

# Become Involved With CADTH

## Introduction

Canadians deserve excellent health care. CADTH provides assessments of medical devices, procedures, and drugs to help hospitals, health authorities, and public drug plans make wise and equitable decisions on which technologies to use to provide care at a reasonable cost that allows for excellent health care now and excellent health care in the future.



CADTH recognizes that patients and their families have valuable, lived experience that can contribute to the evidence base for our assessments. Patients, families, and communities can offer insights on the diversity of individual needs and health care settings across Canada. CADTH's recommendations on publicly funded devices, procedures, and drugs impact Canadian patients. So, it makes sense that patients and the public be aware of, and involved in, our work.

The International Association for Public Participation describes a spectrum of public participation. The public have an increasing impact on decision-making, as the participatory intent moves from inform to consult, to involve, to collaborate, and finally to empower, where the final decision-making is placed in the hands of the public.

We have a range of opportunities for individuals and organizations to become involved in CADTH's work. We identify where each activity falls along the spectrum of participation, we describe the activities and things to consider before leaping in, and the expected outcomes of the involvement.

## For Individuals Who Want to Learn About Medical Devices, Procedures, and Drugs

### INFORM

Read and share assessments

### CONSULT

Give stakeholder feedback

### INVOLVE

Contribute to CADTH Symposium or patient input

### COLLABORATE

Participate in specific assessments or on advisory group

### EMPOWER

Be a community member

### INVOLVE

The **CADTH Symposium** is held every April and attended by roughly 750 delegates involved in health care policy-making, program decision-making, health care delivery, and research. CADTH provides discounted registration and travel grants for members of the patient community.

You can:

- attend in person or watch the proceedings at CADTH/ACMTS YouTube
  - question or comment using social media (#CADTHSymp) or CADTH on Facebook
  - network at the annual Patient Community Meet and Greet
  - submit an abstract each October (watch how)
- present a poster, give a presentation, or join a panel
  - join our Abstract Review Committee each November and December.

### Considerations

The CADTH Symposium takes place in different parts of Canada each year, with a limited number of travel awards of up to C\$2,000 available to those working in a not-for-profit, patient-related organization, or a citizen's organization interested in health policy.

One way of participating is volunteering to review abstracts. It is a way to contribute to a final program that truly reflects patient community perspectives and helps ensure that people from the patient community are visible throughout the event. Allow several hours in November to complete the abstract review.

CADTH staff is available to help you with any questions you have about attending, presenting, or volunteering for the CADTH Symposium

### Outcome

Ideas from roughly 180 posters, presentations, workshops, and panels, are heard and discussed by senior decision-makers in federal, provincial, and territorial departments of health; by decision-makers from drug plans, health authorities, hospitals, and long-term care facilities; by Canadian and international health policy researchers; by health technology agencies' staff; and by patient and community organizations. Also heard and considered are the questions and comments on ideas presented at the CADTH Symposium. Patients often have unique perspectives that are valued by the other participants.

### INFORM

**CADTH assessments** are freely available at [www.cadth.ca](http://www.cadth.ca). Each year, CADTH produces 300 Rapid Responses on devices, drugs, and procedures; 60 to 70 drug assessments; 20 horizon or Environmental Scans; and a few large projects.

### Considerations

Our assessments are written in scientific language in English, although some have accompanying infographic, plain language, or French summaries.

You are welcome to share and discuss our assessments with your health care team. However, CADTH does not give individual medical advice.

You are also welcome to use the references listed in the assessments to find other organizations and authors to learn more.

Please note that technology moves quickly and older reports may be out of date.

### Outcome

Our assessments are evidence-informed and provide balanced reporting of known benefits and harms for drugs, and devices and procedures, often in comparison with other treatment alternatives.

## For Individuals or Organizations Wanting to Learn and Provide Feedback

### CONSULT

For some programs, we share draft assessments, recommendations, and included studies for anyone interested to comment on. This "**stakeholder feedback**" is an opportunity for various parties to comment on the clarity and usefulness of the draft, including any context or perspectives that might be missing. Subscribe to CADTH E-alerts or follow @CADTH\_ACMTS on Twitter for opportunities to provide feedback.

### Considerations

assessment rather than the full report.

All comments are considered, but we do not provide feedback on how comments were used.

In addition to stakeholder feedback, CADTH contracts a clinician and/ or an academic to provide an additional review before our Health Technology Assessments and Optimal Use projects are finalized.

### Outcome

Feedback improves our assessments, which are used by government departments, health authorities, drug plans, hospitals, and long-term care facilities to make funding decisions, or practice or policy changes. Review of assessments in draft also helps those interested in health policy and new technologies stay abreast of the latest research.

## For Patient Groups Who Want to Contribute to Patient Input

### INVOLVE

For the CADTH Common Drug Review and pan-Canadian Oncology Drug Review programs, and for Optimal Use projects (such as CAR T-cell therapies), we invite patient groups to provide "**patient input**." Using a range of methods — staff experiences, perspectives from support groups, interviews, and surveys — patient groups comment on the disease, treatments, expectations for improved treatments, and any lived experiences using the therapy under review.

### Considerations

Groups have seven weeks to prepare patient input after CADTH requests input via social media and CADTH E-alerts. Subscribe to CADTH E-alerts or follow @CADTH\_ACMTS on Twitter to be aware of opportunities to provide patient input.

CADTH reviews drugs upon the request of a pharmaceutical company, cancer agency, or occasionally, the public drug plans. It may be that five diabetes drugs come to CADTH in one year but no drugs for schizophrenia or depression, for example.

