

How CADTH Uses Patient and Clinician Perspectives

Examples from July 2023 to December 2023

Our reports and recommendations include high-level summaries of what we hear from patients, caregivers, and clinicians. More importantly, staff and expert committees consider patient and clinician perspectives during appraisal and deliberation efforts. Between July 2023 and December 2023, patients and clinicians were involved in 27 Reimbursement Reviews, 20 Reimbursement Recommendations, and 3 Health Technology Reviews. Read on to learn how patient and clinician insights are used to achieve various purposes.

Why: To explore if clinical and economic evidence within the review address patients' needs.

Example of how: "pERC recognized the need for more treatment options for patients with CLL (chronic lymphocytic leukemia), notably for treatments that are better tolerated with favourable toxicity profiles [...]. Given the evidence, pERC concluded that zanubrutinib met some of the needs identified by patients because it provides an additional treatment option for oral administration with the potential for fewer side effects and with no apparent deterioration in quality of life." (Rationale for the Recommendation, Reimbursement Recommendation)

Example of how: "The expert stated that treatment options are limited for the approximately 30% of patients with focal epilepsy who do not respond to ASMs (antiseizure medications), and while ASMs may reduce seizure frequency, none offer a cure for epilepsy. [...] The clinical expert stated that [drug] is best suited to patients with focal epilepsy who have not responded to conventional ASMs, and they anticipate it will be used as second-line or third-line therapy, typically as add-on therapy." (Clinician Input, Reimbursement Recommendations)

Example of how: "Evidence from 3 double-blind randomized trials [...] addressed key treatment outcomes noted as important by both patients and clinicians." (Conclusions, <u>Reimbursement Review</u>)



Why: To better understand the impact of illness on a person's life.

Example of how: "The advisors with lived experience that were engaged in this project indicated they had experienced issues accessing diagnostic testing and treatment services for eating disorders. They often found themselves having to advocate for access to the services they believed they needed. Access was felt to be limited by geographic proximity of existing treatment programs or affordability of private treatment where publicly funded programs were unavailable. When they were able to access treatment services, the services were at times not felt to be appropriate for their specific needs (e.g., access to a dietitian without specialized knowledge of eating disorders)." (Discussion and Conclusions, <u>Health</u> <u>Technology Review</u>)

Example of how: "HRQoL (health-related quality of life) is clearly an important outcome for patients living with HIV, and likely particularly important for HTE (heavily treatment-experienced) patients, as these patients are often experiencing AIDS-related complications, such as opportunistic infections and neurologic complications. In addition, patient input to CADTH suggests that HTE patients are particularly concerned about the increased risk of disability and death associated with infection." (Interpretation of Results, <u>Reimbursement Review</u>)

Why: To appreciate the goals of treatment and what it means for these to be met or missed.

Example of how: "Improving survival in patients with cancer should remain the primary goal of therapy, but the clinical experts consulted by CADTH noted that progression-free survival was a more appropriate objective in the context of this review." (What Did We Hear From Clinicians?, <u>Reimbursement</u> Recommendation)

Example of how: "Stakeholder input (from patient groups and clinician groups) pointed to a PASI 90 as the desired benchmark for a primary outcome measure (compared to PASI 75 in previous trials) to demonstrate the possibility of achieving complete or near-complete skin clearance." (Why Did FMEC [Formulary Management Expert Committee] Make This Recommendation?, <u>Reimbursement Recommendation</u>)

Why: To interpret clinical trial results.

Example of how: "The clinical experts and breast pathologist consulted by CADTH noted that there is existing HER2 testing infrastructure in Canada. Given HER2-low is a novel classification, the clinical experts suggested there may be interobserver discordance and lack of reproducibility when differentiating 0 and 1+ to determine HER2 IHC status, as historically, the interpretation of these 2 categories was less rigorous. pERC agreed with the clinical experts that with increased awareness and adequate training, pathologists and oncologists in Canada will be able to correctly identify patients with HER2-low breast cancer." (Discussion Points, <u>Reimbursement Recommendation</u>)



Why: To help CADTH appraise the sponsor's economic model.

Example of how: "The clinical expert input indicated that [drug] may be used in patients with a higher percentage of affected BSA (body surface area) in clinical practice, and the Health Canada indication does not restrict use by the percentage of affected BSA. If patients have a higher baseline percentage of affected BSA requiring more product, roflumilast will be less cost-effective since it has the highest unit costs of all the topical treatments for plaque psoriasis." (Economic Review, <u>Reimbursement Review</u>)

Example of how: "The most important outcome for patients with moderately to severely active UC (ulcerative colitis) is sustained clinical remission and/or response, which are the primary health states in the maintenance phase of the sponsor's model." (Conclusions, <u>Reimbursement Review</u>)

Why: To identify use, equity, or ethical considerations.

Example of how: "A patient with lived experience presented [their] journey living with glioblastoma after being diagnosed in 2018. [...] Living in an urban centre allowed her to access diagnostic and treatment centres more easily and she underscored the need for better access for people who live overside of urban settings in Canada. She emphasized the challenges patients face in obtaining drug coverage, stressing the need for equal access in Canada, noting that the process is lengthy and often requires support from family and friends." (Patient with Lived Experience, <u>Reimbursement Recommendation</u>)

Why: To identify the impacts or barriers to treatment.

