't get a vaccine in the same way we had previously (in pharmacy or through the home nurse).

We'd heard there were less side effects with Novavax, and after 5 doses of mRNA, we both felt it might be good to get that one.

We knew we couldn't just get it at the pharmacy and needed an appointment at the vaccine clinic. Which made it risky for me, as I'm immune compromised and very high risk for a severe outcome if I get an infection (any infection), and the vaccine centres are also testing centres. Plus, healthcare personnel stopped masking. We would've greatly preferred a safer venue, but still felt getting the vaccine was important.

We're in Montréal, so I looked at the Santé Montréal website.
In which it said to call to get an appointment for Novavax (can't book it online).
I called the number listed on the page. The first person I talked to transferred me to my local health centre (CIUSSS)... which isn't one of the places that carried Novavax.

I called again. The person who answered tried to book me for a regular Pfizer vaccine and didn't even know what was "a Novavax."

Luckily, my best friend had went through all that a few months prior (had to call 5 times, got transferred multiple times)... and he had the number to directly call the vaccine clinic downtown. I thought I had the wrong number at first, as there were only options about testing in the recorded message, nothing about vaccination. Thankfully, the person I talked to knew about Novavax and made our appointment.

The vaccine centre isn't very accessible, and if I'd been needing my wheelchair I might not have been able to get in, especially as there was construction in front. It's also more than 30 minutes away.

Once there, the nurse tried to convince me to take another vaccine instead. She said "we don't recommend that one". If I hadn't been well informed, she would've easily convinced me.

Both my spouse and I had to say we refused to take a mRNA vaccine so we could get the Novavax. We couldn't just prefer another choice. But even that wasn't enough. She asked WHY we refused. It felt like I was doing something wrong and had to explain myself.

My best friend was told, the same day by another nurse of the same clinic, that they "agree it can be a good idea to "mix and match" but they **have** to say the Novavax vaccine isn't as good."

The scientific data doesn't show Novavax to be inferior, on the contrary, and it's known to have less side effects. I don't understand why it's made so difficult to get it.

We didn't have any side effects and really hope we can get the new Novavax version next fall. Without having to spend so much time and energy, and go through such stress.

Annie-Danielle Grenier
Montréal, Quebec

Novavax and Pfizer Access Difficulties in Toronto

I am writing to share my experience with the process of obtaining the Novavax COVID-19 vaccine for my teen, who is at higher risk for complications and long COVID, as well as my elderly parents' challenges in getting their spring booster. Our journey has been filled with challenges, and it is important to bring these to your attention.

When Novavax was granted final approval for teens, and after experiencing multiple side effects from the Pfizer vaccines, I was eager to get the Novavax booster. My doctor urged us to vaccinate as soon as possible due to my teen's higher risk and complex needs, which required careful monitoring for side effects.

Our family health team made several requests to obtain the Novavax vaccine for us, but despite multiple attempts to contact Toronto Public Health and the Ministry of Health, we faced repeated refusals. The family health team nurse and I made numerous phone calls to pharmacies in our area, all to no avail. I wrote to the public health nurse following our VAERS cases to obtain the vaccine, only to be redirected to the province, and then back to Toronto Public Health. I wrote to the Medical Officer of Health and my concerns and requests went unanswered.

After three (3) months of effort and ultimately creating a Google alert for any news on Novavax clinics, we finally secured appointments. At the appointment, we were informed that only ten doses of Novavax were being offered weekly in our area. When we inquired why, the public health nurse responded, "Novavax isn't as good."

This entire experience was unnecessarily protracted, required significant effort from me and my medical team, and was fraught with finger-pointing and misinformation about the efficacy of a vaccine. This created undue stress and hardship for our family and put our health at greater risk.

Additionally, this spring, my elderly parents received a letter informing them that it was time for their spring booster. They immediately contacted their local pharmacy where they had received previous doses. They were informed that there was no supply and no information on when they might receive any. The only location offering the booster was their civic centre, which was neither accessible nor comfortable for them. After much waiting and multiple calls to their pharmacy, they finally received their spring booster in July.

