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► **To cite this version:**

Jolene Fisher, Vincent Cottin. Care Delivery Models and Interstitial Lung Disease. Clinics in Chest Medicine, 2021, 42 (2), pp.347-355. 10.1016/j.ccm.2021.03.013 . hal-03541561

**HAL Id: hal-03541561**

**<https://hal.inrae.fr/hal-03541561v1>**

Submitted on 24 May 2023

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Care-delivery models and interstitial lung disease: the role of the specialized center

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### **Disclosure statement**

JHF reports no disclosures.

### **Key words**

Interstitial lung disease, multidisciplinary team, specialized center

### **Key Points**

1. The goals of ILD care delivery models are multifaceted and centered around providing timely access to an accurate diagnosis and effective care plan.
2. The specialized center plays an integral role in ILD care delivery with key components including diagnosis, treatment, monitoring, care coordination, support/advocacy, education and research.
3. There are significant barriers to widespread access of specialized ILD care delivery and innovative strategies that leverage technology are required to bridge these gaps.

### **Synopsis**

Comprehensive interstitial lung disease (ILD) care delivery models have several key components including diagnosis, treatment, monitoring, coordination with other healthcare providers, patient support/advocacy, education and research. The field of ILD is rapidly evolving and specialized centers with ILD specific expertise have emerged as ways to care for complex patients. The role of the specialized center in care delivery is multifaceted and aimed at improving patient care and advancing the field of ILD.

Widespread access to specialized centers is a barrier to ILD care delivery worldwide.

Creative and innovative strategies that leverage technology are needed to bridge gaps in ILD care.

### **INTRODUCTION**

The field of interstitial lung disease (ILD) is rapidly evolving and multifaceted with patients that experience debilitating symptoms and poor prognosis. Care delivery models that utilize specialized centers with access to ILD specific resources have emerged as a way to provide comprehensive care to these patients with complex diseases. The goals of the specialized center are multifold and centered around providing timely access to an accurate diagnosis and effective care plan. Other deliverables include management of treatment side effects and patient comorbidities, patient education and support groups, medical education of both practicing clinicians and trainees and access to clinical trials, lung transplant and end of life care. A multidisciplinary team is integral to providing such complex care delivery and requires access to pulmonology, rheumatology, pathology, thoracic surgery/interventional pulmonology, radiology, palliative care, lung transplant, pharmacy, nursing, social work and administrative support (both clinical and research), with ILD expertise (**Figure 1**).

Universal access to these highly specialized centers with optimal resources and expertise remains a significant challenge that requires innovative strategies to overcome. The aims of this chapter are to (1) summarize the key components of ILD care, (2) describe the role of the specialized center in the delivery of each component of ILD care, and (3) identify the current challenges facing ILD care delivery models and propose viable strategies to overcome these gaps. Key messages are summarized in **Table 1**.

## **KEY COMPONENTS OF ILD CARE AND THE ROLE OF THE SPECIALIZED CENTER IN DELIVERY**

### ***Diagnosis***

ILD subtypes have variable epidemiology, clinical course and management. A timely and accurate ILD diagnosis is critical for clinical decision making, patient counseling and advancing research. The current gold standard for ILD diagnosis is multidisciplinary discussion (MDD) between 'experts' that integrate clinical, radiologic and where available, pathologic features in order to reach a consensus diagnosis.<sup>1-4</sup> Within the tripod of clinical, radiologic and pathologic features, the MDD further incorporates a variety of information that contribute to diagnosis, including autoimmune serology, precipitins, clinical or molecular biology genetic information, molecular classifiers, or reports from other healthcare providers (e.g. occupational medicine specialist, domiciliary visit looking for exposures that may cause hypersensitivity pneumonitis, etc). Utilization of MDDs have been shown to improve diagnostic confidence and decrease inter observer variability.<sup>5-8</sup> MDDs, at minimum, include a pulmonologist and radiologist with ILD expertise and depending on the individual case, other specialty involvement, such as, pathology and rheumatology.<sup>9</sup> Specialized diagnostic resources, including extensive autoimmune serology and histopathology obtained by videothoracoscopic surgical lung biopsy (SLB) or cryobiopsy, may be needed to make an accurate diagnoses. MDD groups that do not include all ILD specific experts benefit from access to larger and more versed MDDs for their more complex cases as the quality of MDD is dependent on experience.<sup>10</sup>

