## Consultation on Appropriate Prescribing and Use of Medications in Canada

English Français (Canada)

## **Consultation Questions**

- 1. Overall, I am satisfied with the interim report.
  - Strongly agree
  - Agree
  - Neither agree nor disagree
  - Disagree
  - Strongly disagree
  - Not sure
  - Prefer not to answer
- 2. Appropriate use, as defined in the interim report, is a priority.

"Appropriate use refers to patients receiving medications appropriate to their clinical needs, in doses that meet their individual requirements, for an adequate period of time, in order to provide the greatest possible benefit, and at the lowest cost to them, their community, the health system and the broader environment."

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Not sure
- Prefer not to answer
- 3. Is anything missing from the overall approach outlined in the interim report?

The Canadian Pulmonary Fibrosis Foundation (CPFF) supports the proposed pillars for a pan-Canadian strategy as well as the proposed program areas for a Canadian Drug Agency. We would add too that these pillars and program areas recognize the nuances of the appropriate use of medicines for rare diseases, including those for pulmonary fibrosis.

4. What role(s) do you think you or your organization will play in the strategy?

The CPFF is a registered Canadian charity established in 2009 to provide answers, hope and support for people affected by pulmonary fibrosis (PF). It

educates and raises awareness about PF; raises funds to invest in research; and represents Canadians affected by PF to governments, healthcare professionals, the media and the public.

PF is a chronic lung disease that makes it progressively harder to breathe. There is no cure, and the prognosis is worse than many types of cancer (with a median survival as low as 5 years). PF is a rare disease.

As an organization primarily focused on supporting people living with and caring for people living with PF, the CPFF is well positioned to provide Health Canada, the Appropriate Use Advisory Committee, and the Canadian Drug Agency policy recommendations around the nuances associated with prescription drugs for rare diseases. This would include convening PF patients and caregivers to inform policy around prescription drugs for rare diseases, providing feedback on the way people living with PF prefer to receive information about their prescription drugs, and sharing data and other insights related to PF prescription medications.

- 5. Are there partners to include in the dialogue that are not represented in the strategy and report (page 11)? (please be as specific as possible)
- 6. How should the proposed pillars be prioritized? (Please rank, with 1 being the most important)

	1	2	3	4	5
Program Design, Implementation & Delivery				X	
Collaboration			X		
Policy		X			
Research and Results	X				
Build, Share, Use Data and Technologies					X

7. Based on the program functions presented, what advice would you offer to a Canadian Drug Agency looking to implement an appropriate use program?

The CPFF recommends that any appropriate use program recognize the challenges faced by people using prescription drugs for a rare disease. People living with a rare disease like pulmonary fibrosis often have unique challenges, including access to the drugs, affordability, side effects, and drug information.

8. Is there any other feedback you would like to provide on the interim report?

The CPFF asked people living with PF their thoughts on the challenges they face regarding the prescription drugs they take. The survey responses received clearly indicate the need for:

- Improved local access to prescription drugs for PF
  - Responses indicated challenges related to having to travel to pick up prescription drugs
- Provincial coverage of prescription drugs for PF
  - The cost of particular PF drugs is prohibitive for many unless covered by provincial formularies or private coverage
- Information to help people living with PF manage the side effects of their prescription drugs
  - Respondents want to receive this information from their primary care provider to help manage the side effects of their prescription drugs, including nausea, loss of appetite, etc.

## **Demographic Questions**

- 1. In what province or territory do you reside?
  - Alberta
  - British Columbia
  - Manitoba
  - New Brunswick
  - Newfoundland and Labrador
  - Northwest Territories
  - Nova Scotia
  - Nunavut
  - Ontario
  - Prince Edward Island
  - Quebec
  - Saskatchewan
  - Yukon
  - Prefer not to answer

- 2. Within the context of appropriate use, how would you identify your primary interest? (select the response that best applies)
  - Patient
  - Caregiver
  - Member of the public
  - Clinician/prescriber
  - Other health professional
  - Health profession association worker
  - Researcher
  - Pharmaceutical industry member
  - Insurer
  - Indigenous health provider
  - Equity-seeking community member
  - Health administrator
  - Policy analyst
  - Health charity worker
  - Provincial/territorial official
  - Federal government official
  - Appropriate use program/initiative leader
  - Other: The CPFF is a patient organization
  - Prefer not to answer

## **Submit**

If there are any changes you would like to make to your responses, please make them now before you click the "Submit" button below.

In order for your feedback to be considered, you must click "Submit".