



Navigating Canada's Health Systems

How you can advocate for your
health

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Overview



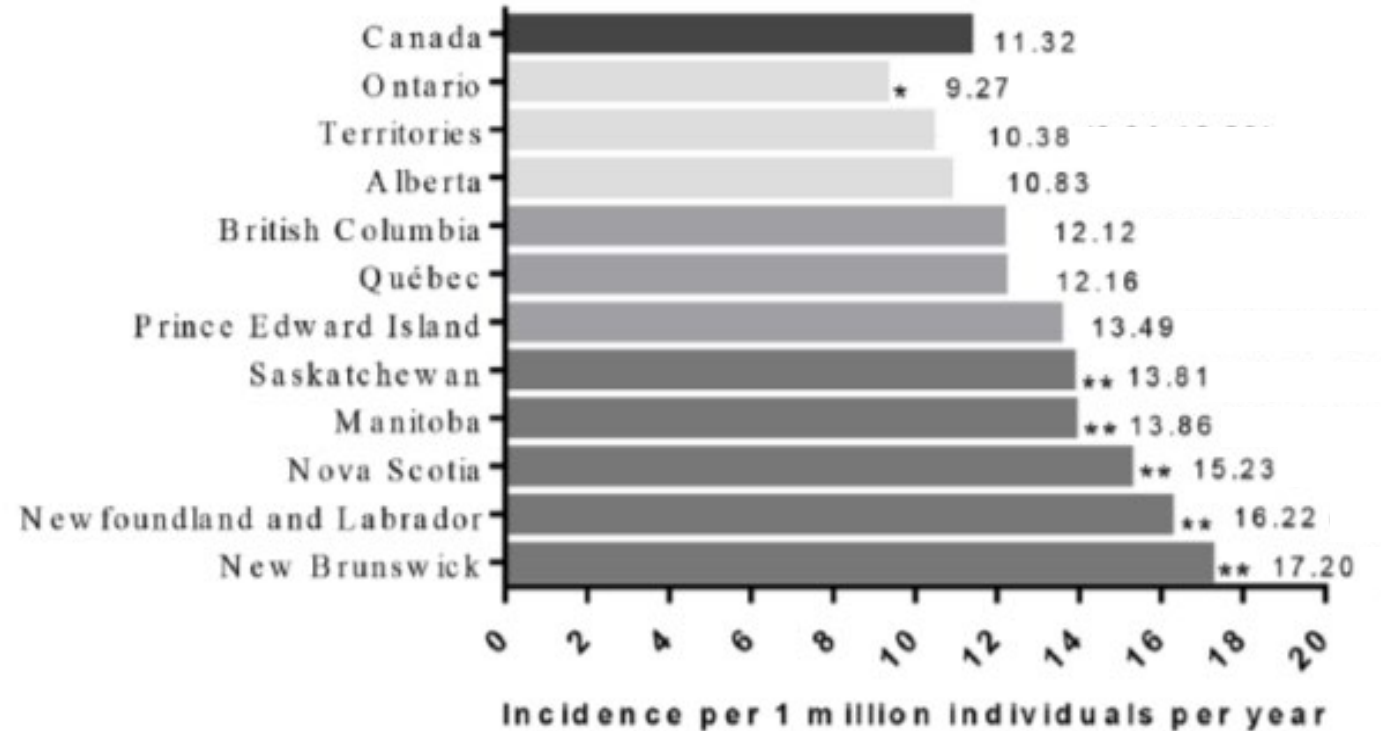
- Cutaneous lymphoma in Canada
- Experience, challenges and ways to advocate across the patients clinical journey with cutaneous lymphoma
 - Diagnosis
 - Treatment
 - Remission / Follow-up care
- Access to treatments in Canada
 - How it works
 - Existing challenges
 - Patient advocacy
- Resources for Patients