Widespread availability of safe and accurate diagnostic testing for ILD remains a significant challenge. Although decreased by the use of video assisted techniques and appropriate patient selection, SLB is still associated with high morbidity and mortality,<sup>11</sup> particularly in centers with less experience.<sup>12</sup> In addition, there can be significant inter observer variability in histopathology interpretation.<sup>13</sup> While less invasive, similar issues have been identified with the use of transbronchial lung cryobiopsy.<sup>14-16</sup> Such 'volume-outcome' relationships have been described across a variety of medical and surgical specialties and used to support the regionalization of specialty care.<sup>17,18</sup> Awareness of the risk and limitations associated with SLB has contributed to efforts aimed at improving ILD diagnosis in its absence, such as developing the concept of a working/provisional diagnosis, the probable usual interstitial pneumonia definition and a molecular classifier.<sup>1,19-21</sup> The expertise of an ILD center may reduce the number of cases in which a biopsy is contemplated and performed, as compared to centers with less ILD familiarity.

The complexities surrounding ILD diagnosis have led to increasing regionalization of care with a push to refer to expert centers. While these regional, expert centers can increase diagnostic accuracy for ILDs, they can also be disadvantaged by limited accessibility. Delayed access to an ILD center is associated with increased mortality, independent of disease severity.<sup>22</sup> Disparate access varies widely and can result from geography, marginalization and lack of healthcare resources. These specific barriers are dependent on jurisdiction with issues such as geography typically more relevant in places like

Canada and Australia as opposed to Europe. Innovative strategies are needed to overcome these barriers and increase access to MDDs and specialized diagnostic testing for patients with ILD.

### ***Management***

The comprehensive management of ILD is complex and rapidly evolving with both pharmacologic and non-pharmacologic components.<sup>23,24-26</sup> There are several reasons for this complexity. ILDs include multiple conditions with variable disease behavior and therefore different goals of therapy. Some of these conditions are potentially reversible or partially reversible such as non-fibrotic hypersensitivity pneumonitis while others, such as idiopathic pulmonary fibrosis (IPF), are progressive. Treatment decisions regarding ILD medications can be nuanced given that many therapies are aimed at slowing disease progression as opposed to disease reversal, necessitating careful consideration of the risk versus benefit profile in each patient. While there has been a recent increase in quality data for the treatment of non-IPF ILD,<sup>27,28</sup> more is required, and treatment decisions for conditions such as hypersensitivity pneumonitis and unclassifiable ILD are often heavily influenced by 'expert opinion'. In the absence of management guidelines, decisions regarding treatment of connective tissue disease (CTD)-ILD are best done in conjunction with rheumatology to identify therapies that ideally treat both pulmonary and non-pulmonary disease manifestations.

Comprehensive management further includes access to pulmonary rehabilitation, lung transplant, symptom management/palliative care, advanced care planning and patient education, support and advocacy.<sup>26,29,30</sup> The infrastructure of specialized ILD centers are typically best equipped to deliver such comprehensive care, with access to the required resources often limited outside of these select programs.

### ***Longitudinal monitoring***

Longitudinal monitoring of ILD patients is central to informing management decisions.<sup>25,31,3,32</sup> Regular clinical assessments provide a mechanism to monitor symptoms, screen for disease progression, and identify treatment side effects and/or comorbidities. Information obtained from these interactions guide decisions related to treatment initiation, alteration, or discontinuation and appropriate timing of lung transplant referral, and/or end-of-life planning. In patients with provisional or working diagnoses, longitudinal monitoring provides an opportunity to reconsider the diagnosis which can become clearer overtime (e.g. development of extrapulmonary CTD symptoms). While the specialized center often plays an important role in the long-term monitoring of fibrotic ILD, access to a local pulmonologist has several advantages.

Disease behavior is widely variable among patients with ILD, and access to an expedited clinical assessment is ideal in the event of acute deterioration. Shared-care models can facilitate faster access to appropriate expertise for patients. Local care providers can liaise with 'expert' ILD centers on a patient's behalf in order to make timely care decisions. This type of care delivery model has the additional advantage of 'off-loading'



ILD centers with long waiting lists of some follow-up visits, allowing them to efficiently focus their expertise where it provides the most added value.