Both experiences highlight significant issues in the vaccine distribution process, particularly for those who are vulnerable and with higher needs. Better coordination and accurate information are essential to prevent others from facing similar challenges.

I urge you to address these issues to improve the process, supply issues, and communication regarding vaccine efficacy and distribution. Thank you for your attention to this matter.

Lisa Petsinis

Toronto, Ontario

Characterizing the clinical and economic burden of COVID-19 among individuals with immunocompromising conditions in Ontario, Canada: A matched, population-based observational study

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Qian, C[1], Nam, A[2], Johnston, K[1], Tinajero, M[1], **Hamilton, MA[2]**

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Introduction

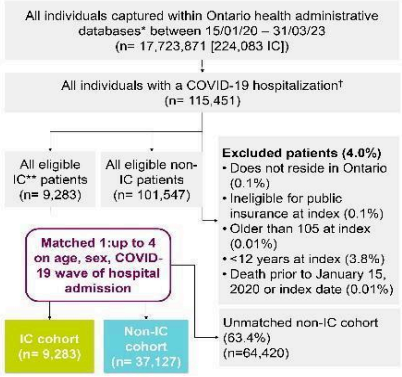
- COVID-19 continues to be associated with substantial burden, particularly among immunocompromised (IC) patients[1,2]
- IC individuals are more likely to experience suboptimal immune responses to vaccines, and thus experience more severe COVID-19 related outcomes

Objective

This study aimed to describe and compare the burden of illness, resource utilization, and healthcare costs during and following COVID-19 hospitalizations among IC and non-IC patients in Canada

Methods

Figure 1: Study cohort diagram



*Data housed and linked at ICES
†Only initial COVID-19 hospitalizations were considered for each patient
**IC status was determined at index hospitalization, using data prior to and including the index hospitalization, and included those with ≥1 of: solid organ or stem cell transplant; hematological malignancy; rheumatoid arthritis; multiple sclerosis; or primary immunodeficiency

Outcomes & Statistical Methods

- Clinical burden, healthcare resource use (HCRU), and costs were assessed during index COVID-19 hospitalization and post-discharge (within 30- and 180-day periods post discharge) and compared between IC and non-IC patients
  - Relative risks, relative rates and 95% confidence intervals (CIs) of clinical outcomes were estimated using log-binomial and modified Poisson regression
  - Relative and absolute mean (95% CI) differences in costs were estimated using gamma regression
  - Models were adjusted for neighborhood deprivation, long-term care residency, baseline comorbidities (i.e., Charlson comorbidity index [CCI], frailty), and COVID-19 vaccination status

Results

Cohort Characteristics

- 9,283 eligible IC patients hospitalized with COVID-19 (mean age 68.7 years; 52.1% female) were matched to 37,127 non-IC patients (Figure 1)
- In comparison to non-IC patients, IC patients were more likely to:
  - Have more comorbidities, according to hospitalization records from the past 2 years
  - Live in neighborhoods with lower degrees of material deprivation
  - Have a Hospital Frailty Risk Score[3] >15
  - Have received a complete COVID-19 vaccination regimen

