

Dr. Holger Schünemann,
Dr. Robby Nieuwlaat,
Leadership Team Canadian Guidelines for Post COVID-19 Condition (CAN-PCC)
McMaster University, GRADEadm@mcmaster.ca

SUBJECT: CAN-PCC November Public Comment Survey on Draft Recommendations

Dear Dr. Schünemann and Dr. Nieuwlaat,

We are writing to voice our concerns regarding the Draft Recommendations in the recent public survey from CAN-PCC.

We want to first acknowledge the difficulty of your undertaking given the volume of COVID-19 research. We have confidence in many of the recommendations you have made to date and are especially glad to see November's Draft Research Recommendation #9, as formal evaluation of specialized services will provide essential data to best support patients.

That said, we have significant concerns about Draft Recommendation #2, which suggests exercise in adults with acute COVID-19 infection to prevent Post Covid Condition. This recommendation has caused considerable alarm within our community due to its potential risks.

The Long Covid Committee at the Canadian Covid Society is a core group composed of individuals with lived experience of long Covid, as well as medical professionals, representing diverse backgrounds across Canada. Through a patient-oriented and science-based lens, they unite their experiences, knowledge and skills to guide, support and create resources aimed at improving the health of patients, families and communities affected by long Covid.

Our committee has been hearing from our patient and parent communities who have reacted negatively regarding Draft Recommendation #2 in the November Survey. These expressions have brought on feelings of frustration, deep dismay and loss of trust in the CAN-PCC initiative.

Regarding Draft Recommendation #2, we have several specific concerns and questions:

- Post-exertional malaise can affect up to 50% of patients with long Covid, with a mechanism that is not clearly understood. There is [growing evidence](#) that further exercise can worsen these symptoms, and there has been caution regarding any form of Graded Exercise Therapy right from the [start of the pandemic](#). Given these concerns, why was an exercise recommendation included here?
- In your Evidence to Decision assessment, you provided some studies running for up to 12 weeks, which show no definitive evidence. However, [there is strong evidence](#) that organ dysfunction can manifest months after the initial infection. Did your process consider these longer-term impacts?
- You mention that this recommendation would not apply to those "who have been told for other reasons that exercise is not recommended (e.g. diagnosed with myocarditis)." However, [subclinical myocarditis](#) is often underdiagnosed, and this could put people at risk.

Additionally, transparency in your process is crucial for confidence in your recommendations. We have some questions about your research and consultation process in general:

- Was the strongest and most up-to-date evidence considered in drafting your recommendations?
- [Publications from the Patient Led Research Collaborative](#) highlight the importance of trusting the research and experience of people whose lives and health have been impacted by long Covid. What weight does CAN-PCC give to consultations with patient partners in drafting your recommendations?
- Many patients and health care professionals have provided feedback via your surveys. We would like to know what weight you give to survey responses in making your final recommendations?

If these questions about the review process, patient consultation, and real-world patient circumstances were addressed, they could allay many of the concerns we have outlined in this letter.

We acknowledge that drafting guidelines for a new disease with a meagre evidence base is quite challenging, and we are committed to working with you to produce a set of guidelines that helps build knowledge for better long Covid management. We would like to offer our support as you navigate this process.

Regards,

Kashif Pirzada, MD, CCFP(EM)
Emergency Physician
Assistant Clinical Professor, Toronto Metropolitan University
Co-Chair, Canadian Covid Society

Adriana Patino
Long Covid Committee Co-Chair and Board Member, Canadian Covid Society

Annie-Claude Trottier
Long Covid Committee Co-Chair, Canadian Covid Society

Cara Smusiak
Communications Chair and Board Member, Canadian Covid Society

Nancy Delagrave
Co-founder and Coordinator, Canadian Covid Society

For contact, adriana.patino@covidsociety.ca