### ***Medical education***

ILD-related continuing medical education for trainees, general practitioners, radiologists, pulmonologists, thoracic surgeons/interventional pulmonologists, pathologists and rheumatologists, is an essential component of ILD care delivery. ILD patients frequently report a lack of ILD awareness among their health care providers which results in delayed specialist referral, diagnosis and treatment.<sup>33,34</sup> 'Real world' registry data has shown high rates of SLBs (even in those with a definite usual interstitial pneumonia pattern on high resolution computed tomography) and corticosteroid use with lower than expected rates of antifibrotic therapy in patients with IPF.<sup>35</sup> These findings are not necessarily surprising, given the complexity and rapid evolution of ILD diagnosis and management, and implies there is a need for ongoing ILD related knowledge translation and dissemination to the medical community. There is data to support such endeavors with a national French survey of physicians caring for IPF patients showing improved knowledge and management of IPF after implementation of an education outreach program.<sup>36</sup> Specialized ILD centers are typically equipped with the necessary infrastructure, such as staff and accreditation, required to deliver these programs.

It is also important to recognize that clinical feedback to physicians referring to ILD centers provides a mechanism for informal medical education. For example, a referring

pulmonologist would typically propose a first-choice diagnosis, which may or may not be modified by the MDD at the ILD center. These clinical feedback loops have important educational roles. The MDD has an additional training effect on participating physicians, whether trainees or more senior members.<sup>8,10,37</sup>

Ensuring pulmonology trainees gain competence in the diagnosis and management of ILD is an integral component of improving ILD care delivery. The specialty clinic plays an important role in trainee education, providing a mechanism for high volume ILD clinical exposure. A survey of British Thoracic Society trainee members found that the majority felt their ILD training was inadequate.<sup>38</sup> Additional studies identifying specific barriers to trainee ILD education and mechanisms for improvement are required. The ILD specialty clinic is also a key component of ILD subspecialty clinical and research training programs.

### ***Patient education, support and advocacy***

Many ILDs are progressive conditions associated with poor quality of life and limited life expectancy. ILD patients and caregivers frequently report inadequate emotional and psychological support.<sup>33</sup> A survey of patient perspectives on the benefits of a specialized ILD center found patients placed a high value on gaining a better understanding of their disease and access to a specialized nurse that provided education and support,<sup>39</sup> reinforcing the importance of patient education, support and advocacy as key components of ILD care delivery. Patients frequently search the Internet for information related to their disease, yet ILD websites are often inaccurate and outdated.<sup>40</sup>

Specialized ILD clinics can provide highly valued disease related education to patients through many avenues, including direct discussion at clinic visits with an ILD physician and/or nurse educator, provision of disease specific education handouts, lists of reliable online resources and formal education programs. Specialized clinics can also facilitate patient and caregiver support groups that provide additional psychosocial and emotional support for patients and families dealing with ILD.

Specialized ILD clinics can promote community engagement through relationships with non-medical partners, such as patient foundations or patient associations. ILD physicians or nurses from the specialized center may take an active role in the scientific committee of a patient foundation. Here the role of the ILD center goes beyond providing education to the patient during a clinic visit or a specific educational activity, by delivering important educational messages that will be conveyed by the patient foundation. These relationships are a key component of ILD care delivery and provide valuable platforms for education, fundraising and research advancement. They also give the patient a seat at the table, helping identify and advocate for patient relevant outcomes.

### ***Research and access to clinical trials***

There has been significant advancement in drug therapies for ILD and ongoing rapid development of new drugs that require rigorous testing. In many cases of fibrotic ILD, current therapies only offer a slowing of disease progression as opposed to reversal or

cure. Subsequently, the ability to offer and effectively conduct clinical trials is a key component of ILD care delivery. Without this ability, drug development will be stifled and we will fall short of our ability to find effective therapies to advance the field of ILD. There are several barriers to physician and patient participation in clinical trials, including access to the required organizational structure, which is often only available at specialized centers. Components often needed include access to a MDD, research personnel (such as trial coordinators), institutional infrastructure (such as research ethics boards), and clinics with a high volume of ILD patients.

Specialized ILD clinics can facilitate other important forms of research that require access to high volumes of ILD patients, such as prospective patient registries. This ‘real world’ data on epidemiology, disease course, treatments, and outcomes is especially valuable when studying heterogeneous and less common diseases like ILDs. Large, national patient registries have published findings on ILD natural history, treatment and outcomes that would be challenging to obtain by other research avenues.<sup>35,41,42</sup> In addition, registry research can give patients a voice<sup>39</sup> and provide opportunities to study and develop useful patient centered outcomes.<sup>43</sup>

## **CHALLENGES FACING ILD CARE DELIVERY MODELS AND PROPOSED SOLUTIONS**

Specialized centers are generally highly appreciated by both referring physicians and patients, playing a central role in ILD care delivery. However, limitations of these models can include a lack of widespread and timely access for patients. Disparities in accessing

the specialized center can exist due to long waiting lists, marginalization and geography.