Table 1: Baseline patient characteristics

Variable	IC (n=9,283)	Non-IC (n=37,127)
Age [mean(SD)]	68.7 (15.7)	68.7 (15.7)
Sex, F [n(%)]	4,834 (52.1)	19,335 (52.1)
COVID-19 wave of hospitalization [n(%)]		
Wave 1 (15/01/20-31/08/20)	329 (3.5)	1,314 (3.5)
Wave 2 (1/09/20-28/02/21)	814 (8.8)	3,254 (8.8)
Wave 3 (01/03/21-31/07/21)	847 (9.1)	3,388 (9.1)
Wave 4 (01/08/21-14/12/21)	293 (3.2)	1,172 (3.2)
Wave 5 (15/12/21-28/02/22)	1,942 (20.9)	7,767 (20.9)
Wave 6 (01/03/22-18/06/22)	1,527 (16.4)	6,108 (16.5)
Wave 7 (19/06/22-31/03/23)	3,531 (38.0)	14,124 (38.0)
CCI		
Unknown*	4,112 (44.3)	22,000 (59.3)
Mean (SD)*	2.5 (2.0)	2.1 (2.1)
Material deprivation quintile [n(%)]		
1 (least deprived)*	1,581 (17.0)	5,530 (14.9)
5 (most deprived)*	2,081 (22.4)	9,159 (24.7)
LTC resident [n(%)]†	793 (8.5)	3,598 (9.7)
Frailty score > 15 [n(%)]*	1,391 (15.0)	3,537 (9.5)
Vaccination status [n(%)]		
Unvaccinated	2,517 (27.1)	12,876 (34.7)
Partially vaccinated	428 (4.6)	1,643 (4.4)
Fully vaccinated*	6,338 (68.3)	22,608 (60.9)
Fully vaccinated + booster	4,715 (50.8)	15,302 (41.2)
IC conditions [n(%)]		
Rheumatoid arthritis	3,926 (42.3)	-
Haematological malignancy	2,435 (26.2)	-
Solid organ transplant	1,751 (18.9)	-
Multiple sclerosis	907 (9.8)	-
Primary immunodeficiency	461 (5.0)	-
Allogenic/autologous BMT	381 (4.1)	-

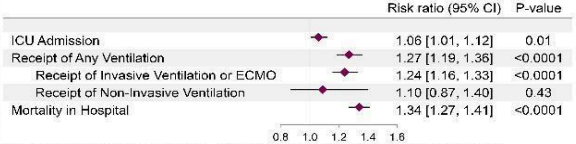
Abbreviations: BMT, bone marrow transplant; CCI, Charlson Comorbidity Index; IC, immunocompromised; LTC, long term care; non-IC, non-immunocompromised; SD, standard deviation.
*Defined as having received any of the following: 1) one dose of Janssen, or 2) two doses of a Health Canada authorized vaccine, or 3) one dose of a non-Health Canada authorized vaccine and one dose of a Health Canada authorized vaccine), or 4) three or more doses of a vaccine (Health Canada authorized or not). †p<0.05

References: 1. Public Health Agency of Canada (2022). Canadian COVID-19 vaccination coverage report. 2. Government of Canada (2023). COVID-19 Epidemiology update: Current situation. 3. Gilbert et al. (2018). *Lancet* 391(10132):1775:1782

Clinical outcomes during and post index hospitalization

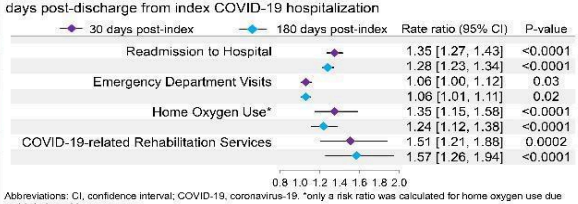
- In comparison to non-IC patients, IC patients were at significantly greater risk of the following, after adjusting for baseline patient characteristics (Figure 2):
  - ICU admission (**+6%**)
  - Receipt of any ventilation (**+27%**)
  - Receipt of invasive ventilation, including ECMO (**+24%**)
  - In-hospital mortality (**+34%**)
- Within 30-days post-discharge, IC patients experienced significantly greater adjusted rates of (Figure 4):
  - All-cause readmission to hospital (**+35%**)
  - Emergency department visits (**+6%**)
  - Home oxygen use (**+31%**)
  - COVID-19-related rehabilitation services (**+51%**)
- Within 180-days post-discharge, the rates of HCRU among IC patients remained significantly higher than HCRU rates among non-IC patients; the rate of hospital readmissions decreased slightly over time (Figure 3)

Figure 2: Relative risk of clinical outcomes among IC vs. non-IC patients during index COVID-19 hospitalization



