Optimizing access to care for patients with idiopathic pulmonary fibrosis: A multi-stakeholder national forum

Summary report and recommendations for policy-making

October 2016

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA

CANADIAN PULMONARY FIBROSIS FOUNDATION

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The Canadian Pulmonary Fibrosis Foundation (CPFF) is a registered Canadian Charitable Foundation established to provide hope and support for people affected by pulmonary fibrosis. Robert Davidson, president of the CPFF, created the organization in 2009 to raise money to find causes and treatments for PF, provide education and support for people affected by pulmonary fibrosis, and help answer those non-medical questions frequently asked by those suffering with the disease. The CPFF is a not-for-profit charitable organization.

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The forum, hosted by the Institute of Health Economics (IHE)
in partnership with the Canadian Pulmonary Fibrosis Foundation (CPFF),
was supported by an unrestricted grant from Boehringer Ingelheim (Canada) Ltd./Ltée.

Preface

The Institute of Health Economics (IHE; *www.ihe.ca*), in partnership with the Canadian Pulmonary Fibrosis Foundation (CPFF), held a forum on April 25th, 2016 in Toronto, Ontario, entitled *Optimizing access to care for patients with idiopathic pulmonary fibrosis: A multi-stakeholder national forum*, to discuss the need for patient-led policy recommendations and a patient charter for idiopathic pulmonary fibrosis (IPF), given recent developments in other countries. The forum participants also explored aspects of care that are most valuable to patients, and how these align with current policies. The forum was supported by an unrestricted grant from Boehringer Ingelheim (Canada) Ltd./Ltée.

The forum included about 30 participants, ranging from policymakers and health system administrators, experts in health technology assessment, patients, and care providers, who gathered to discuss previously drafted evidence-informed policy recommendations on IPF. These recommendations were developed by a smaller group of patients and caregivers in Fall 2015.

Please note that this document represents a summary reflection of issues raised by participants, and **does not necessarily represent a consensus view** of the participants or of the organizations involved.

The presentations and background material for this meeting can be found online at: *www.ihe.ca/research-programs/knowledge-transfer-dissemination/roundtables/ipfnf/about-ipfnf*.

Please direct any inquiries about this report to Don Husereau, Senior Associate, Institute of Health Economics, at *dhusereau@ihe.ca*.

THE STRUCTURE OF THE FORUM WAS AS FOLLOWS:

Moderator: Chris Henshall

PART I: Healthcare policy and idiopathic pulmonary fibrosis: Values of patients and society – shared interests? Do we need recommendations/a charter?

Speaker: Robert Davidson, President, CPFF

Panelists: - Nicola Cassidy [remotely], Irish Lung Fibrosis Association (ILFA)
- Chris Ryerson [remotely], University of British Columbia
- Bill Tholl, HealthCareCan

PART II: What do patients value and what needs to be considered?

Speaker: Meena Kalluri, Assistant Professor, Division of Pulmonary Medicine, Faculty of Medicine, University of Alberta, and IPF Specialist Physician

Panelists: - Durhane Wong-Rieger, Canadian Organization for Rare Disorders
- Clarys Tirel, Ontario Lung Association (OLA)
- Samantha Reed, Caregiver

PART III: How can we make this work?

Speaker: Martin Kolb, Professor, Division of Respirology, Department of Medicine, McMaster University, and IPF Specialist Physician

Panelists: - Genevieve Tremblay, Quebec Lung Association (QLA)
- Kevin Wilson, Ministry of Health, Saskatchewan
- Don Husereau, IHE
- Barbara Barr, Patient

PART IV: Recommendations and a charter for policymakers and health service administrators: Feasible and relevant?