Example of how: "Identifying individuals who would receive a significant benefit is crucial when considering electrostimulation referrals. Patients' values and preferences, accessibility, and cost of using electrostimulation can also play a significant role in the decision-making process. During our patient engagement activities, another barrier was identified, which was the lack of proper training for using the electrostimulation device." (Conclusions and Implications for Decision or Policy-Making, <u>Health</u> <u>Technology Review</u>)

Example of how: "While the guidelines did not comment on treatment delivery or implementation considerations in detail, the patient contributor to this report expressed a preference for the oral medication form due to its convenience (compared to infusions). The patient also highlighted potential barriers to access, such as the risk of losing medication access when requiring full-time CPAP (continuous positive airway pressure) therapy due to declining health." (Conclusions and Implications for Decision- or Policy-Making, <u>Health Technology Review</u>)

cadth

Example of how: "The advisors with lived experience engaged in this project expressed a desire to normalize the ability to access treatment in de-medicalized settings like community hubs. Harm-reduction models could be considered where the focus is on improvement over time rather than complete recovery. These models may provide an interim solution for people who are not ready to participate fully in a treatment program. Peer support for both youth and parents was identified as a positive element of treatment programs." (Discussion and Conclusions, <u>Health Technology Review</u>)

Why: To enhance the quality and relevance of our work.

Example of how: "To enhance the quality and relevance of this work, CADTH engaged a wide range of people with extensive personal and/or professional experience with emergency department care within the Canadian health system. Patients, family members, community members, and emergency department clinicians and staff were engaged as expert consultants, peer reviewers, and HTERP (Health Technology Expert Review Panel) members. Others participated in multistakeholder dialogue sessions." (Expert Guidance, <u>Health Technology Review Recommendation</u>)

Thank you to the patient groups who contributed to recommendations published from July 2023 to December 2023:

Bardet Biedl Syndrome Foundation; Canadian Association of Psoriasis Patient; Canadian Association Psoriasis Patients; Canadian Breast Cancer Network; Canadian Cancer Survivor Network; Canadian Epilepsy Alliance; Canadian Neuroendocrine Tumour Society; Canadian Organization for Rare Disorders; Canadian Psoriasis Network; Canadian Skin Patient Alliance; Canadian Von Hippel-Lindau Alliance; Colorectal Cancer Resource & Action Network; Crohn's and Colitis Canada; Crohn's and Colitis Canada; Cutaneous Lymphoma Foundation; Eczéma Quebec; Eczema Society of Canada; Edmonton Epilepsy Association; Epilepsy Association of Calgary; Epilepsy South Central Ontario; Epilepsy Southwestern Ontario; Epilepsy Toronto; Gastrointestinal Society; KCCure; Kidney Cancer Canada; Kidney Foundation of Canada; Leukemia & Lymphoma Society of Canada; Lymphoma Canada; Muscular Dystrophy Canada; Pancreatic Cancer Canada; Parkinson Association of Alberta; Parkinson Canada; Parkinson Québec; Parkinson Society British Columbia; Rethink Breast Cancer; The MAGIC Foundation; Vasculitis Foundation Canada.

Thank you to the clinician groups who contributed to recommendations published from July 2023 to December 2023:

Atlantic Provinces Dermatology Association; Atlantic Specialist Group/University of Calgary Inflammatory Bowel Disease Unit; British Columbia Movement Disorders Specialist Group; Canadian Dermatology Association; Canadian Endocrinologists Treating Bardet Biedl Syndrome; Canadian Gastrointestinal Oncology Evidence Network; Canadian League Against Epilepsy; CanVasc; Cell Therapy Transplant Canada; Department of Hematology, Oncology, and Bone Marrow Transplant, British Columbia Children's Hospital; Dermatology Association of Ontario; Division of Nephrology, Department of Medicine, Dalhousie University/Nova Scotia Health; Fraser Health Dermatology; Hemodialysis Specialty Physician Group - Division of Nephrology; Inflammatory Bowel Disease Centre of British Columbia; Kidney Cancer Research Network of Canada; Lymphoma Canada, Ontario Health-Cancer Care Ontario Hematology Cancer Drug Advisory Committee; National Movement Disorder Expert Group; Neuromuscular Disease Network for Canada; Ontario Health-Cancer Care Ontario Breast Cancer Drug Advisory Committee; Ontario Health-Cancer Care Ontario Gastrointestinal Drug Advisory Committee; Ontario Health-Cancer Care Ontario Genitourinary Cancer Drug Advisory Committee; Ontario Health-Cancer Care Ontario Genitourinary Drug Advisory Committee; Ontario Health-Cancer Care Ontario Hematology Cancer Drug Advisory Committee; Pediatric Endocrinology Nurses; Pediatric Hematology/Oncology program at the Janeway Children's Health and Rehabilitation Centre in St. John's, Newfoundland and Labrador; Saskatchewan Kidney Doctors; The Ottawa Hospital.

Thank you to the patient and clinician partners who were involved in our Health Technology Reviews and Horizon Scans from July 2023 to December 2023:

Alan Drummond, Alexander Hoechsmann, Ayisha Kamran, David A Petrie, Dawn Peta, Frank Scheuermeyer, Greg Clark, Ivy Cheng, Joe Cherian, Joe Nemeth, Kerstin de Wit, Lori Korchinski, Maggie Keresteci, Marie-France Tourigny-Rivard, Marisa Vigna, Mary Reeves, Patricia Candelaria, Paul Mak, Robert DeMarco, Sameer Sharif, Sandra Ketler, Scott Williams, Stewart Midwinter, Tania Principi, Tanya Penney, Tasleem Nimjee, Tim Chaplin, and Valerie McDonald.

Disclaimer

CADTH is a not-for-profit organization responsible for providing Canada's health care decision-makers with objective evidence to help make informed decisions about the optimal use of drugs and medical devices in our health care system.

CADTH receives funding from Canada's federal, provincial, and territorial governments, with the exception of Quebec.