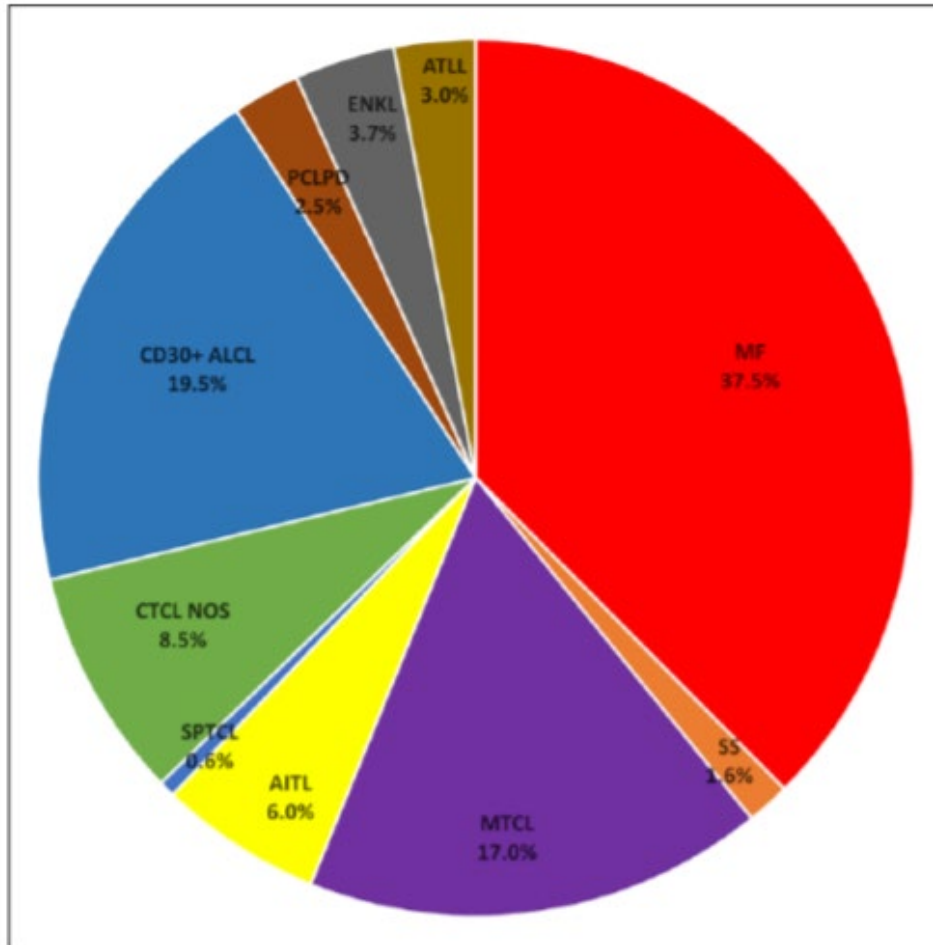
Cutaneous lymphoma in Canada

Cutaneous lymphoma landscape in Canada

- Cutaneous T-cell lymphoma (CTCL) is the **most common skin lymphoma**
- It represents a heterogeneous group of non-Hodgkin lymphomas
- The incidence rates of all CTCL types in Canada were on the rise during 1992 to 1998 and then stabilized
- Environmental Impacts



Canadian landscape



- Incidence rate of ~11 cases per million individuals per year
 - Incidence of 10.2 cases/million/year in the US
- Patients' clinical characteristics
 - Average age of ~59.4 years when diagnosed
 - Predominantly in males
 - Comparison with other countries
 - Impacted by ethnicity
- Most prevalent subtype in Canada is Mycosis Fungoides (37.5%), CD30+ ALCL (19.5%) and MTCL (17%)
- Clustering of cutaneous lymphoma patients

Clinical journey



Clinical journey - Diagnosis

- Experience

- Challenges

- Advocacy

- Patients often experience rashes for years before diagnosis; will have a wide spectrum of disease presentation
- Diagnosed initially by knowledgeable dermatologists or oncologists
- Typical procedures done to diagnose cutaneous lymphoma include:
 - a complete physical exam;
 - a skin and/or lymph node biopsy (removal of a small piece of tissue) to be examined by a pathologist under the microscope
 - blood tests;
 - and possibly imaging tests such as CT and/or PET scans.
- Diagnosis is confirmed by a **dermatopathologist** or **hematopathologist** with expertise in cutaneous lymphoma.