Speaker: Kathryn McGarry, MPP (Cambridge), Ontario

Panelists: - Gillian Bethel, Ministry of Health and Long-Term Care (MOHLTC), Ontario
- Amy Henderson, Canadian Lung Association (CLA)
- Fiona Clement, University of Calgary

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Table of Contents

Background

The need for IPF-specific recommendations

Idiopathic pulmonary fibrosis (IPF) is a disease characterized by loss of health-related quality of life and premature mortality. There are several reasons that IPF patients may warrant special considerations for healthcare policy-making. Firstly is the low number of identifiable people diagnosed with the illness. Although the exact number of Canadians with IPF (that is, disease prevalence) is unknown, best estimates of the number of Canadians with established disease, based on international studies, range from 6,822 to 14,259 Canadians, or an estimated 10 to 25 per 100,000 of the existing population.[1] This makes IPF a rare disease, or consistent with more common international definitions of rare disease that use a threshold between 40 and 50 cases per 100,000 people (global average was 40 per 100,000 people).

A second factor that may warrant special consideration is the severity of the disease and lack of available treatment options, factors that Canadian and international studies of social values have shown the public values.[2] These factors are also considered by licensed product (that is, Health Canada) and reimbursement (that is, Common Drug Review) regulators when deciding to create special priority for reviews and, ultimately, access to care. The rapid loss of function and rapid mortality from IPF also makes this disease similar to many cancers, requiring intensive treatment and palliative therapy with considerations of end-of-life care. Current data suggests that 50% of patients die, usually from lung failure, between two and five years from the time of diagnosis, with younger patients typically surviving longer.[3]

Toward patient-led policy-making recommendations

In October 2015, we held the first Canadian roundtable discussion that led to provisional recommendations regarding special considerations for policy-making and healthcare decision-making for interventions in patients with IPF.[4] The meeting included 11 representatives of key

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[1] R. B. Hopkins et al., "Epidemiology and survival of idiopathic pulmonary fibrosis from national data in Canada," *Eur. Respir. J.* 48 (2016): 187-95.

[2] Nick Dragojlovic et al., "Challenges in measuring the societal value of orphan drugs: Insights from a Canadian stated preference survey," *The Patient* 8, no. 1 (2015): 93-101, doi:10.1007/s40271-014-0109-5; Warren G. Linley and Dyfrig A. Hughes, "Societal views on NICE, cancer drugs fund and value-based pricing criteria for prioritising medicines: A cross-sectional survey of 4118 adults in Great Britain," *Health Economics* 22, no. 8 (August 2013): 948-64, doi:10.1002/hec.2872; Emmanouil Mentzakis, Patricia Stefanowska, and Jeremiah Hurley, "A discrete choice experiment investigating preferences for funding drugs used to treat orphan diseases: An exploratory study," *Health Economics, Policy, and Law* 6, no. 3 (July 2011): 405-33, doi:10.1017/S1744133110000344; Arna S. Desser, Jan Abel Olsen, and Sverre Grepperud, "Eliciting preferences for prioritizing treatment of rare diseases: The role of opportunity costs and framing effects," *PharmacoEconomics* 31, no. 11 (November 2013): 1051-61, doi:10.1007/s40273-013-0093-y; Arna S. Desser et al., "Societal views on orphan drugs: Cross sectional survey of Norwegians aged 40 to 67," *BMJ* (Clinical Research Ed.) 341 (2010): c4715.

[3] Brett Ley and Harold R Collard, "Epidemiology of idiopathic pulmonary fibrosis," *Clinical Epidemiology* 5 (November 25, 2013): 483-92, doi:10.2147/CLEP.S54815; American Thoracic Society and others, "Idiopathic pulmonary fibrosis: Diagnosis and treatment. International Consensus Statement," 2000, *http://dspace.iss.it/srdspace/handle/2198/930*.

[4] For more information on the October 2015 roundtable, see *http://www.ihe.ca/research-programs/knowledge-transfer-dissemination/roundtables/oacpipf/about-oacpipf*.

stakeholders: patients, care providers, and policy researchers from across Canada. The purpose of the meeting was to discuss the current state of evidence and information regarding IPF. This led to draft recommendations for policymakers and healthcare administrators who must make purchasing or reimbursement decisions regarding the care and treatment of patients with IPF.

