Joint Patient Advocacy Group Submission

to the

Pharmaceutical and Life Sciences Sector Task Force

Government of Canada

June 4, 2026

Submitted by 24 National Patient Advocacy Organizations

Key Takeaways

- Measure Canada's competitiveness by whether innovation reaches patients — not just by research investment or regulatory timelines.
- Track time to patient access, equity across jurisdictions, and patient-reported outcomes as core system performance indicators.
- Embed patient partnership earlier and more consistently across the full pathway — from research and development to post-market use.
- Recognize and resource patient organizations as implementation partners in Canada's life sciences infrastructure.

Martin LeBlanc, Co-Chair
Michelle Boudreau, Co-Chair
Pharmaceutical and Life Sciences Sector Task Force
Government of Canada

Dear Mr. LeBlanc, Ms. Boudreau, and Task Force members,

On behalf of the undersigned patient advocacy organizations, we welcome the creation of the Pharmaceutical and Life Sciences Sector Task Force and its mandate to strengthen Canada's life sciences competitiveness while improving access to innovative medicines.

We are writing to recommend that patient access, lived experience, and patient partnership be treated as central measures of Canada's life sciences competitiveness. Canada's competitiveness should not be measured only by research investment, clinical trial activity, regulatory timelines, or reimbursement decisions. It should also be measured by whether innovation reaches people in a timely, equitable, and meaningful way.

Patient involvement should be seen not as a final consultation step, but as a practical driver of better decisions, better implementation, and better outcomes. Measures such as time to patient access, equity across jurisdictions, patient-reported outcomes and experience, and key access delays should be tracked across the full pathway — from research and development to regulatory review, health technology assessment, reimbursement, implementation, and post-market use.

Patient organizations are active system operators. We contribute to evidence generation through patient-reported experience measures and patient-reported outcome measures that inform Canada's Drug Agency (CDA) and Institut national d'excellence en santé et services sociaux (INESSS), the pan-Canadian Pharmaceutical Alliance (pCPA), and reimbursement processes. We support shared decision-making, provider education, diagnostic access, treatment adherence, patient navigation, clinical trial recruitment and retention, advocacy with provincial/territorial health plans and private insurers, and clinical guideline development. These activities help move innovation from research into real-world access, use, outcomes, and health system value.

Canada cannot be globally competitive if patients experience long delays between therapeutic innovation and patient access. Access delays are not only reimbursement issues; they are system performance issues. When patients wait for diagnosis, specialist assessment, public or private coverage, consistent provincial listing, or local implementation, costs are shifted elsewhere through avoidable healthcare use, out-of-pocket costs, productivity loss, caregiver strain, disease progression, disability, and expensive late-stage disease management. According to Innovative Medicines Canada, it currently takes an average of 736 days following Health Canada approval for Canadian patients to access a medicine through a public drug plan — compared to 226 days through private coverage, and more than a year sooner in most peer countries.

Canada's federated model also creates uneven access across provinces and territories. This undermines patient outcomes and makes Canada less attractive for life sciences investment because the pathway from approval to uptake is variable, slow, and difficult to evaluate. The Task Force should therefore consider access and implementation as central to Canada's life sciences strategy.

We recommend that the Task Force:

1. **Recognize time to patient access as a system performance indicator.** Canada should measure time from Health Canada approval to health technology assessment, negotiation, public listing, private coverage, clinician

uptake, and patient initiation of appropriate therapy. These measures should be stratified by province and territory, population group, rurality, income, and other equity-relevant factors. Reporting these measures would create a clearer basis for accountability and targeted improvement.

2. Develop a national time to patient dashboard. A national dashboard should monitor delays from diagnosis to appropriate therapy, identify jurisdictional gaps, and support targeted system improvement. This would help governments, payers, clinicians, researchers, industry, and patient organizations understand where innovation is being slowed and where investment in implementation is needed. Patient organizations would welcome the opportunity to help inform the design of such a tool so that it reflects real patient journeys and supports practical system improvement.

3. Formalize patient partnerships across the full pathway. CDA and INESSS have made important progress in considering lived experience, but patient partnership should be embedded earlier and more consistently in early health technology assessment consultations, trial design, post-market surveillance, real-world evidence planning, implementation planning, and the evaluation of new therapies.

4. Treat patient organizations as implementation partners. Patient organizations support navigation, education, adherence, symptom recognition, shared decision-making, clinical trial awareness, provider engagement, and guideline implementation. These roles should be recognized and resourced as part of Canada's innovation infrastructure. Where appropriate, these contributions should be formally recognized in implementation planning and supported through sustainable partnership models.

Canada has the scientific expertise, clinical leadership, patient community capacity, and policy infrastructure to become more competitive in pharmaceuticals and life sciences. However, competitiveness must be measured by whether innovation reaches people in real life.