### Outcome

Patient, caregiver, and clinician insights build on our understanding of the trial results and how they might play out in Canada. Individual experiences can also provide new information on outcomes and consequences not captured in the randomized controlled trials or economic models.

Each CADTH expert committee has a recommendation — or deliberative — framework appropriate to its mandate and used to consider multiple perspectives and sources of information. Recommendations and advice given by the

expert committees rely on data from across their frameworks and do not depend on one source of data or one perspective alone.

## For individuals Who Want to Contribute to the Direction of CADTH Assessments

### COLLABORATE

We sometimes seek individuals with lived experience to contribute to CADTH's Scientific Advice, Health Technology Assessments, and Optimal Use projects, and sometimes ask groups to help us plan, contribute to, and share findings of horizon and Environmental Scans, Rapid Responses, and other projects.

#### Considerations

Opportunities for involvement may differ from project to project.

At CADTH, we identify, synthesize, and critique published studies rather than conduct primary research. Patient and family insights can therefore help direct or redirect how published evidence is interpreted and used. Often lived experiences and patient family perspectives help CADTH better understand the disease area and the Canadian health care landscape.

The time commitment usually is one or two teleconferences (one to one-and-one-half hours), reviewing various draft documents over the project length (one to 12 months), and helping connect CADTH with other relevant experts and stakeholders.

The reports of all completed projects are published on the CADTH website, apart from Scientific Advice projects, which are shared only with the pharmaceutical company involved.

#### Outcome

Contributions of individuals are noted in project protocols and reports.

*The Guidance for Reporting Involvement of Patients and the Public* (GRIPP2) updated checklist short form recommends specifying the aim of involvement, methods used, outcomes of engagement (both positive and negative), extent to which patient and public involvement influenced the study overall, and critical reflections, so that others can learn from the experience. While CADTH has not consistently used GRIPP2, it would be a useful checklist for CADTH to follow.

## For Individuals or Organizations With Ideas on How CADTH Can Change

### CONSULT

Interested individuals, patients, families, and patient groups are welcome to contribute feedback on proposed process changes highlighted in *CADTH Pharmaceutical Reviews Updates* or CADTH News. Subscribe to CADTH e-alerts or follow @CADTH\_ACMTS on Twitter for opportunities to provide feedback.

We also hear ideas and concerns via the patient community and at stakeholder meetings. CADTH staff often attend conferences and meetings of other organizations to share our activities and learn from others. The annual CADTH Symposium is also a good opportunity for sharing challenges and new ideas with CADTH staff and the wider health policy community.

At any time, individuals or groups are welcome to write to or call CADTH (Requests@cadth.ca) with concerns and ideas. We have a dedicated patient engagement team who welcome new ideas and can respond to problems and concerns.

In 2019, a patient and community advisory committee is being created to provide CADTH with high level advice on issues relevant to CADTH's mandate from the perspectives of those using the Canadian health care system.

#### Considerations

During stakeholder feedback, all comments are considered, but we do not provide individual feedback to the suggestions given.

Often, ideas take time to put into practice. Some ideas might be outside of CADTH's mandate; other good ideas might impact other organizations and require more time and consultation before they can be implemented.

#### Outcome

Specific to patient engagement, CADTH has extended timelines, created a feedback loop for patient groups to comment on the accuracy of summaries, introduced feedback letters, piloted a health technology assessment patient navigator, run workshops, and created training videos and other resources in response to suggestions from the patient community.

## For Individual Participation in an Expert Committee or CADTH Board

### EMPOWER

The mandate of the Health Technology Expert Review Panel is to provide advice to CADTH and to its jurisdictional stakeholders, who promote the optimal use of health technologies, such as medical devices and procedures. The panel has a public member representing the views and values of contemporary Canadian society.

The Canadian Drug Expert Committee makes recommendations on the funding of drugs submitted through the CADTH Common Drug Review process, within the publicly funded health care system in Canada (excluding Quebec). Its approach is evidence-based and its advice reflects medical and scientific knowledge, current clinical practice, economics, ethical considerations, patient perspectives, and social values. The committee has two public members to represent the general public and offer a lay perspective.

The role of the pCODR Expert Review Committee is to make cancer drug funding recommendations to participating provincial and territorial Ministries of Health, provincial cancer agencies, and federal drug programs that can be used by these jurisdictions to guide their cancer drug funding decisions. Their recommendations must consider the evidence-based reviews of the clinical effectiveness and cost-effectiveness of cancer drug products conducted by the CADTH pan-Canadian Oncology Drug Review and the input provided by patient advocacy groups and jurisdictions. Included in the committee are three patient members who have personal experience with cancer and have developed a deep understanding of the treatment and care of cancer.

CADTH's Board of Directors also has two public members in addition to jurisdictional, health systems, and academic members. The Board provides the strategic direction to guide CADTH's success as the Canadian "go-to" provider of evidence and advice on the use of drugs and other health technologies.

#### Considerations

In response to a call for members, interested individuals must apply to a selection committee and demonstrate how they meet core competencies. All members to the committees need to have a good understanding of health technology assessment to meaningfully engage in the deliberations. They need to be able to act with integrity, independent of specific interests, and be able to respect a diverse range of values and beliefs.

Terms last for two or three years, with monthly full-day, in-person meetings and extensive preparation required. All members receive an honorarium. Biographies of current expert committee members are available on the CADTH website.

#### Outcome

In all committees, public or patient members are active participants with committee responsibilities and voting rights. The public and patient members have the respect of their fellow committee members and participate in deliberations. They offer new insight to explore, contradict, or confirm assumptions held by others at the table. Alongside other expert committee members, the patient and public members consider patient perspectives, explore patient needs in relation to public values, and consider how patient needs are reflected in the clinical trial evidence.