

## Working Group – Improving care in progressive fibrosing ILD: the need for multidisciplinary guidelines informed by key stakeholders.

The following is a summary of Working Group discussions based on background information ([https://www.ihe.ca/public/uploaded/Background%20report\\_multidisciplinary%20care%20.pdf](https://www.ihe.ca/public/uploaded/Background%20report_multidisciplinary%20care%20.pdf)). This document is a description of issues and preliminary solutions identified by members but should not be interpreted as a consensus recommendation or an endorsement by all members of the Working Group.

### Working Group Members

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### Background and summary of issues discussed:

- Due to the complex nature of interstitial lung diseases, accurate diagnosis of progressive fibrosing interstitial lung diseases (PF-ILDs) requires input from a multidisciplinary team consisting of a respirologist with specific interest and training in PF-ILD, supported by regular multi-disciplinary discussion (MDD) meetings with consultant thoracic radiologist and pathologist (and potentially, rheumatologist), both with interest and experience in PF-ILD.<sup>1</sup>
  - This MDD approach to diagnosis is supported by international guidelines and a position statement issued by the Canadian Thoracic Society.<sup>2</sup>
  - MDD is often facilitated by a specialized interstitial lung diseases (ILD) program, typically a tertiary care centre with expertise in both diagnosis and management of ILD.<sup>3</sup>
  - Evidence from Canadian centres and abroad demonstrates that reducing the timing of referral to a tertiary centre with expertise in ILD significantly improves outcomes for patients.<sup>4-6</sup>
- While diagnosis and management of patients through ILD specialty centres is desirable for patients<sup>7</sup>, implementing this in practice represents significant challenges:
  - The non-specific nature of PF-ILDs means primary care physicians will appropriately refer patients to a community-based respirologist for further investigation.

- Referral to an ILD centre, then, is typically done by a community respirologist who must rule out more common respiratory diseases – wait lists in Canada for these specialists can take 6-12 months.
- Referral to an ILD centre can also be performed by a rheumatologist specializing in connective tissue disorder, rheumatoid arthritis or other autoimmune diseases associated with ILD – wait lists for rheumatologists can be >12 months.
- Due to the nature of the disease (e.g., shortness of breath), travelling from remote locations to a specialty centre, which can be desirable for appropriate diagnosis and management, may be challenging or not possible for patients and families.
- Some regions in Canada may additionally have delays associated with necessary workup – for example, chest CTs are required and need updating (after 12 months) but patients may face wait times in some provinces.
- Management of ILD patients can be complex, resource intensive, and with specific health human resource challenges.
  - There are few specialists trained in ILD, and financial barriers due to billing and licensing arrangements can make it difficult to train and license more physicians.
    - Furthermore, some highly specialized ILD doctors may also conduct research and need connection to academic research hospitals.
  - There is a relative lack of community-based rheumatologists outside of large urban centres. Connective tissue disorders and autoimmune conditions associated with PF-ILDs are also infrequently seen among rheumatologists, leading to less awareness and experience with the condition
  - Similarly, PF-ILD/ILD is less commonly seen by community-based respirologists, leading to less awareness and experience with diagnosis and management of the disease.
  - Patients with PF-ILDs may also require support from other care disciplines, including cardiothoracic surgeons and lung transplantation teams, occupational therapists, cardiologists, immunologists, palliative care experts, respiratory therapists, physiotherapists, and dietitians.
  - PF-ILD patients may also require or benefit from emergency department visits, hospitalization, oxygen and pharmacotherapy.
  - The complexity of these supports and specialist referral patterns and supports necessitates support for patients, optimally through nurse or patient care navigators.
- The multidisciplinary approach, while representing the gold standard in the diagnosis of ILD, is not always practicable in clinical practice due to the geographical distance between participants, lack of trained specialists or time constraints.

## Policy Options and Next Steps for Canada

Given these limitations, the group discussed desired conditions and approaches to organizing and providing care for patients with PF-ILD in the future. Some option identified by this Working Group included:

- **Awareness and resources for community-based respirologist**
  - There is no overwhelming consensus on tests and procedures leading up until diagnosis and treatment - Checklists could provide more specificity for community-based respirologists and would be helpful to inform MDD
  - There may be lack of education among community-based respirologists that the standard of care has changed (treatments available)
  - The increasing use of on-line referral (e.g., Ontario e-consult) platforms could be helpful to facilitate communication with academic ILD centres or MDD.
  - There may also be barriers to other specialists (like family docs) to be able to order certain tests
- **Training of PF-ILD/ILD specialists**
  - There is an increasing need for respirologists with specialized ILD training. Training 1-2 people per Canadian city might still not fulfill anticipated capacity.
- **Financing and reimbursement of healthcare**
  - The time commitment required by ILD specialists calls current fee-for-service arrangements into question. Alternatives include salaried physicians (as in Europe) or finance agreements that incorporate research.
  - Rearrangement of care to include virtual services or referral may require reconsideration of billing arrangements.
  - There is still a need to revisit oxygen reimbursement policies in some provinces as they have been designed for COPD patients.
  - Similarly, there is a need to revisit provision of palliative care services as they are largely designed for and delivered to cancer patients.
- **Organization of care**
  - Improving access then requires networks/partnerships between hospitals, community-based specialists and well-trained specialists. There is evidence from other disciplines involving complex care that shared-care models can be effective.<sup>8</sup>
  - Some form of “shared care” between hospitals/community-based specialists and specialized centres is one approach<sup>9</sup> – there is still little direct evidence of the impact of multidisciplinary care after diagnosis.
  - The need for virtual care and shared-care aligns with patient values – as travel to dedicated centres may be challenging or not possible.

## Implications for Further Research

These options constitute a “best guess” at an optimal approach for PF-ILD patients that considers the Canadian healthcare system structure, the preferences and values of Canadian patients and the availability and training of necessary specialists. Additional implementation and health services research required should address the following questions:

- 1. What are the referral pathways currently being developed or used for the evaluation of PF-ILD patients?**

While referral pathways in Canada have developed “organically” by jurisdiction, additional lessons could be learned through further literature review and nationwide survey of those currently delivering care.

- 2. How do optimal care pathways for patients with PF-ILD of autoimmune etiology align with current practice patterns for rheumatology specialists?**

The increasingly important role of connective tissue disorders and autoimmune diseases will require input of specialists in rheumatoid diseases.<sup>10,11</sup> Future effort should focus on identifying key opinion leaders in rheumatology (beyond scleroderma specialists) with an interest in defining a more comprehensive integrated care model

- 3. What referral pathways most align with patient values?**

Qualitative study of patients in regards to what values should be most highly considered when delivering care will be helpful in creating policy that more closely aligns with patient values.

- 4. Which aspects of care are most desirable and what else is needed (i.e., specialized training, availability of specialists, novel platforms (such as Ontario e-consult) to support optimized referral?**

Initial discussion and articulation of options from this Working group (above) suggest options for change that focus on awareness/tools, re-organization of care, and changes to reimbursement policy for goods and services. A larger multidisciplinary discussion, and working with a larger group of stakeholders, could identify further options or refine what is proposed here.

- 5. What processes are sustainable or of good economic value within the Canadian health system, that optimize outcomes for patients?**

While some initial work has been done to identify the costs associated with specialized centres, further work could be done to estimate the potential cost-effectiveness of optimized approaches.

- 6. What is the epidemiology of PF-ILD in Canada and how do geographic barriers (i.e. urban vs rural status) differentially impact the patient journey to diagnosis and treatment?**

The Working Group felt that equitable care may be lacking. However further research on the role of geography in providing optimal care could help shed more light on the issue.

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