



Canadian Skin Patient Alliance
Alliance canadienne des
patients en dermatologie

for patients, by patients

Written Submission for the Pre-Budget Consultations in Advance of the Upcoming Federal Budget

Canadian Skin Patient Alliance

111-223 Colonnade Rd S., Ottawa, ON Canada K2E 7K3
T: 613.224.4266 or 877.505.CSPA (2772) • F: 877.294.1525 • info@canadianskin.ca

www.canadianskin.ca

Follow our social channels @CanadianSkin



LIST OF RECOMMENDATIONS

1. That the government provide increased funding to provincial and territorial health systems across the country to **address the backlog** of services, treatments, and clinical trials created by the COVID-19 pandemic.
2. That the government provide funding to provincial and territorial governments and directly to healthcare providers, including dermatologists, to **support the expansion of virtual dermatology and primary care** and that includes funding for healthcare providers to purchase or update technological infrastructure.
3. That the government **create new funding opportunities to support patient organizations** across Canada who are helping their patient communities navigate the health system during and after the COVID-19 pandemic.
4. That the government, through its role at Health Canada, the Patented Medicine Prices Review Board, the Canadian Agency for Drugs and Technologies in Health and the pan-Canadian Pharmaceutical Alliance, **recognize the value of treatments for patients living with skin disorders that are delivered at home or in the community** and expedite their review, negotiation and funding.
5. That the government include a patient representative on Tier 3 drug shortage committees to more effectively address **drug shortages** and communicate with patients.

Recommendation 1. That the government provide increased funding to provincial and territorial health systems across the country to address the backlog of services, treatments, and clinical trials created by the COVID-19 pandemic.

The COVID-19 pandemic revealed cracks in Canada's health system. In the early days of the pandemic, in-office visits and therapies delivered in clinic were significantly reduced – for many patients, these were not available at all. Now, as these resources have begun to return, patients are facing long wait times for a visit, which compromises their ability to receive a diagnosis, receive effective care and access appropriate treatments.

Cancer patients, including skin cancer patients, experienced sharply reduced access to care – including diagnosis and treatment plans – as a result of health systems deprioritizing this care in order to prepare for the impacts of COVID-19. According to a survey led by the Canadian Cancer Survivor Network,¹ more than half (54%) of the 1,243 cancer patients, caregivers and people awaiting confirmation of a cancer diagnosis surveyed reported their appointments, tests and/or treatment were postponed and cancelled. These delays have had a profound impact on the cancer patient community: 74% of CCSN survey respondents said these delays had a major impact on their mental and emotional health, which increased to 82% among those awaiting a diagnosis. Cancer patients are nervous about what the future holds in terms of their access to care: 56% of CCSN's survey respondents expressed fears for the future of their care (which increased to 74% among those awaiting a diagnosis) and 43% fear their cancer will progress (68% among those pre-diagnosis).

People living with chronic skin disorders also experienced reduced access to care during the pandemic. For example, phototherapy is a treatment that relies on a specific form of light waves and is used for a variety of skin disorders, including psoriasis, atopic dermatitis (eczema), vitiligo and cutaneous T-cell lymphoma. This treatment option is often accessed by patients who are not eligible for systemic or biologic therapies. Phototherapy is almost entirely delivered in clinics and hospitals in Canada and access to phototherapy was significantly reduced and, in many cases, no longer available at all. This has compounded the barriers to accessing this needed service faced by skin patients prior to the pandemic.

Clinical trials for promising treatments were also impacted by the pandemic. The CCSN found that 43% of cancer patients reported that their clinical trial was put on hold or stopped. Clinical trials remain an important treatment option for people living with cancer as well as chronic conditions and the impacts of the pandemic on this important research should also be addressed by plans to support the health system in Budget 2021.

An increase in funding is essential to ensuring that patients across Canada can access the services they have been waiting for, and to address the growing health needs of the skin patient community.

¹ Canadian Cancer Survivor Network, *Impact of COVID-19 on Cancer Patients and Their Ability to Receive Treatment*, July 15, 2020: <https://www.slideshare.net/jackiemanthorne/impact-of-covid19-on-cancer-patients-and-their-ability-to-receive-treatment>

Recommendation 2. That the government provide funding to provincial and territorial governments and directly to healthcare providers, including dermatologists, to support the expansion of synchronous and asynchronous virtual dermatology and primary care and that includes funding for healthcare providers to purchase or update technological infrastructure.

Skin disorders are often dismissed as “just a rash”. For patients, they are far more than that. Skin diseases and conditions often reflect imbalances in inflammatory and other systems, and can be caused by a virus, cancer, bacteria, fungi, genetics, wounds, hormones, allergens, and other disorders. Living with a skin condition can have profound effects on overall well-being, including physical, emotional, social and financial aspects. For skin patients, being able to access their care provider is essential to being diagnosed, accessing tests, developing a care and treatment plan, and supporting their mental health.

The use of virtual care and other digital approaches can improve skin patients’ access to care, especially in rural and remote communities. During the pandemic, these approaches were successfully implemented in hospitals and urban areas as well. The visible aspects of skin disorders are often one of the main challenges for patients. In the context of virtual care, however, the fact that these disorders are often visible supports the success of virtual care to diagnose and manage them.