Participants first discussed factors that require consideration when implementing service for IPF patients. The following key factors were identified:

- There are many important considerations for IPF that are not specific to IPF, and apply to other degenerative, chronic, and fatal conditions (such as amyotrophic lateral sclerosis [ALS], cystic fibrosis, and cancer) that also require a focus on palliation and providing end-of-life support as well as symptom management.
- Unlike other similarly debilitating diseases, there may be less awareness of the severity of IPF as well as less available resources, compared to these other diseases.
- An important consideration is the value of integrated care approaches, especially as it is convenient for patients and can improve patient experiences through providing effective patient navigation, improving diagnostic accuracy (and reducing unnecessary utilization of services, including new interventions), improving specialist productivity, and creating a platform for standardized approaches to care.
- Given the above, any new intervention for IPF has the potential to be more effective and cost-effective in the context of a multidisciplinary team.
- Because of considerable uncertainty regarding emerging and existing treatments, it is important to consider how to collect information on an ongoing basis, in order to best revisit past decisions and re-assess available interventions.

The draft recommendations were based on an examination of evidence and current international considerations for IPF and other rare diseases, and have now become the basis of the development of a "Canadian Patient Charter" and the basis of this national forum. The draft recommendations for policymakers can be found at: *www.ihe.ca/publications/optimizing-access-to-care-for-patients-with-idiopathic-pulmonary-fibrosis-summary-report-and-draft-recommendations*.

National Forum

Objectives

The stated objectives of the national forum in April 2016, as shared with forum participants, were as follows:

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 (for example, use of stopping rules, education, multidisciplinary care), as well as criteria needed for policy decision-making.

A summary reflection of issues raised by participants at the national forum is found below; it does not necessarily represent a consensus view of the participants or of the organizations involved.

Themes emerging from discussion

The need for recommendations and a patient charter

- A patient charter is a needed and useful tool to raise awareness about IPF and provide strategic objectives and guidance to those working locally. Ultimately, a charter speaks to national or pan-Canadian policy objectives.
- Recommendations drafted here may be more useful on a local or regional level of healthcare delivery. It may be useful to further develop an action plan that addresses more regional needs and objectives.
- Policymakers require evidence at both national and local levels to support required action in IPF. This highlights the importance of using existing evidence and creating new evidence (for example, through patient registries) regarding burden of illness and the effectiveness of available interventions.
- Specific goals that relate to optimizing health care for those with IPF may extend beyond IPF, as IPF is part of a broader set of chronic respiratory diseases. The best fit for a charter, policy recommendations, and an action plan must consider current policy priorities. On the other hand, IPF as a disease has many unique features, which will require special consideration.

What do patients value and what needs to be considered?

- In addition to the considerations outlined in the objectives (for example, measures of clinical benefit, consideration of severity, and availability of alternatives), patients ultimately value care that is patient-centered and well-coordinated. In Canada, there are still many examples of care in IPF that are not well-coordinated.
- When care is not sufficiently patient-centered, patients must act as agents of change. This requires collective action through organized advocacy, including working with local care deliverers, as well as provincial and national thoracic societies and lung associations.
- All activities related to advocacy still require compelling evidence that quality or approaches to care are lacking.

How can we make this work?

- The first challenge for policy-making is to provide consistent access to care across provinces while considering the fair allocation of resources. This highlights the role of promoting communication across care centres and physicians, and of supporting and promoting standards of care.
- The willingness on behalf of patients to consider various options is useful. Patients should also be encouraged to recognize the multiple and various structures involved with delivery of care and how they can feed into this.
- Allocation of scarce healthcare resources may sometimes lead to discussions of limits to care. Although there may be alternatives to limits, these will depend on what aspect of care is being delivered. For example, limits to lung transplants (available lungs and capacity to

transplant) may have different evidence-based solutions than limits to rehabilitation, oxygen, or pharmaceuticals.