Recognizing time to patient access as a core system performance indicator, embedding patient partnership across the full pathway, and identifying gaps through a national time to patient dashboard — supported by targeted investment and collaborative implementation — would improve both patient outcomes and Canada's attractiveness as a market for innovation.

Patient organizations are ready to work with the Task Force, governments, industry, clinicians, researchers, and payers to co-develop practical solutions that improve timely access, reduce inequities, and strengthen measurable patient outcomes. We would welcome the opportunity to contribute to the design of tools, indicators, and partnership models that support both patient benefit and a stronger life sciences system in Canada.

Please reach out for more information to Lindsay Timm, Executive Director, Canadian Cancer Survivor Network at ltimm@survivornet.ca, and Riley Sanders, Head of Government Relations and Public Affairs, Global Airways and Allergies Patient Platform at rsanders@gaapp.org.

Sincerely,

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Disease and Condition Access Index

The following draft index illustrates how patient organizations could help the Task Force connect prevalence, innovative pharmaceutical opportunities, and real-world access barriers. Prevalence figures are included as estimates. Where direct national prevalence was not available, crude estimates use Statistics Canada's July 1, 2024 population estimate of 41,288,599. [2]

Condition	Canadian prevalence or burden	Innovative pharmaceutical opportunities	Current gaps affecting optimal therapy and regional access
CHRONIC LUNG CONDITIONS			
Asthma	4.8 million diagnosed (2024)	Biologics for severe phenotypes; novel anti-inflammatory pathways; improved inhaled combinations.	Under-recognition of severe disease; inconsistent referral; uneven testing access; regional variation in coverage criteria. [3]
COPD	2.0 million diagnosed; 1.8 million measured (ages 35–79)	Novel inhaled combinations; biologic approaches for selected patients; exacerbation-reducing medicines.	Low spirometry access; late diagnosis; high exacerbation burden; regional variation in coverage and newer medicines. [3] [4]
Pulmonary fibrosis	Approx. 12,300–16,500 people (crude estimate)	Anti-fibrotic medicines; precision approaches; pipeline medicines for progressive fibrosing disease.	Delayed ILD referral; variable imaging and multidisciplinary diagnosis; regional variation in eligibility and renewals. [6]
RARE DISEASE			
Primary Brain Tumours	Approximately 42,500 primary CNS tumours were diagnosed in 41,590 Canadians between 2018 and 2022.	Precision oncology medicines; genetic and genomic testing to support highly targeted, individualized treatments.	Delayed diagnosis; limited trial and treatment options; regional variation in treatment access and approval; high out-of-pocket costs.
Alpha-1 antitrypsin deficiency	Approx. 7,500–8,300 with severe deficiency (crude estimate)	Disease-modifying approaches; augmentation-type therapy models; gene- and RNA-based research.	Under-testing in COPD and liver disease; limited cascade testing; inconsistent reimbursement across regions. [7]
Cystic fibrosis	4,571 people	Modulator medicines; next-generation genetic and RNA-based approaches; medicines for infection and inflammation.	Unequal access to advanced medicines; pediatric-to-adult transition gaps; limited options for ineligible patients. [8]
Pulmonary arterial hypertension	More than 2,000 with PAH; up to 4,000 living with it	Classes targeting pulmonary vascular pathways; combination regimens; novel pathway-modifying medicines.	Delayed diagnosis; limited primary-care awareness, delays to access treatment[5]

Condition	Canadian prevalence or burden	Innovative pharmaceutical opportunities	Current gaps affecting optimal therapy and regional access
Rare gastrointestinal diseases	IBD example: 825 per 100,000	Targeted immune medicines; oral small molecules; biologics and biosimilars; precision approaches.	Diagnostic delay; limited specialist capacity; uneven endoscopy and biomarker access; regional step-therapy variation. [9]
ONCOLOGY			
Pediatric, Adolescent, and Young Adult (AYA) Cancers.		Precision oncology guided by comprehensive genomic profiling (such as the Terry Fox PROFYLE initiative); target-specific small molecules and immunotherapies; and access to specialized international clinical trials for ultra-rare mutations.	Significant regional variation and funding delays for advanced next-generation sequencing (NGS); lack of age-appropriate clinical trial infrastructure across provinces; and systemic "pediatric-to-adult transition gaps" where AYA patients lose access to specialized care, navigation, and clinical trials as they age out of pediatric systems.
Lung cancer	32,900 projected new diagnoses (2025); 32,645 five-year prevalence (2018)	Immunotherapies; targeted oncology medicines; precision medicines linked to molecular testing.	Late-stage diagnosis; inconsistent LDCT screening; molecular testing delays; uneven trial access. [10] [11]
Prostate cancer	30,400 projected new diagnoses (2025); 72,725 five-year prevalence (2018, excluding Quebec)	Targeted oncology medicines; radiopharmaceuticals; hormone-pathway therapies; precision approaches linked to genomic and biomarker testing.	Uneven PSA and diagnostic pathways; MRI and biopsy waits; variable access to genomic testing, radioligand therapy, clinical trials, and supportive survivorship care. [10] [11]
GI and colorectal cancers	Colorectal: 26,400 new diagnoses (2025); 59,160 five-year prevalence (2018)	Immunotherapies for biomarker-selected patients; targeted medicines; precision options for rarer subtypes.	Inequitable and high screening criteria; colonoscopy delays; limited biomarker testing; regional access variation for newer medicines. [10] [11]
Breast cancer	31,900 new diagnoses (2025); 84,465 five-year prevalence (2018)	Targeted oncology medicines; immunotherapies for selected subtypes; antibody-based and precision medicines.	Unequal screening, genetic and molecular testing, reconstruction, and psychosocial care; inequitable prosthetic coverage/access; regional approval variation. [10] [11]
Bladder Cancer	12,600 new cases (2025)	Antibody-drug conjugates (ADCs); FGFR inhibitors; Immune checkpoint inhibitors	Delayed and inconsistent access; diagnostic delays; equity gaps; inequitable access to biomarker testing. [10] [11]