Although many specialties have benefited tremendously from advances in telemedicine and virtual care, primary care providers and dermatologists have been slower to adopt virtual dermatology care. Reasons for this include the capital expense and perceived difficulties in integrating these platforms with electronic medical records and patient communication channels (e.g., secure email). In order to reverse this trend and improve access to care for skin patients across the province, investments are required in infrastructure and appropriate remuneration for dermatologists providing this service.

The capacity of teledermatology to avoid inappropriate referrals, reduce wait times for specialty care, and improve clinical attendance were identified by the Canadian Agency for Drugs and Technologies in Health (CADTH) in a review of teledermatology services conducted nearly 10 years ago.² Even in 2010, teledermatology diagnoses were found to be as reliable as those in conventional clinic-based care – since that time, there have been important advances in the technological aspects of virtual care.

During the pandemic, many care providers quickly switched to different virtual care platforms, which are not streamlined for them to use, which can hamper patient care. Patients were often confused about how to access their care provider and voicemail services were often full as clinics closed or reduced their in-person services.

From a health system perspective, a robust asynchronous (“store-and-forward”) virtual dermatology program could reduce unnecessary referrals to dermatologists by empowering primary care teams to consult directly with a dermatologist and continue to manage their patient’s condition(s). Synchronous (“real-time”) virtual care options should also be available to ensure continuity of care for all skin patients.

² CADTH, *Teledermatology Services: Rapid Review of Diagnostic, Clinical Management, and Economic Outcomes*. Issue 135. October 2010. https://www.cadth.ca/media/pdf/H0502_Tele dermatology_Report_e.pdf

Recommendation 3. That the government create new funding opportunities to support patient organizations across Canada who are helping their patient communities navigate the health system during and after the COVID-19 pandemic.

Patients are facing increased levels of uncertainty, greater barriers to accessing care and treatment, and deeper impacts on their mental health as a result of the COVID-19 pandemic. Patient organizations are stepping in to combat misinformation, conduct research to understand the depth and breadth of the impact of the virus on our patient communities, and provide increased supports and resources.

We are a critical part of effectively responding to this virus. Patient organizations are experiencing increased need while funding from traditional sources is reducing or disappearing. **It is essential that the government's response to COVID-19 include funding for patient organizations who are helping our patient communities through this unprecedented era.**

Recommendation 4. That the government, through its role at Health Canada, the Patented Medicine Prices Review Board, the Canadian Agency for Drugs and Technologies in Health and the pan-Canadian Pharmaceutical Alliance, recognize the value of treatments for patients living with skin disorders that are delivered at home or in the community and expedite their review, negotiation, and funding.

Skin patients deserve to be treated with respect and dignity by the health system, which includes its embrace of new treatment options for psoriasis, atopic dermatitis (eczema), acne, rosacea, hidradenitis suppurativa, and skin cancers, among others.

For example, many new and effective medicines to treat cancer are available in oral or self-injectable forms, which enables patients to be treated in the community without the added burden of attending clinic appointments to receive intravenous medicines. These cancer medicines are not a different version of the same cancer treatment but different molecules that are frequently the first-choice line of therapy for cancer patients. **Prioritizing these treatments during the COVID-19 era will help support successful treatment and management of a variety of skin disorders in the community, keeping patients out of hospital and reducing their exposure to the virus.**

Recommendation 5. That the government include a patient representative on Tier 3 drug shortage committees to more effectively address drug shortages and communicate with patients.

The COVID-19 pandemic exacerbated the number and severity of drug shortages in Canada. The Canadian Skin Patient Alliance worked with the Best Medicines Coalition and peer organizations to navigate the shortage of hydroxychloroquine (HCQ) in Canada after theories of its effectiveness in treating COVID-19 emerged. HCQ is used to treat many different conditions, including psoriatic arthritis, myositis, lupus, and Sjogren's disease, and was added to Health Canada's Tier 3 list of drug shortages, which recognizes drugs in actual shortage with the greatest potential impact.³ Each Tier 3 committee is designed to have a broad swathe of representation from drug manufacturing, through distribution and delivery to patients and the pharmacy counter or in hospital. This recognizes the complex process by which drugs reach patients. However, it does not include patients or patient representatives. Without the specific inclusion of patient perspectives on these Tier 3 committees, we risk a disconnect between the actions taken to resolve a drug shortage and the reality on the ground, compromising the health and safety of patients across the country. **We recommend that a patient representative be formally included in Tier 3 drug shortages committees and provided with support and resources to liaise with the relevant patient communities when drug shortages arise.**

About the Canadian Skin Patient Alliance

The [Canadian Skin Patient Alliance](https://www.cspa.ca/) (CSPA) is a national non-profit organization dedicated to improving the life of people in Canada living with diseases, conditions and traumas that affect the hair, skin and nails. We advocate for best care and treatment options for all skin patients; we provide educational resources to our patient community; and we support the members of our [Affiliate Member](#) organizations who work specifically on their disease areas such as acne, scleroderma, melanoma and psoriasis.

³ <https://www.drugshortagescanada.ca/blog/8>