- Successful patient advocacy requires developing education and tools for patients so that they are empowered. Patient empowerment may require efforts to educate the public before they become patients. Patients' stories are not enough, but without them nothing happens.
- There may be opportunities for producing better evidence in Canada through policy approaches that consider gathering more evidence to assess the impact of decisions.
- Feasible and relevant recommendations and patient charter for policymakers and health service administrators.
- Ultimately, good patient-centered care requires patients to help prioritize what services are necessary and to work along with lung associations, patient associations, and professional societies to send a consistent message. It requires champions.
- Good patient-centered care also requires patients to become more involved with evaluating the impact of policy-making. Patients may have opportunities to shape the use and analysis of real-world evidence, particularly through clinician-led registries.
- There is still a notable lack of a "lung disease strategy" in Canada, despite the excessive morbidity represented by lung disease. There are commonalities faced by patients with IPF and other lung diseases that are important to recognize.

Final Recommendations

Based on the draft recommendations from the October 2015 roundtable, and the discussion emerging from this meeting, the following final recommendations resulted from the national forum. They include the following considerations for policymakers who are making decisions related to the delivery of services for IPF patients:

1. **What information needs to be considered?**

   At minimum, policymakers should consider clinical benefit, patient experiences and values, severity/morbidity of the disease (including premature death), and availability of alternatives.

2. **How should this information be considered?**

   When considering information, consultation during health technology assessments (HTAs) or other processes intended to support payers with a wider range of stakeholders should take place, including patients, caregivers, and physicians.

3. **How should decisions be implemented?**

   When implementing decisions, consideration should be given to alternatives to starting and stopping rules, and compelling evidence should be considered to support limits to care. Policymakers should also consider integrated care centres and dedicated IPF sub-specialists for delivery of services related to IPF.

The final recommendations, which are criteria presented as a checklist and series of questions to guide decision-making, appear in Table 1, along with a brief rationale for each. Further details for each recommendation can be found after the table.

TABLE 1: Checklist for policymakers

#	Recommendation	Question	Rationale
1.	**What information needs to be considered?**		
	Clinical benefit		
	Health-related quality of life	How does the new treatment affect the way that patients feel and function? Is the measure to determine this effect valid?	• IPF has dramatic impact on HRQL • There are no gold standard measures
	Quality of death and dying	Does the new intervention improve the many dimensions of the experience of dying that go beyond simple control of physical distress?	• IPF is a fatal disease and requires consideration beyond HRQL
	Effect on survival and disease progression	Does the treatment likely affect survival or reliable measures of disease progression?	• IPF is a fatal disease and patients and caregivers value longer survival
	Patient experiences and values	Was the current experience with the disease (as told by patients) and what patients would value with a new treatment considered?	• IPF is not well understood
	Severity/morbidity of the disease, including premature death	Do decisions regarding policies that affect the management and treatment of IPF consider the life-threatening nature of the illness?	• Diseases that are significantly life-threatening warrant special consideration
	Availability of alternatives	Do decisions regarding policies that affect the management and treatment of IPF consider the number of available alternatives?	• There are few alternatives to effectively treat IPF • Lung transplant is the only treatment that can prolong survival
2.	**How should this information be considered?**		
	Wider consultation with stakeholders	Were key stakeholders, including patients, caregivers, and physicians consulted regarding policies that affect the management of IPF?	• IPF is a complex disease to manage • Caregivers, often family members, and patients may have special insights
3.	**How should decisions be implemented?**		
	Avoid starting and stopping rules for rationing service	Is a stopping rule being considered?	• Stopping rules may have a significant negative impact on patients with a terminal condition • There are viable alternatives to stopping rules
	Consider integrated care centres and dedicated IPF sub-specialists for delivery	Are new policies that affect the management and treatment of patients considering how and where care will be delivered?	• Integrated care centres as a means of reducing inappropriate utilization through improved diagnostic accuracy, and as a potential means to increase the effectiveness (and cost-effectiveness) of treatment

Rationale for specific recommendations

When deciding on whether to fund new goods and services (that is, innovative products, processes, or approaches to care) for patients with IPF, healthcare policymakers should consider using the following criteria.