Clinical journey - Diagnosis

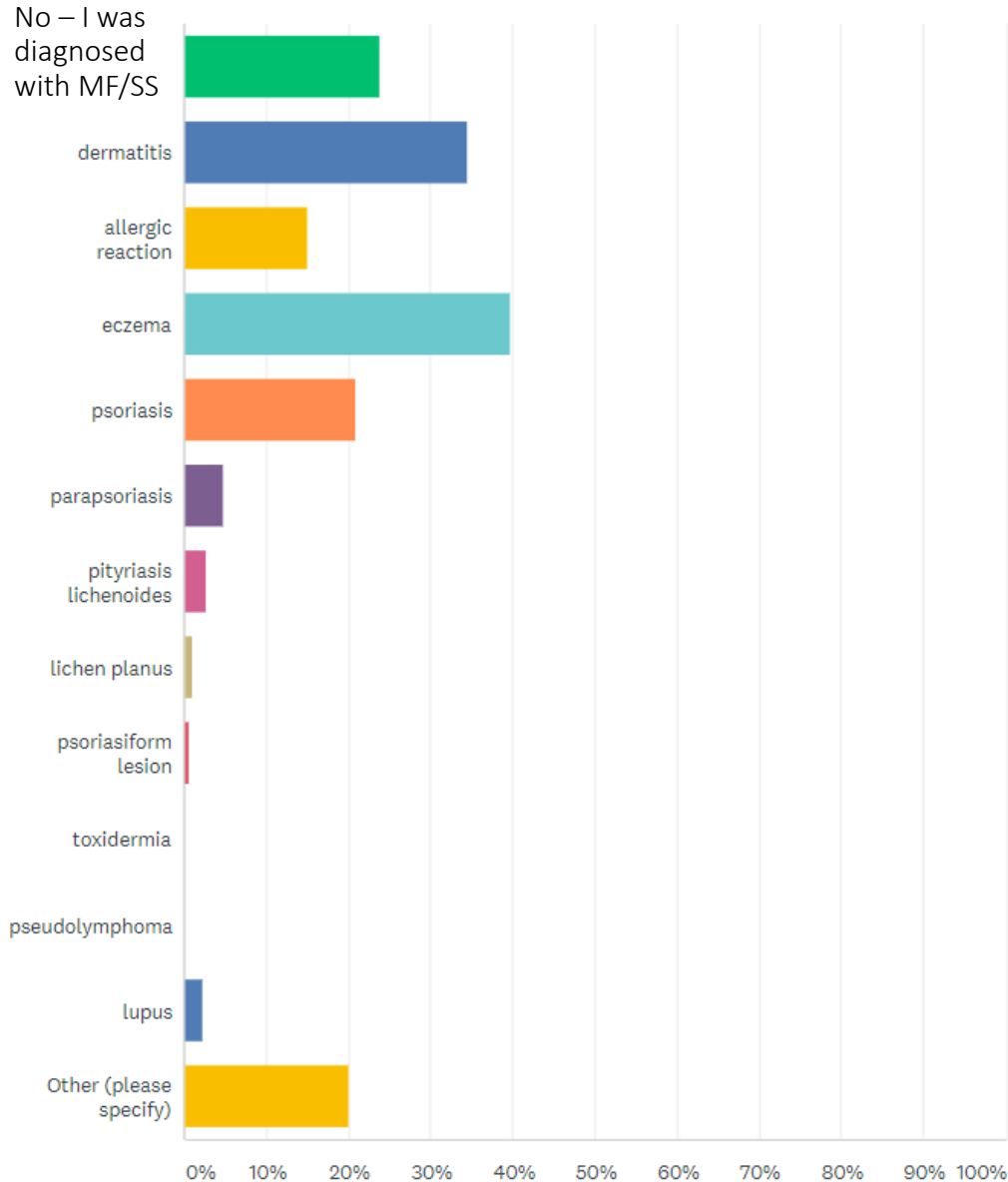
- Experience

- Challenges

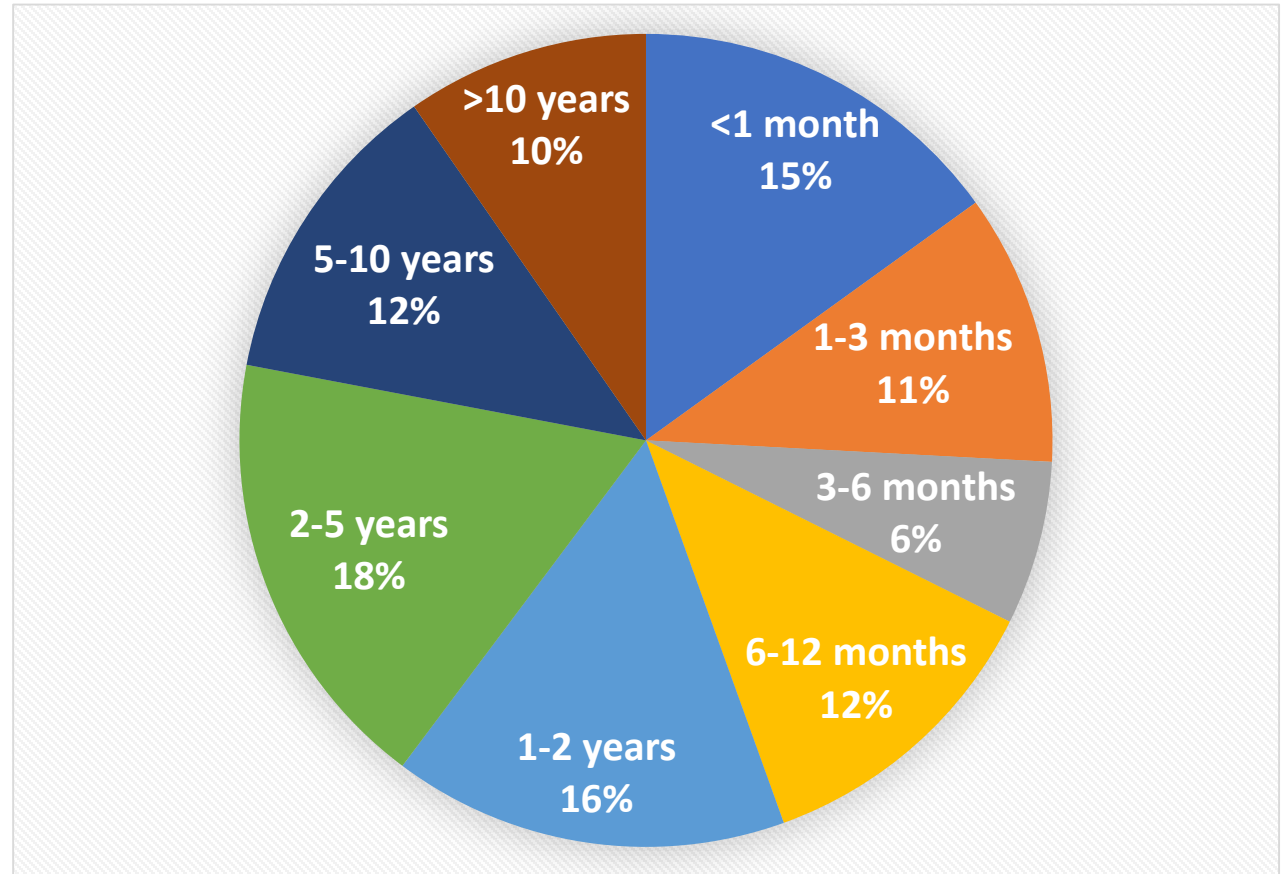
- Advocacy

- Patients with cutaneous lymphoma typically have thickened plaques or patches that may look like other conditions such as eczema, psoriasis, or drug eruptions
- Referrals to multiple healthcare providers
- Requires many diagnostic tests (biopsies)
- Knowledgeable hematopathologist and access to staining for proper testing
 - Many subtypes of cutaneous lymphoma that can be difficult to diagnose

Misdiagnosis



After initial presentation to their healthcare provider with symptoms or for a check-up, the majority of patients received their correct diagnosis a **minimum of 1 year later.**



Lymphoma Canada. Unpublished results. 2021



“Took 6 months to finally get a diagnosis dermatologist insisted it was atopic dermatitis.” – Cutaneous lymphoma patient

