

How CADTH Uses Patient Perspectives

Examples From March, June, July, and August 2021

High-level summaries of what we heard from patients and caregivers are included in our reports and recommendations. More importantly, patient perspectives are considered by staff and expert committees. These insights are used to achieve a range of different purposes, as subsequently described.

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

Example of how: "Patients identified a need for treatment options that could maintain remission, have fewer side effects, improve quality of life, and be accessed closer to home or as an outpatient treatment in their geographic regions. Overall, pERC concluded that [drug] provides older patients and patients with comorbidities with a treatment option that has an impact on the disease and improves survival. However, it does not offer fewer side effects and must be initiated as inpatient therapy in medical facilities with experience and expertise in delivery of this type of treatment." Reimbursement Recommendation, Rationale for Recommendation (Canjhealthtechnol.ca, Vol 1 No.8)

Why: To understand what it is like to live with illness, as experienced by patients.

Example of how: "As described by the patient input received for this review, common symptoms of diabetes include extreme fatigue, unusual thirst, frequent urination, and weight change." Reimbursement Review, Disease Background (Canjhealthtechnol.ca, Vol 1 No.9)

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

Example of how: "A deep discussion of clinical outcomes, particularly overall survival, progression free survival, and health-related quality of life (QoL), revealed the goals of treatment with stereotactic ablative radiotherapy. In CADTH's conversations with the patient collaborator, the outcome that was discussed most by the patient was health-related QoL, including pain and fatigue, indicating the importance of remaining active and being able to return to work after treatment." Health Technology Review, Patient Engagement (Canjhealthtechnol.ca, Vol 1 No. 3)

Example of how: “Patients have a long-term exposure to blood transfusions and chelation, with many patients receiving treatment for decades. The cycle of transfusion is time-consuming, it interferes with work and school and is a burden to normal social and home life, and iron chelation is not only onerous but also limiting in terms of mobility. Moreover, before scheduled transfusion time, patients experience fatigue, low energy, and decreased mental acuity associated with low hemoglobin. Children are unable to do sleepovers; families are restricted in terms of travel; and adults report limitations in terms of their work, social life, and overall quality of life. Overall, patients desire improvement in health-related quality of life, reduced adverse effects, and decreased burden of treatment.” Reimbursement Recommendation, Summary of Patient Input (Canjhealthtechnol.ca, Vol 1 No. 6)

Why: To help interpret clinical trial results.

Example of how: “It was also clear from the patient group input received for this submission that patients consider improved quality of life to be an important outcome of treatment... Overall scores revealed that the [drug] twice daily group was better at maintaining patients’ health related quality of life compared to placebo.” Reimbursement Review, Interpretation of Results (Canjhealthtechnol.ca, Vol 1 No.10)

Example of how: “The involvement of a patient prompted the research team to discuss which adverse effects of stereotactic ablative radiotherapy were of concern to the patient collaborator. Pain and fatigue were mentioned and reported in the results, where available.” Health Technology Review, Patient Engagement (Canjhealthtechnol.ca, Vol 1 No. 3)

Example of how: “The patient input identified fatigue and pain as being the most important disease related symptoms to control. Adverse events related to treatment which were difficult to tolerate were varied in the patient input, but included vomiting, nausea, pain, rash, neuropathy, hair loss, and low platelets. Adverse events of any grade for fatigue, rash were similarly reported across the doublet and control groups. Reimbursement Review, Interpretation of Results (Canjhealthtechnol.ca, Vol 1 No.9)

Why: To help CADTH’s appraisal of the sponsor’s economic model.

Example of how: “Improved quality of life associated with improved symptoms was incorporated into the model, as were reduced numbers of physician visits, dilatations, and food impactions. Adverse events resulting from treatments were associated with costs but not quality of life decrements.” Reimbursement Review, Pharmacoeconomics (Canjhealthtechnol.ca, Vol 1, No.10)

Example of how: “The sponsor considered a broad range of potential treatment-emergent adverse events in the model and their respective impact on quality-of-life. Microvascular complications such as eye disease, lower extremity disease, and kidney disease as well as macrovascular complications such as ischemic heart disease, myocardial infarction, stroke, and heart failure were all accounted for, with impacts on quality of life dependent on the type of adverse event.” Reimbursement Review, Pharmacoeconomics (Canjhealthtechnol.ca, Vol 1 No.10)

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

Example of how: “Notably, many hospitals do not see high-risk neuroblastoma patients frequently, and administration of [drug], including management of toxicities, was acknowledged by patient groups to have a steep learning curve.” Reimbursement Review, Critical Appraisal (Canjhealthtechnol.ca, Vol 1 No.8)

Example of how: “CDEC discussed patient input that highlighted the difficulties associated with multiple, potentially high-volume injections associated with glycemic management in patients with a total daily dose greater than 200 units. Moreover, CDEC noted that the unmet need becomes more pronounced as patients require a greater total daily dose for glycemic control.” Reimbursement Recommendation, Discussion Points (Canjhealthtechnol.ca, Vol 1 No.8)

Example of how: “Ethical and equity issues are sometimes revealed when experiences are shared. Affordability was a concern of both our engaged person living with type 1 diabetes and the patient group representatives. Representatives with the CNIB Foundation noted that people who are visually impaired may be unable to use diabetes management devices like hybrid closed loop systems and continuous glucose monitors, and often require assistance to read the screens and address the alarms.” Health Technology Review, Patient Engagement (Canjhealthtechnol.ca, Vol 1 No. 3)

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ABOUT CADTH

CADTH is an independent, 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.

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