Innovative strategies that leverage technology are required to bridge these gaps.

### ***Multidisciplinary discussion***

Limited availability of MDD is a key barrier to accurate and timely ILD diagnosis. Access to MDD can be increased by utilizing various virtual platforms, including remote chart and imaging review, telemedicine and video conferencing. A retrospective, cross-sectional study from Canada showed that remotely accessed MDDs are feasible, decrease waiting time and frequently lead to a change in diagnosis and management.<sup>44</sup> In addition, referring physicians report satisfaction with the process and improvement in their own assessment and management of ILD patients. While routine use of a remote MDD will benefit from additional study and validation, it is likely to have an increasing place in ILD care delivery. However, the organization of virtual MDD remains a barrier to use in many centers due to lack of secure virtual platforms for data sharing, the time commitment required, absence of remuneration/funding for this type of care model and the importance of an in-person assessment for determining CTD features, antigenic exposures and frailty. Virtual consultations with patients may overcome some of these barriers.

Virtual MDDs may not solve the issue of patient volume 'overload' experienced at some ILD centers. Additional strategies to most efficiently utilized MDD resources can be considered in this setting. For example, ILD cases may be triaged to follow a specific

MDD 'path' according to complexity. Similar approaches have been successfully used in other disciplines, such as Oncology.<sup>45</sup> In the case of ILD, a patient with a UIP pattern, no identifiable cause for ILD and over the age of 65 may not require a full MDD discussion, in contrast to more complex cases, such as, unclassifiable ILD or chronic hypersensitivity pneumonitis without an identified antigen.

### ***Longitudinal monitoring***

Longitudinal monitoring of ILD patients solely at specialized centers has several disadvantages. First, many specialized centers do not have the capacity to see new referrals in a timely fashion and to conduct all follow-up visits. Second, attending ongoing follow-up visits can be a significant burden for patients that have to travel far distances. Third, it may be challenging (both for the patient and ILD clinic) to accommodate urgent assessments in the event of a clinical deterioration. Lastly, for successful collaboration, it is important to respect the pre-existing patient-doctor relationship of referring physicians, who are intellectual and financial stakeholders in patient care. There are several viable strategies that can be used to circumvent some of these issues. Certain follow-up visits can be done remotely using phone or videoconference by the ILD physician or nurse. Blood work and pulmonary function testing can be done locally with results sent to specialized centers and prescription renewals can be done remotely.

Home-based patient monitoring programs that incorporate home spirometry have emerged as viable vehicles for ILD care delivery.<sup>46</sup> These programs utilize eHealth technology to monitor patients remotely. Patient reported outcomes and physiologic data, such as spirometry, are collected and transmitted real time to ILD care providers. Home spirometry has shown promise for detecting ILD progression and use as a clinical trial endpoint.<sup>47,48</sup> Home-based monitoring programs can decrease cumbersome travel for patients and empower them to take an active role in their disease management, while allowing their physicians to do more frequently monitoring.

In many cases, it is helpful for the patient to have a local pulmonologist who can alternate follow-up visits with the ILD center. There are several advantages to this model including decreasing travel burden on patients, off-loading ILD centers with long waiting lists and local access to an expedited assessment in the event of a clinical deterioration. While the ILD center often plays a central role in confirming or changing the diagnosis and treatment plan, local pulmonologists can provide valuable ongoing monitoring and liaise with expert centers on behalf of their patient in the event of a clinical change. Some ILD centers provide expert opinions to local pulmonologists without directly seeing patients. The best care pathway and balance between remote, in-person and shared follow-up varies between centers and is dependent on local needs and priorities.

### ***Racial, ethnic and gender disparities and ILD care delivery***

Racial, ethnic and gender disparities are well described determinants of health and healthcare access.<sup>49-51</sup> It is not known how these characteristics influence access to specialized ILD care or its delivery. Patient gender has been shown to significantly influence whether a patient receives an IPF diagnosis, suggesting gender bias may exist amongst ILD physicians.<sup>52</sup> In addition, a patient's ILD care needs, expectations and goals may vary according to culture and region of origin and are factors that need to be considered when delivering care.<sup>30</sup> Research studies evaluating the role that race, ethnicity and gender play in how specialized ILD care is accessed and delivered are urgently required.