“Symptoms started over 2 years ago but my initial dermatologist just thought I had psoriasis and didn’t test until I went to the emergency.” – Cutaneous lymphoma patient

“Dermatologist diagnosed visually - but 28 biopsies before a confirmed diagnosis. It kept coming back Spongy Dermatitis.” – Cutaneous lymphoma patient

“I was misdiagnosed for 16 years.” – Cutaneous lymphoma patient

“Probably had it for 20-30 years before diagnosis.” – Cutaneous lymphoma patient

“Because CTCL is a rare cancer and MDs were not considering CTCL as a diagnosis it took a while to reach a proper diagnosis as I was getting much worse.”

– Cutaneous lymphoma patient

“I had the rash for at least 12 months before diagnosis.” – Cutaneous lymphoma patient



Clinical journey - Diagnosis

- Experience

- Challenges

- **Advocacy**

- Proper communication of ALL signs and symptoms to doctor
- Ask your doctor if they are confident in your diagnosis
- Ask for a second opinion related to your diagnosis
- Ask to get a copy of your pathology reports and relevant documentation; ask if the pathologist that read the report is an expert in lymphoma and CTCL
- Ask for referral to patient support groups

Clinical journey – Treatment

- Experience

- Challenges

- Advocacy

- **Patients with early stage cutaneous lymphoma**

- Approach → treatments offered are conservative
- Skin-based treatments
 - Topical steroids (can take this for several years)
 - More extensive disease may involve light therapy (Narrow band UVB 311 or PUVA)
 - Nitrogen mustard; mechlorethamine (topical chemotherapy; hard to get in Canada)
 - Oral retinoids (vitamin A derivatives)

Speak with your doctor to determine the best treatment option for your cutaneous lymphoma



Clinical journey – Treatment

- Experience

- Challenges

- Advocacy

- **Patients with advanced stage cutaneous lymphoma**
 - Approach → more intensive therapies to treat the spread of lymphoma
 - Radiation – CTCL are very sensitive to radiation
 - Tumours or lesions on the skin (in low doses)
 - Total Skin Electron Beam (if the patient has a lot of disease) (*rare in Canada*)
 - “Immune Therapy” (often first thought for those that are not behaving aggressively)
 - Oral retinoids (alitretinoin)
 - Interferon (immune booster often in early stage disease)
 - Extracorporeal photophoresis (if a lot of blood involvement)
 - Chemotherapy (more aggressive)
 - Chlorambucil (oral, and more gentle – elderly and frail patients)
 - Gemcitabine (IV, more aggressive)
 - Weekly low dose methotrexate (oral, and more gentle)

Speak with your doctor to determine the best treatment option for your cutaneous lymphoma



Clinical journey - Treatment

- Experience

- **Challenges**

- Advocacy

- **Newer Agents and Challenges**

- None of these are perfect – most are partial responses
- Hard to predict which one to try (go by side effect profile of the treatment) – individualized
- Most are IV (some are oral)
**important to consider distance to cancer centre*
- Funding Access (different across provinces)

Newer Agents

- HiDAC inhibitors
 - Vorinostat
 - Romidepsin
- Pralatrexate
- Brentuximab
- Mogamulizumab
- Alemtuzumab

Speak with your doctor to determine the best treatment option for your cutaneous lymphoma



Clinical journey - Treatment

- Experience

- Challenges

- Advocacy

- Most patients will go through multiple lines of treatment
- Multiple new agents available – challenge in deciding best option and predicting response
- Adherence challenges with long-term oral medication
- For chemotherapy, no option is curable (only controlling)
 - Curative option is allogeneic bone marrow transplant (high toxicity/mortality); relapse can still occur
- Frequency of treatment may require constant travel to cancer centre
- Funding and access for treatments across Canada

Clinical journey - Treatment

- Experience

- Challenges

- **Advocacy**

- Ask to speak with a drug access facilitator at your cancer centre to understand financial impacts and access to treatments
- Ask about treatment options available in Canada; outside of Canada
 - If not available at cancer centre, ask if there is a special access program (federal), exceptional access program / special authority (provincial) or patient support program (manufacturer) to access the treatment
- Ask if a clinical trial is an option for you

Clinical journey – Remission / Follow-Up Care

- Experience

- Challenges

- Advocacy

- Often treatment is long-term, or remissions are short
- Acceptance of chronic disease and lifestyle modification to adapt
- Dealing with the side effects of treatments (short-term, long-term, late effects)
- Fear of disease becoming worse or progressing is the greatest fear and impact to patients (Lymphoma Canada, 2021).