1. What information needs to be considered?

Clinical benefit

- Health-related quality of life
    - How does the new treatment affect the way that patients feel and function?
    - Is the measure to determine this effect valid?
- Quality of death and dying
    - Does the new intervention improve the many dimensions of the experience of dying that go beyond simple control of physical distress?
- Effect on survival and disease progression
    - Does the treatment likely affect survival or reliable measures of disease progression?

Rationale: Studies that have explored what experiences and outcomes are important to patients have identified several emerging themes regarding how IPF negatively impacts quality of life. This includes frustration with diagnosis and management of care, a lack of information about their disease, negative perception from decreased libido or inability to continue sexual activity, reduced independence and the need to rely on friends and family, difficulties with carrying on relationships, and financial concerns with a diminished ability to work.[5]

Patient input on new drug applications to the Canadian Agency for Drugs and Technologies in Health (CADTH), gathered by the Canadian Pulmonary Fibrosis Foundation, similarly indicates these concerns. Patients have also acknowledged the limitations of existing treatments and the need for a treatment that will meaningfully slow the progress of disease in the absence of a cure.[6] All respondents to a survey of 217 Canadian IPF patients and caregivers indicated they hoped to slow the progression of the disease to allow them greater quality of life. This is also consistent with other formal studies in the area, which indicate patient enthusiasm for trying new therapies, especially those that might change disease course.[7]

To capture how patients with IPF feel and function during the disease course, generic instruments that capture health-related quality of life (HRQL), such as the Short-Form-36 (SF-36) survey and Saint George's Respiratory Questionnaire (SGRQ), have been used and shown to be sensitive to

[5] Jeffrey J. Swigris et al., "Patients' perspectives on how idiopathic pulmonary fibrosis affects the quality of their lives," *Health and Quality of Life Outcomes* 3 (2005): 61, doi:10.1186/1477-7525-3-61.

[6] CADTH, Common Drug Review CDEC Final Recommendation - Pirfenidone resubmission. Notice of final recommendation, April 15, 2015.

[7] Amanda Belkin and Jeffrey J. Swigris, "Patient expectations and experiences in idiopathic pulmonary fibrosis: Implications of patient surveys for improved care," *Expert Review of Respiratory Medicine* 8, no. 2 (April 2014): 173-78, doi:10.1586/17476348.2014.880056.

changes in disease progression.[8] However, it has been increasingly recognized that these instruments may not be suitable for capturing all relevant information (that is, either quality of life "domains" or information that informs these), or may capture information that is not important to patients. Other disease-specific measures have been or are being developed but may require further validation; currently, there is no gold standard instrument for measuring impact on HRQL.

Given significant "knowledge gaps" associated with existing patient-reported outcome measures (such as the SGRQ),[9] there have been some attempts to develop IPF-specific measures that better capture relevant experience. While the SGRQ has been demonstrated to be "useful",[10] an SGRQ instrument modified to more directly measure experiences in IPF patients has been developed.[11] Another tool, A Tool to Assess Quality of Life in Idiopathic Pulmonary Fibrosis (ATAQ-IPF), has also been developed,[12] and validation across countries has been performed.[13]

Patient experiences and values

- Was the current experience with the disease (as told by patients) and what patients would value with a new treatment considered?

Rationale: The importance of patient and citizen involvement in health care and decision-making has grown in prominence. It is also well-identified and promoted in a number of WHO reports, including the Ottawa Charter[14] and disease-specific issues on malaria[15] and tuberculosis.[16] Participants in the October 2015 roundtable on IPF had noted that, unlike other similarly debilitating diseases, there may be less awareness of the severity of IPF as well as less available resources, compared to these other diseases.

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[8] J. A. Chang et al., "Assessment of health-related quality of life in patients with interstitial lung disease," *Chest* 116, no. 5 (November 1999): 1175-82.

[9] Jeffrey J. Swigris and Diane Fairclough, "Patient-reported outcomes in idiopathic pulmonary fibrosis research," *Chest* 142, no. 2 (August 2012): 291-97, doi:10.1378/chest.11-2602.

