

## Working Group – Exploring the optimal use of integrated care models for fibrosing interstitial lung diseases.

The following is a summary of Working Group discussions based on background information (<https://www.ihe.ca/public/uploaded/Policy%20brief%20integrated%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

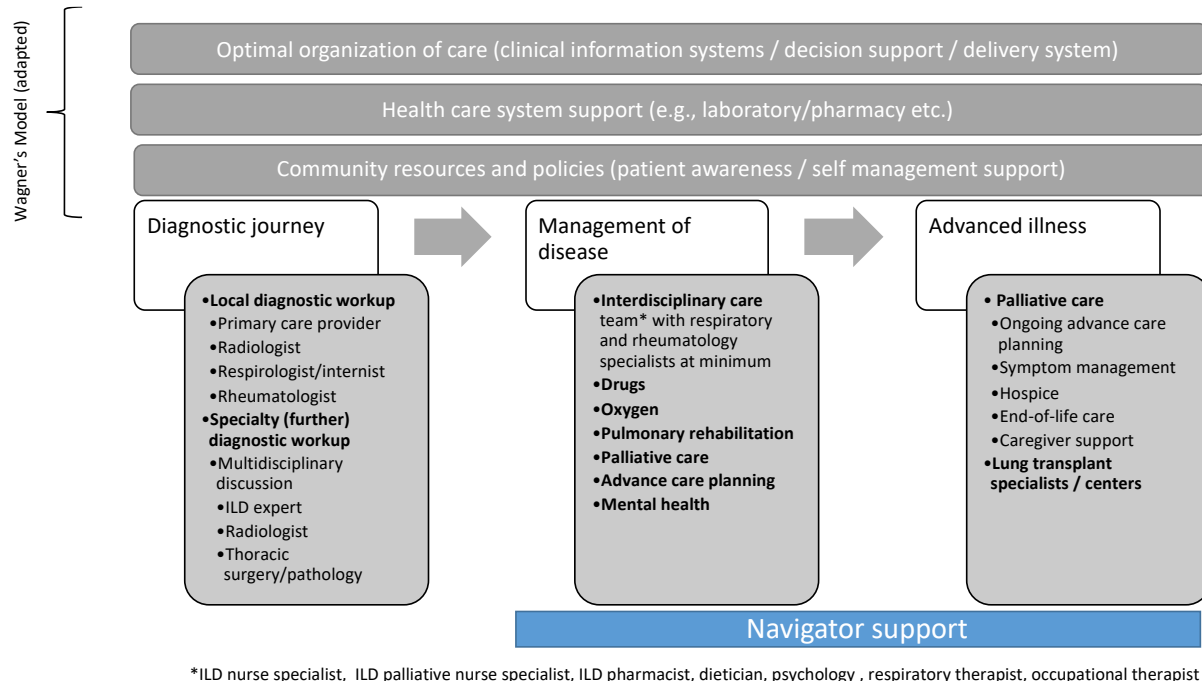
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### Background and summary of issues discussed:

- Given the complexity of issues related to care of patients with progressive-fibrosing interstitial lung diseases (PF-ILDs) and the physical, mental, social, economic and emotional burden that it is associated with them, patients require care from multiple disciplines in addition to trained respirologists. These could include, and are not limited to the following:
  - Patient care navigators and multidisciplinary team care coordinator
  - Physicians with specialties in respirology, radiology, rheumatology, sleep disorders, thoracic surgery, palliative care and general practice.
  - Nurses with specialized training in PF-ILDs, oxygen, palliation, respiratory care and associated medical specialty areas.
  - Occupational therapists who can facilitate activities in daily life, including energy conservation strategies and aids to daily living
  - Physiotherapists who can assess physical ability and facilitate pulmonary rehabilitation with specific exercises
  - Pharmacists who provide advice on drug dosage regimens and strategies for improving adherence and tolerance of drugs.
  - Dieticians to provide nutritional support for weight changes or help with side effects from drug therapy.
  - Psychologists to determine the psychological impact of disease and treatment and provide support for services such as palliative care or connecting to others with the disease.
  - Social workers to provide support in accessing and financing health services and interventions e.g. medication costs, insurance coverage.

- There is emerging evidence that describe improvements to the quality of life of patients<sup>1</sup>, management of disease<sup>2</sup>, reductions in emergency room visits<sup>3</sup>, physician visits<sup>4</sup>, physician workload<sup>5</sup>, and improvements in palliative and end-of-life care<sup>3</sup> when a multidisciplinary service with care navigation is employed.
- While there is general recognition that multidisciplinary supports are required for various phases of disease (i.e., the diagnostic workup or ‘diagnostic journey’; ongoing management of disease; and management of advanced illness)<sup>6</sup>, there is no clear definition of what constitutes multidisciplinary care in Canada or how these various disciplines should be brought together or coordinated.<sup>7</sup>
- A depiction of necessary care components based on Working Group discussion, and adapting Wagner’s model of integrated care for chronic conditions is shown in Figure 1. Figure 1

Figure 1 Components of integrated care necessary for diagnosis, and routine / advanced care management of PF-ILD



- One approach to bringing together needed components of care is through dedicated ILD specialty centres. These centres can be linked to other specialty areas and supports with interest or training in ILD including cardiothoracic surgeons and lung transplantation teams, occupational therapists, rheumatologists, immunologists, palliative care experts, respiratory therapists, physiotherapists, and dietitians.
- Beyond diagnosis and management of patients, centres can also help patients with access to research/clinical trials and advanced genetic testing. They are also able to provide education,

navigation and facilitate communication between specialists, between patients and care providers and between patients and their families.