Clinical journey – Remission / Follow-Up Care

- Experience

- Challenges

- Advocacy

- Incurable; long-term chronic disease
- Secondary cancers can be common – take care of skin (sun protection, gentle washes)
- Treatments can be immunocompromising and may require extra safety practices
- May still be dealing with symptoms or side effects after treatment requiring lifestyle changes
- May not be alternative treatment options if relapse occurs

Clinical journey – Remission / Follow-Up Care

- Experience

- Challenges

- **Advocacy**

- Share your experience with your treatment and disease
- Monitor your signs/symptoms and communicate changes with your doctor
- Ask for all reports related to your cancer care
- Continue to educate and stay on top of treatment options available in case of relapse
- Join support groups and connect with other patients going through a diagnosis/treatment – offer advice and guidance

Access to treatments in Canada

Where do patients fit in?



How it works

Public coverage (Governments)

- Regulatory authorization
 - Is it **safe** and **effective**?
- Health technology assessment
 - Is it **clinically effective & cost effective** when compared to other available treatments?
- Price negotiations with public payers (pan-Canadian Pharmaceutical Alliance)
- Review by individual public plans (cancer agencies, institutions)
- **Patients must meet specific criteria**
 - Prior authorization
 - Exceptional Access / Special Authority

Private coverage (100,000+ plans)

- Regulatory authorization
 - Is it **safe** and **effective**?
- Some plans: Health technology assessment (higher-priced therapies)
 - Is it **clinically effective & cost-effective** when compared to other available treatments?
- **Patients must meet specific criteria**
 - Prior authorization



Spotlight on HTA: CADTH

- Initial feedback
 - Patient organization-led surveys matter!
- Feedback on the draft CADTH recommendation
- Feedback on the “provisional funding algorithm”
 - Advice to public drug plans about where to fit this treatment into the landscape of other treatments when drug plan decision-makers are deciding whether / how to cover them

Your input
to these
surveys &
discussion
groups is
important!

Existing challenges



Public coverage

- Not all drugs approved by Health Canada are publicly funded
- Uncertain outcomes from pricing negotiations (pCPA)
- Pricing of oncology therapies
- Drug coverage varies by province and territory

Private coverage

- Private payers relying on public HTA recommendations (CADTH, INESSS)
- Pricing of oncology therapies

| Triple Jeopardy Impacts to Patients

1

Lack of local access to new cancer drugs that are approved in other provinces/territories

2

May be unable to access a new drug funded within their province if they do not meet institutional or provincial eligibility requirements

