Questions & Answers
CCAN Code of Conduct Governing Corporate Funding

CCAN Drug Review Working Group

This document accompanies the *CCAN Code of Conduct Governing Corporate Funding* (the Code) for CCAN member organizations.

Question 1:
Why was the Code developed?

Answer:
The Code was developed to demonstrate the commitment of CCAN and its member organizations to adhering to consistent and transparent policies regarding corporate funding. As CCAN works to strengthen the patient voice in areas such as drug review processes, it is essential that CCAN member organizations are recognized as being credible, independent sources of information and opinion.

Question 2:
How does the Code help to establish the credibility of CCAN member organizations?

Answer:
The Code helps to achieve three main objectives:

1. To support CCAN member organizations in asserting and maintaining their independence from commercial influences.
2. To clarify the position of CCAN member organizations to entities with whom they have business relationships, and to the wider public.
3. To visibly bring CCAN member organizations who may make patient submissions to the same level of transparency and ethical conduct as other participants in the pCODR process.

Having a consistent code of conduct is becoming standard practice for patient organizations worldwide. Indeed, the CCAN Code was modelled after established patient organization codes in Europe and around the world. To date, Canada has not had a code of practice for patient organizations.

Similar codes are common among industry and government stakeholders. For example, the pan-Canadian Oncology Drug Review (pCODR) and other drug review bodies in Canada require that patient groups making submissions about a drug under review adhere to many of the policies in the CCAN Code. The pCODR Secretariat has indicated that a code of conduct would carry significant weight within that organization. The pharmaceutical industry also is bound by company-specific and industry-wide codes of conduct.

Question 3:
Who is the CCAN Code intended for?

Answer:
The CCAN Code is provided by CCAN for use by its member organizations. All member organizations are encouraged to adopt the Code. All CCAN staff are required to sign the Code.

Question 4:
Why is the Code optional for CCAN member organizations?

Answer:
The Code requires member organizations to adhere to specific behaviours, some of which may be new to them. Organizations may need time to adjust to these requirements.

Also, some member organizations may not be in a position to adhere to the Code. For example, it may not be possible for a start-up patient organization to meet the requirement that no more than 50 per cent of sponsorship (financial or in-kind) be from a single source. Over time, however, the organization could work towards this goal.

Question 5:
How was the Code developed?

Answer:
The Code was developed by the CCAN Drug Review Working Group in response to concerns expressed by the pan-Canadian Oncology Drug Review (pCODR) and other stakeholders (Ontario Public Drug Programs (OPDP), Canadian Agency for Drugs and Technologies in Health (CADTH)) about the financial relationships between patient groups making submissions to the review process and the companies that manufacture the drugs under review.

The Code was based on that of the European Cancer Patient Coalition (ECPC). It was also informed by:

- the codes of the International Association of Patient Organizations (IAPO) and the Canadian Cancer Society;
- the requirements of drug review processes across Canada (pCODR, Ontario Public Drug Programs, BC Pharmacare, Canadian Agency for Drugs and Technologies in Health (CADTH)); and
- the pharmaceutical industry association (Rx&D) guidelines on stakeholder relationships.

The Code was approved by the CCAN Board in June 2011.

Question 6:
How will the Code be enforced?

Answer:
CCAN will not have a formal enforcement process. Member organizations will be invited to recommit by signing onto the Code annually. The CCAN Secretariat will investigate potential violations that are brought to our attention.

The Code will be reviewed by CCAN annually to ensure that it remains up to date. The review process will consider CCAN member organization feedback and any changes to the codes of conduct of stakeholder organizations. Changes will be reviewed and approved by the CCAN Board.

Question 7:
When will the Code be implemented?

Answer:
The Code will be presented at the October 2011 Members Council meeting for endorsement. Members will be invited to sign the Code and renew their commitment annually at Members Council meetings.

Question 8:
The Code specifies that patient organizations must not promote a product, however a big part of our organization's activities is advocacy for new drugs. Also, for some cancers there is only one drug treatment, so we cannot avoid speaking about the value of a specific medication.

Answer:
"Promotion" is defined as endorsing a specific brand-name product. A patient organization that promotes a product lends its own credibility and the trust of its constituents to the brand. As a result, patients may be more likely to consider using the product.

Situations where patient organizations are in a position to potentially promote a product are:

a) Recognizing the financial contributions of a corporate funder
b) Providing product information intended for patients and the public (on a website or in a brochure, for example)
c) Advocating for a particular drug to be approved or funded.

<u>a) Corporate recognition</u>
Funders of projects of sponsorships (categories 1.1 and 1.2 in the Code) are recognized at the corporate and not the product level. For example, the patient organization and the funder may agree to place the company's corporate logo on signage for a meeting, or on a brochure

produced with the funds provided. However, the appearance of a product logo would constitute promotion.

b) Product information

An important role of patient organizations is to raise awareness about new treatment options (which may include specific drugs or other technologies) and to provide factual and balanced information on the place of a new treatment in therapy. Patient organizations are not in a position to recommend a specific treatment to a patient or to suggest that one treatment is preferable to others.

To reduce the perception of promotion, patient organizations are encouraged to communicate information about all new drugs and other forms of treatment in a consistent and objective manner. Also, the organization may wish to include a disclaimer on their website to the effect that the information is provided for educational purposes only and that patients should speak to their doctor about treatment options.

c) Advocacy

Advocacy activities, such as making patient submissions for drug reviews or petitioning governments to fund a particular drug, are not considered promotion because these activities are intended to improve access to the treatment, rather than recommend that it be prescribed. Information presented by patient organizations objectively communicates the value that patients place on the specific treatment, from their own perspectives, compared to standard treatment regimens.

Many patient organizations appeal to the news media to garner public attention to the need for approval or funding of a particular treatment. To avoid being promotional, messages intended for the news media should speak to the need for access to the treatment and its potential value to a patient population, but should not recommend a specific treatment. For example, “We advocate that the government funds Drug A, because it has been proven to be a potentially valuable treatment option for patients with cancer B. We believe that oncologists should be able to prescribe this medication for all patients who may benefit.” In contrast, a promotional statement would be: “We advocate that the government funds Drug A, because we believe it is the best option for patients with cancer B.”

To ensure that patient submissions and other advocacy activities are not perceived as being promotional, the following guidelines should be followed.

- Information presented to drug review bodies should be presented as:
  - based on evidence and not opinion
  - representative of the experiences and perspectives of as a broad a patient population as possible
  - addressing topics that are relevant to the review process
- Drugs and other technologies should be referred to by their class whenever possible (for example, all drugs with the same mechanism of action, all diagnostic procedures or surgical treatments using the same technology). If a specific product is mentioned, its generic name should be used first, followed by the brand name. The intent of including the brand name is to make the communication clearer and this usage does not connote promotion of a particular product.