- While there is evidence of effectiveness of a centre-based approach to PF-ILD management<sup>2,8</sup>, it represents significant challenges in the Canadian context:
  - 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 their families.
  - Further to this, patients with PF-ILD have expressed a desire to have better community-based resources for navigation and other supports related to self-management and awareness of disease. They have expressed an interest for information about care at all stages of illness.
  - Unlike other respiratory conditions (e.g., cystic fibrosis, pulmonary arterial hypertension) that have been managed using a centre-based approach, PF-ILD represents a larger and growing population of patients. There are an inadequate number of ILD subspecialty trained respirologists to populate centres that will serve all patients.
    - There are also limits to designating who can provide care within a given healthcare system. Provincial authorities largely pay physicians as free entities who are regulated by their own professional colleges and without government restrictions to practice in a certain location.
    - Furthermore, some highly specialized ILD doctors may also hold research interests and desire connection to academic research hospitals.
  - Some patients can be adequately managed through community-based specialists with interest or training in ILD.
- Other approaches to combining necessary components of integrated care (i.e., specialty goods and services) are distributed models of care (i.e., local centres), distance-led approaches including asynchronous and synchronous tele-health, shared-care or spoke-and-hub approaches.

## Policy Options and Next Steps for Canada

Given the need for multidisciplinary care but the limitations in delivering all care through specialized ILD centres, the group discussed desired conditions and approaches to organizing and providing care for the ongoing management of patients with PF-ILD in the future. Some options identified by this Working Group included:

- **The need for hybrid models of care:**
  - The size and complexity of care management means having a completely centralized model of care is not feasible. Yet, the need for highly specialized training and

services also means a de-centralized service model entirely dependent on community-based resources is also untenable.

- An integrated, “shared care” or hub-and-spoke between hospitals/community-based specialists and specialized centres is one approach--- it also aligns with patient values – as travel to dedicated centres may be challenging or not possible.
  - There is evidence from other disciplines involving complex care that shared-care models can be effective.<sup>9</sup>
- **Defining the hub-and-spoke approach to care**
    - Working Group participants felt a hub-and-spoke model would allow specialized care centres to focus on supporting regional care centres and community specialists through providing province-wide navigation to specialty services, educational resources for care providers and patients, access to multidisciplinary discussion which may be required for diagnosis, and access to clinical research.
    - Specialized centres are also important for capacity building through providing training opportunities for future ILD specialist clinicians and researchers.
    - Specialized care centres would also provide regular care for their specific catchment areas in addition to being tasked with identifying where regional deficits exist which could lead to strategic capacity building.
    - Hub-and-spoke integrated care models have also been applied to other therapeutic areas where individuals are faced with potential gaps in care or poor care co-ordination, that can leads to an adverse impact on care experiences and care.

## Implications for Further Research

Recommending a hub-and-spoke model for PF-ILD patients is a “best guess” approach to care that considers the Canadian healthcare system structure, the preferences and values of Canadian patients and the availability and training of necessary specialists. The Working Group felt that additional implementation and health services research required should address the following questions:

### 1. What are the minimal standards / components for an integrated care of PF-ILD in Canada?

The Working Group felt that at minimum, integrated care approaches employing a hub-and-spoke model should have access to specialized ILD respirologists, pathologists, thoracic surgeons, radiologists, rheumatologists, pulmonary rehabilitation specialists, and specialty nurses within their centres (See Figure 1). The centres would also be tightly linked to palliative care transplant, and research services. However, more definition of this model is needed.

### 2. What are the current international and national approaches to integrated care and multidisciplinary management models of care that are applicable to ILD?

While some Working Group members were able to discuss how multidisciplinary care is delivered within their own clinics and institutions, a survey or horizon scan of current models would be informative for better defining an integrated care approach. The Working Group thought it might be feasible to conduct a small survey of those (16 centres) involved in Canada.

### 3. What is the cost-effectiveness of different approaches to organizing care, from a Canadian health care payer perspective?

An ideal model of care may also be informed through patient input in regards to what models most align with patient values and additional analyses that seek to conceptually cost a hub-and-spoke approach to care. This could be accomplished through pilot studies that attempt to further measure and assess the costs and effectiveness of these approaches. Any new model should also be assessed through audit and ongoing evaluation given the lack of strong evidence pointing to any one approach.

One such Canadian approach to multidisciplinary collaborative is a model developed at the University of Alberta ILD clinic in Edmonton<sup>10</sup>. The model is based on the Wagner's model of chronic care with emphasis on interdisciplinary teams, community-based care, self-management support and education along with ACP using an early-integrated palliative approach in an outpatient setting. Economic analysis of the model showed reduction in costs of CAD 7700/patient at end of life when compared to care received in other respirology clinics and non-respirology care<sup>10</sup>. The cost reductions were driven by reduced hospitalizations and associated hospital deaths. In addition to reducing costs, the model resulted in improved care and patient centred outcomes.

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