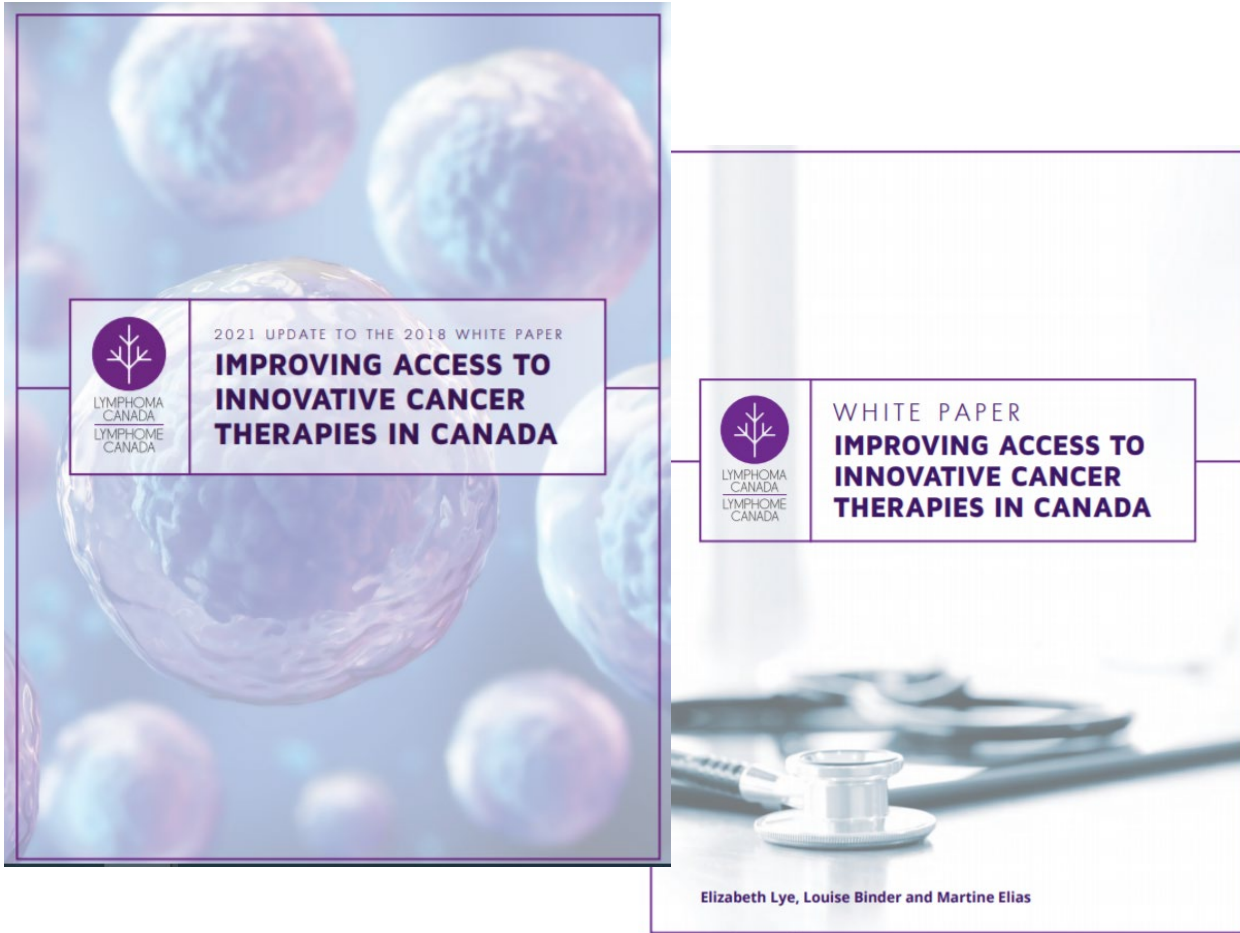
3

May experience a lack of full public coverage for therapies and may need to consider additional travel or treatment related costs

Patient advocacy

Changing public policy	Patients taking action
Access to care in Canada Improving programs and services in Canada	International surveys (Lymphoma Coalition) Every 2 years: next one in 2022
Specific issue or campaign	Write a letter to your representative (MP / MPP / MLA / MNA)
	Share your story with patient organizations & others
Accessing a specific new treatment in Canada	Patient organization surveys for health technology assessments
Raising awareness	Engage with patient organizations on social media
	Participate in patient story campaigns

Learn more about the Canadian landscape



- Providing patient feedback on cancer therapies

[CADTH](#)

[INESSS](#)

- [How Drugs are Reviewed in Canada](#) (Health Canada)
- [Canada's approach to drugs for rare diseases](#) (Health Canada)

White Paper on Cancer Drugs and Access in Canada
<https://www.lymphoma.ca/resources/policy/>

Support Resources for Patients

Patient Organizations

Lymphoma Canada

www.lymphoma.ca

Canadian Skin Patient Alliance (CSPA)

www.canadianskin.ca

Cutaneous Lymphoma Foundation

www.clfoundation.org/

Provincial Cancer Agencies

- Drug access facilitator
- Information and support resources
- Inter-provincial agreements/ travel assistance programs

Government of Canada

- Special Access Programme (SAP)

Pharmaceutical Companies

- Patient Support Programs



Thank you!



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