Condition	Canadian prevalence or burden	Innovative pharmaceutical opportunities	Current gaps affecting optimal therapy and regional access
Pancreatic Cancer	7,500 new cases (2025)	Precision medicine, biomarker-driven therapies, KRAS-targeted therapies; and immunotherapy combinations.	Late diagnosis; limited early detection options; uneven access to molecular testing, specialized HPB centres, lack of screening; inconsistent access to testing, clinical trials, specialist care, and new therapies across jurisdictions. [19][20]
Liver Cancer (HCC and CCA)	Liver cancer, including cholangiocarcinoma: 4,800 new cases (2025). Estimated deaths 3,600 people (2025)	Immunotherapy and targeted therapies, Radiation therapy	Biomarker testing and liquid biopsy testing access barriers; limited clinical trial access.
Ovarian cancer	3,000 new diagnoses (2026)	Precision oncology medicines; targeted maintenance medicines; options linked to genetic and tumour testing.	No population screening; late diagnosis; uneven genetic testing; limited regional gynecologic-oncology capacity. [11] [12]
Melanoma and skin cancer	Melanoma: 10,800 (2025); non-melanoma: 76,100 (2014)	Immunotherapies; targeted oncology medicines; cell and gene therapies approach for advanced and high-risk disease.	Rural dermatology access; biopsy waits; inconsistent prevention programs; regional variation in advanced care. [13] [14]
Leukemia	6,600 new diagnoses (2024)	Targeted hematology medicines; cell and gene therapies; precision medicines linked to MRD and molecular testing.	Uneven hematology, testing, trial, and cell-therapy access; regional variation in approval and sequencing. [12]
Multiple Myeloma	4,300 new diagnoses (2025)	Targeted immunotherapies, especially cell and gene therapies; minimal residual disease testing (MRD)-mediated treatment protocols; earlier treatment initiation for high-risk precursor disease.	Diagnostic delays; inequal access to care & treatment (hematology services, biomarker tests, clinical trials, new therapies); high cost of cell therapies.[10]
CHRONIC SKIN CONDITIONS			
Atopic dermatitis	Approx. 1.8 million people (crude estimate)	Biologics; oral small molecules; non-steroidal topicals; pharmaceuticals targeting inflammatory pathways.	Burden often minimized; delayed referral; high out-of-pocket costs; uneven specialist and coverage access. [15]

Condition	Canadian prevalence or burden	Innovative pharmaceutical opportunities	Current gaps affecting optimal therapy and regional access
Chronic urticaria	Approx. 0.5–1% of the population; roughly 206,000–413,000 people (crude estimate)	Biologics and targeted immune-pathway medicines; emerging oral small molecules.	Delayed diagnosis; specialist waits; step-therapy burden; variable coverage; quality-of-life impacts. [16]
Psoriasis	Approx. 1 million people	Biologics; oral targeted medicines; biosimilars; pharmaceuticals addressing skin and joint inflammation.	Delayed PsA diagnosis; specialist waits; step-therapy and affordability barriers; regional formulary variation. [17]
IMMUNOLOGY			
Arthritis	More than 6 million people	Biologics; targeted synthetic medicines; biosimilars; medicines supporting treat-to-target control.	Long rheumatology waits; delayed diagnosis; limited allied-health access; uneven biosimilar transition policies. [18]


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Breast Cancer Canada


CANADIAN CANCER SURVIVOR NETWORK


Canadian Immunocompromised Advocacy Network


CHOLANGIO-HEPATOCELLULAR CARCINOMA
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CCRAN
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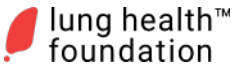
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