[10] Jeffrey J. Swigris et al., "The psychometric properties of the St George's Respiratory Questionnaire (SGRQ) in patients with idiopathic pulmonary fibrosis: A literature review," *Health and Quality of Life Outcomes* 12 (2014): 124, doi:10.1186/s12955-014-0124-1.

[11] Janelle Yorke, Paul W. Jones, and Jeffrey J. Swigris, "Development and validity testing of an IPF-specific version of the St George's Respiratory Questionnaire," *Thorax* 65, no. 10 (October 2010): 921-26, doi:10.1136/thx.2010.139121.

[12] Jeffrey J. Swigris et al., "Development of the ATAQ-IPF: A tool to assess quality of life in IPF," *Health and Quality of Life Outcomes* 8 (2010): 77, doi:10.1186/1477-7525-8-77.

[13] Janelle Yorke et al., "Cross-Atlantic modification and validation of the A Tool to Assess Quality of Life in Idiopathic Pulmonary Fibrosis (ATAQ-IPF-cA)," *BMJ Open Respiratory Research* 1, no. 1 (2014): e000024, doi:10.1136/bmjresp-2014-000024.

[14] World Health Organization, *Ottawa Charter for Health Promotion* (Geneva, Switzerland: World Health Organization, 1986).

[15] World Health Organization, *Community Involvement in Rolling Back Malaria* (Geneva, Switzerland: World Health Organization, 2002).

[16] World Health Organization, *The ENGAGE-TB Approach: Operational Guidance Integrating Community-Based Tuberculosis Activities into the Work of Nongovernmental and Other Civil Society Organization* (Geneva, Switzerland: World Health Organization, 2012).

Severity/morbidity of the disease, including premature death

- Do decisions regarding policies that affect the management and treatment of IPF consider the life-threatening nature of the illness?

Rationale: IPF is a fatal condition with no cure (other than lung transplantation) or treatments to stop disease progression. The disease course is rapid with distressing symptoms of dyspnea, and 50% of patients die within four years of diagnosis. There is considerable evidence to suggest society places an increased value on improvements in health for relatively fatal illnesses.

Availability of alternatives

- Do decisions regarding policies that affect the management and treatment of IPF consider the number of available alternatives?

Rationale: There are no available alternatives shown to prolong survival, other than lung transplantation. Some pharmacological therapies have been shown to alter disease course. Lung transplantation remains the single evidence-based option for prolonging survival in patients with IPF. However, there are no formal evaluations of its cost-effectiveness. There are similarly no economic evaluations of other non-drug approaches to care, including how care is delivered and organized (that is, through specialty clinics), or the use of disease management programs, education, and other supportive measures.

2. How should this information be considered?

Wider consultation with stakeholders

- Were other key stakeholders, including patients, caregivers, and physicians consulted regarding policies that affect the management of IPF?

Rationale: Due to the complexity of the disease and evolving information regarding its treatment, dedicated sub-specialists and other care providers should be consulted in health technology assessments (HTAs) or other processes intended to support payers. Participants in the October 2015 roundtable had highlighted that the complex nature of the disease means consultation with experts (and patients) is required in order to avoid misapplying thinking from other diseases that appear to be but are not similar, such as COPD.

3. How should decisions be implemented?

Avoid starting and stopping rules for rationing service

- Is a stopping rule being considered?

Rationale: Stopping rules have sometimes been considered in lung and other degenerative disorders, when continuing treatment is considered medically futile.[17] Rules of futility are commonly employed in cancer therapy, when progression occurs despite active therapy. A common and accepted definition of futility requires an action that is virtually certain not to achieve a goal.[18] Scholars have further suggested virtual certainty means a small proportion (less than 5% or

[17] A. K. Simonds, "Ethics and decision making in end stage lung disease," *Thorax* 58, no. 3 (2003): 272-77.