Abbreviations: CI, confidence interval; ECMO, extracorporeal membrane oxygenation; ICU, intensive care unit

Figure 3: Relative rate of clinical outcomes among IC vs. non-IC patients 30- and 180-days post-discharge from index COVID-19 hospitalization

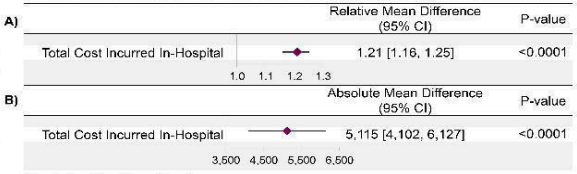


Abbreviations: CI, confidence interval; COVID-19, coronavirus-19. *only a risk ratio was calculated for home oxygen use due to this being a binary measure.

Costs during and post index hospitalization

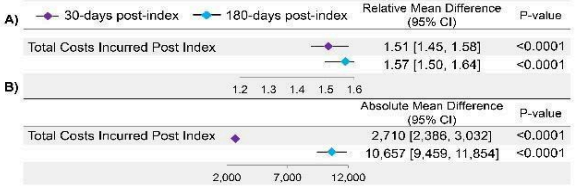
- The mean (SD) cost of an index COVID-19 hospitalization was $25,496 ($42,520) for an IC patient and $21,983 ($38,504) for a non-IC patient.
- Total costs incurred during index COVID-19 hospitalization were **21% higher** in the IC cohort relative to the non-IC cohort, after adjusting for patient characteristics (Figure 4A)
  - The absolute mean difference in cost per IC versus non-IC patient per index COVID-19 hospitalization was **$5,115** (Figure 4B)
- Total adjusted costs incurred 30- and 180-days post-discharge were **51% and 57% higher** in the IC cohort versus the non-IC cohort, respectively, after adjusting for patient characteristics (Figure 5A)
  - The absolute mean difference in HCRU costs per IC versus non-IC patient were $2,719 30-days post-discharge, and $10,657 180-days post-discharge (Figure 5B)

Figure 4: A) Relative mean difference and **B)** absolute mean differences in total costs incurred during index COVID-19 hospitalization among IC vs. non-IC patients



Abbreviations: CI, confidence interval

Figure 5: A) Relative mean difference and **B)** absolute mean difference in total costs incurred 30- and 180-days post-discharge from index COVID-19 hospitalization among IC vs. non-IC patients



Abbreviations: CI, confidence interval

Discussion

- Between January 2020 and March 2023, 9,283 patients with IC were hospitalized with COVID-19 from a total of 224,083 patients with IC in Ontario.
  - Although the IC subgroup represented 1% of the total population, they accounted for approximately 10% of all COVID-19 hospitalizations
  - IC patients experienced significantly greater clinical burden during hospitalization, associated with greater healthcare resource use and costs
  - Each IC patient incurred $5K more per hospitalization, $2.7K more 30-days post-discharge, and $10.7K more 180-days post-discharge compared to a non-IC patient with similar baseline risk factors (e.g., age, sex, vaccination status, SARS-CoV-2 strains circulating at time of admission)
- **Strengths:** This study used population-based data capturing all COVID-19 hospitalizations from a population of >17 million residents in Canada
- **Limitations:** Unmeasured confounding between IC and non-IC cohorts remain; given the lack of complete prescription data for younger patients and lack of in-hospital prescription data in the databases used, the use of additional prophylactic treatments for COVID-19 (e.g., remdesivir) were not adjusted for. IC patients may have been more likely to receive these treatments, which may lead to underestimation of risk of outcomes among the IC cohort.

Conclusions

- IC patients experienced more severe COVID-19 outcomes in hospital and post-discharge in comparison to non-IC patients, resulting in greater costs associated with the care of IC patients in hospital and post-discharge
- COVID-19 mitigating policies and prophylactic treatments are needed to continue to protect IC populations

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