

Optimizing Access to Care for Patients with Idiopathic Pulmonary Fibrosis

What is best? What is feasible?

A multi-stakeholder National Forum

SoHo Metropolitan Hotel

318 Wellington St W,
Toronto, ON

Monday, April 25th, 2016

08:00 to 17:00

In October 2015, we held the first Canadian consensus discussion that led to provisional recommendations regarding special considerations for policy-making and healthcare decision-making for interventions in patients with idiopathic pulmonary fibrosis (IPF).

These draft recommendations, created by representatives of patients, informal caregivers, and physician care providers, and based on an examination of evidence and current international considerations for IPF and other rare diseases, will now be the basis of this roundtable discussion.

This National Forum brings together a group of 30-40 societal representatives including policymakers and health system administrators, experts in technology assessment, as well as patients, formal and informal care providers, and others who may be impacted by future IPF policy.

The **objectives** of this roundtable are to:

1. **Discuss** the need for patient-led policy recommendations and a patient charter, given recent developments in other countries.
2. **Explore** aspects of care that are most valuable to patients, and how these align with policy objectives.
3. **Discuss** the feasibility of draft recommendations to policymakers regarding the minimum set of factors that should be considered when implementing treatment programs for IPF (e.g., use of stopping rules, education, multidisciplinary care) as well as criteria needed for policy decision-making.

The session will be invitation-only and conducted using Chatham House rules. There will be a summary of key points raised at the meeting that will be prepared but these will be non-attributable to allow for open dialogue during discussions. We hope the discussion will be iterative with reflection back of key points raised during the dialogue.

AGENDA

Start	End	Activity	Lead
08:00	09:00	Breakfast	<i>Moderator: Chris Henshall</i>
09:00	09:20	Opening and Opening Remarks	Mehmood Alibhai, B-I Don Husereau, IHE
09:20	11:00	<p>Healthcare policy and idiopathic pulmonary fibrosis: Values of patients and society – shared interests? Do we need recommendations/ a charter?</p> <p><i>Speaker: Robert Davidson, President, Canadian Pulmonary Fibrosis Foundation</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> • Nicola Cassidy [remotely], Irish Lung Fibrosis Association • Chris Ryerson [remotely], University of British Columbia • Bill Tholl, HealthCareCan <p>Questions and Answers from Audience</p>	<i>Moderator: Chris Henshall</i>
11:00	11:30	BREAK	
11:30	12:30	<p>What do patients value and what needs to be considered?</p> <p><i>Speaker: Meena Kalluri</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> • Durhane Wong-Reiger, CORD • Clarys Tirel, Ontario Lung Association • Samantha Reed, Informal caregiver <p>Directed discussion with first session panelists</p> <p>Questions and Answers from Audience</p>	<i>Moderator: Chris Henshall</i>
12:30	13:30	LUNCH	
13:30	15:00	<p>How can we make this work?</p> <p><i>Speaker: Martin Kolb, Professor, Division of Respiriology, Department of Medicine, McMaster University</i></p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> • Genevieve Tremblay, Quebec Lung Association • Kevin Wilson, Saskatchewan • Don Husereau, IHE • Barbara Barr, Patient 	<i>Moderator: Chris Henshall</i>
15:00	15:15	BREAK	

15:15	16:45	<p>Recommendations and a charter for policymakers and health service administrators: Feasible and relevant?</p> <p><i>Speaker:</i> Kathryn McGarry, MPP, Ontario</p> <p><i>Panelists:</i></p> <ul style="list-style-type: none"> • Gillian Bethel, MOHLTC, Ontario • Amy Henderson, Canadian Lung Association • Fiona Clement, University of Calgary 	<i>Moderator:</i> Chris Henshall
16:45	17:00	Wrap Up and Next Steps	<i>Moderator:</i> Chris Henshall Don Husereau , IHE

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