[18] Deborah L. Kasman, "When is medical treatment futile?" *Journal of General Internal Medicine* 19, no. 10 (2004): 1053-56. doi:10.1111/j.1525-1497.2004.40134.x.

even 1%) of patients are likely to achieve the goal. [19] The American Thoracic Society, in a joint statement with other critical care physicians, suggests treatments that may not achieve their goal (in intensive care units) should not be recommended for patients.[20]

Assessing the need to continue treatment, while possibly viewed as necessary by policymakers from a point of rationing scarce resources,[21] means pre-emptively introducing discussions of end-of-life and palliative care that impinge on the autonomy of clinicians and patients.[22] With some interventions, such as oxygen and some drugs where there is clear evidence that a substantial proportion (that is, more than 5%) of people will still benefit even with functional decline that is predictive of poor prognoses,[23] continued treatment would be regarded as not futile. However, the threat to discontinue by re-assessment will most certainly have a negative psychosocial impact on patients and caregivers.

In these cases, alternatives to re-assessment at the end of life or stopping therapy should be considered unless there is clear and compelling evidence to support their futility. Policymakers should consider alternatives that do not require assuming unnecessary opportunity costs. Outcome-based risk-sharing arrangements are one potential alternative, which can be implemented through linking jurisdictional administrative data to an existing national registry (the Canadian Registry for Pulmonary Fibrosis [CARE-PF]). This will provide an opportunity to revisit decisions. Other alternatives may include limiting new treatments to narrow subpopulations who will receive the greatest societal benefit, or entering financial risk-sharing agreements that account for increased expenditure (and potential benefit) when a stopping rule is not applied.

Consider integrated care centres and dedicated IPF sub-specialists for delivery

- Are new policies that affect the management and treatment of patients considering how and where care will be delivered?

Rationale: New treatments should be restricted to dedicated sub-specialists or integrated care centres as a means of reducing inappropriate utilization through improved diagnostic accuracy, and as a means to increase the effectiveness (and cost-effectiveness) of treatment. Opportunities to fund these centres should be considered when negotiating prices for highly expensive treatments.

Next Steps and Concluding Remarks

The recommendations discussed in this forum are only a small part of a wider set of actions and strategies led by patients to optimize IPF care. While these recommendations may be helpful for local decision-making, empowering patients as well as developing a patient charter and other tools for promoting consistent delivery of services are necessary.

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[19] Ibid.

[20] Gabriel T. Bosslet et al., "An official ATS/AACN/ACCP/ESICM/SCCM policy statement: Responding to requests for potentially inappropriate treatments in intensive care units," *American Journal of Respiratory and Critical Care Medicine* 191, no. 11 (2015): 1318-30.