### ***Future of ILD care delivery***

With the exponential pace of knowledge generation, medicine is becoming increasingly subspecialized. ILD specifically has seen many changes in the past decade, with ongoing new discoveries. With such rapid advances, effective knowledge translation and dissemination becomes an increasingly daunting task as care delivery becomes more complex. As a field, the ILD community can leverage collective international expertise to continuously improve ILD care delivery. There are many opportunities for integrating both national and international expertise into local care delivery models. One example would be providing the ability to bring exceptional cases to a national or international MDD. The framework for these types of endeavors already exists in some places, with the European Research Network (ERN-LUNG, <https://ern-lung.eu/>) being one example. Such frameworks can be expanded upon to include other jurisdictions. Infrastructure for



national and international clinical care collaborations can also provide a mechanism for less formal interactions, such as asking for advice on a specific aspect of a case (i.e. chest computed tomography or histopathology slides). These types of collaborations can increase access to highly specialized ILD care for both remote and marginalized communities and provide additional platforms for education and research. Establishing funding structures that support the time and resources needed to deliver this complex care is critical.

## **SUMMARY**

In summary, comprehensive ILD care delivery has several key components including diagnosis, treatment, monitoring, support/advocacy, education and research. The role of the specialized center in care delivery is multifaceted (**Figure 1**), with an overarching goal of improving patient care and advancing the field of ILD. The current role of the specialized center in ILD care delivery models faces significant feasibility and generalizability challenges. Creative and innovative strategies are needed to find ways to optimally deliver ILD care to the highest number of patients possible.

Clinics Care Points:

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#### **FIGURE LEGENDS**

**Figure 1.** Key components of interstitial lung disease care delivery. CME, continuing medical education, MDD, multidisciplinary discussion.

**Table 1. Summary of Key Messages**

<b>KEY COMPONENTS OF ILD CARE AND THE ROLE OF THE SPECIALIZED CENTER IN DELIVERY</b>	
<i>Care delivery component</i>	<i>Key messages</i>
Diagnosis	<ul style="list-style-type: none"> <li>• Accurate and timely ILD diagnosis is a key component of ILD care.</li> <li>• MDD requires access to specialty resources that are typically only available at specialized ILD centers.</li> </ul>
Management	<ul style="list-style-type: none"> <li>• ILD management is multifaceted with pharmacologic and non-pharmacologic components.</li> <li>• Treatment decisions can be nuanced and are often guided by expert opinion given that many cases do not fall into existing management guidelines.</li> <li>• The infrastructure needed to provide comprehensive ILD management is typically limited outside of the specialized center.</li> </ul>
Longitudinal monitoring	<ul style="list-style-type: none"> <li>• Longitudinal monitoring of ILD patients is essential to informing management decision making.</li> <li>• A ‘shared-care’ model between local pulmonologists and ILD centers can facilitate timely access to care, minimize patient travel and ‘off-load’ specialty clinics.</li> </ul>
Medical education	<ul style="list-style-type: none"> <li>• ILD related medical education for clinicians and trainees is a key component of ILD care delivery.</li> <li>• Additional research on ILD knowledge gaps and effective education strategies are required.</li> </ul>

Patient education, support and advocacy

- Patient education, support and advocacy is a key component of ILD care delivery.
- Specialized ILD clinics facilitate patient education, support and advocacy through direct patient interaction and community engagement.

Research and access to clinical trials

- Access to clinical trials is an important part of ILD care delivery.
- The infrastructure, momentum and commitment to research required to conduct clinical trials in ILD is typically available at specialized centers.

#### CHALLENGES AND SOLUTIONS FACING ILD CARE DELIVERY

<i>Challenge</i>	<i>Key messages</i>
Multidisciplinary discussion	<ul style="list-style-type: none"><li>• Limited access to an ILD center and a specialized MDD is a barrier to a timely diagnosis and effective treatment plan for patients with ILD.</li><li>• Using virtual MDDs are a strategy to increase MDD access.</li></ul>
Longitudinal monitoring	<ul style="list-style-type: none"><li>• Remote monitoring and shared care models with local physicians can decrease travel burden for ILD patients, provide timely access to care, off-load specialized clinics and contribute to the continuing medical education of referring physicians.</li></ul>
Racial, ethnic and gender disparities and ILD care delivery	<ul style="list-style-type: none"><li>• Research on race, ethnic and gender disparities in ILD care access and delivery is urgently needed.</li></ul>
Future of ILD care delivery	<ul style="list-style-type: none"><li>• International collaborations and networks are the future of ILD care delivery.</li></ul>