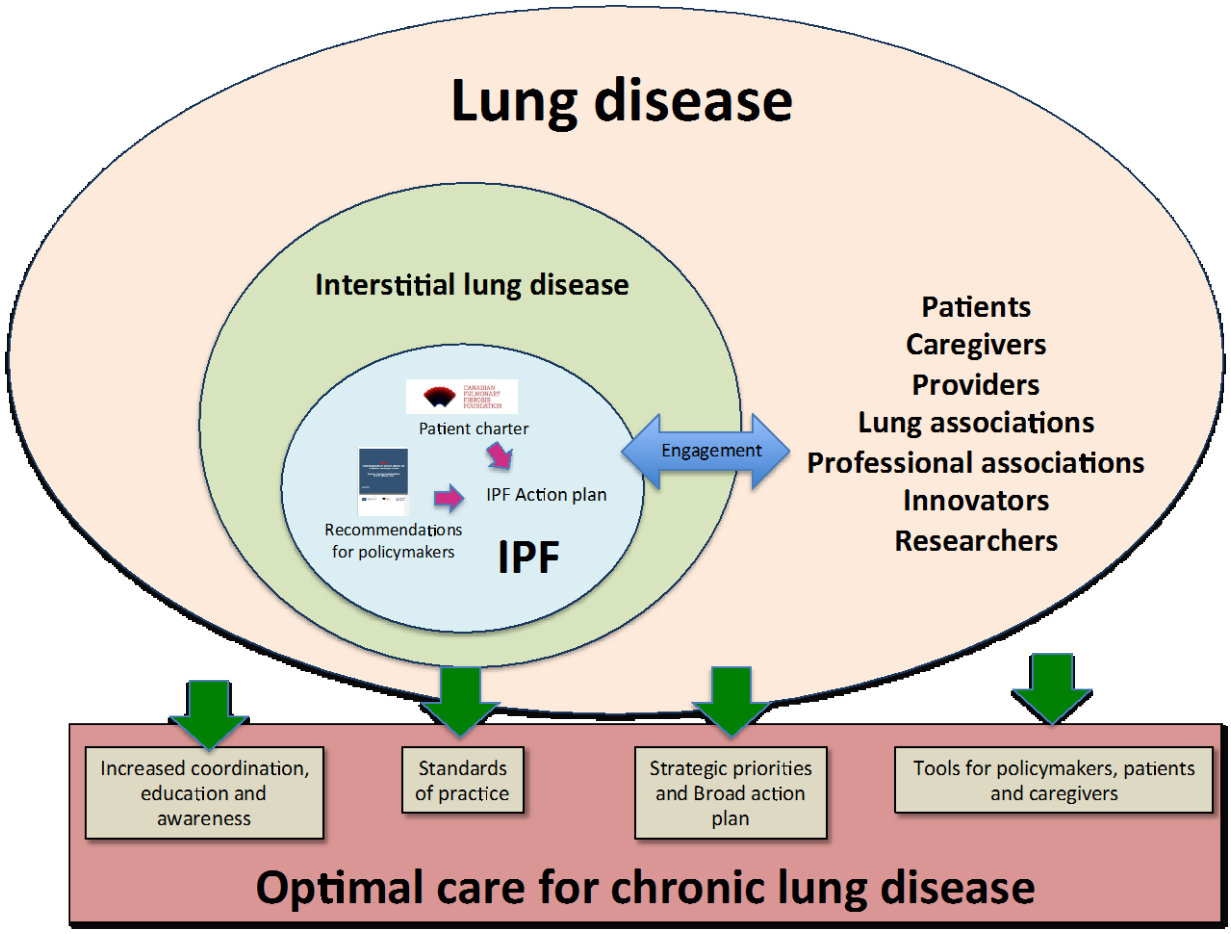
[21] Robert Fowler and Michael Hammer, "End-of-life care in Canada," *Clinical and Investigative Medicine* 36, no. 3 (2013): E127-32.

[22] Simonds, "Ethics and decision making in end stage lung disease."

[23] J. J. Egan, "Follow-up and nonpharmacological management of the idiopathic pulmonary fibrosis patient," *European Respiratory Review* 20, no. 120 (2011): 114-17.

Further to this, despite the unique nature of IPF, creating awareness and setting priorities that are relevant to policymakers must be done in the context of other lung diseases. A broader set of actions and priorities that addresses lung disease in Canada and allows for leveraging infrastructure dedicated to care of interstitial lung diseases (of which IPF is one) and lung disease more broadly may be necessary for truly optimizing IPF care (see Figure 1).

FIGURE 1: Optimizing IPF care requires an examination of lung disease priorities as a whole



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The Institute of Health Economics (IHE) is a non-profit Alberta-based research organization committed to producing, gathering, and dissemination evidence-based findings from health economics, health policy analyses, health technology assessment and comparative effectiveness research to support health policy and practice. Established in 1995, it is a unique collaborative arrangement among government, academia, and industry.

The IHE has a staff of 25 that includes health economists, health technology assessors, research methodologists and policy analysts, information specialists, and project and administrative personnel. The Institute is a member of the International Network of Agencies for Health Technology Assessment (INAHTA) and the World Health Organization's Health Evidence Network (WHO HEN) and is the secretariat for Health Technology Assessment International (HTAi) (www.htai.org).

The IHE regularly designs and conducts consensus development conferences and policy dialogues for provincial and national public and private sector organizations on a wide range of issues. More detailed information on the IHE is available on our website (www.ihe.ca).

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