Pulmonary Fibrosis Foundation
Interstitial Lung Disease Patient Diagnostic Journey (INTENSITY) Survey
Fact Sheet

Survey Overview

The Pulmonary Fibrosis Foundation (PFF) commissioned the Interstitial Lung Disease Patient Diagnostic Journey (INTENSITY) survey with support from molecular diagnostics company Veracyte, Inc. to advance understanding of patients' diagnostic experiences with interstitial lung diseases (ILDs), including idiopathic pulmonary fibrosis (IPF). The survey assessed the steps and time required for patients to receive a diagnosis, specific obstacles hindering timely diagnosis, and the physical and emotional impact of patients' diagnostic journeys. Independent healthcare-research organization Outcomes Insights conducted the 600-person survey (300 women/300 men) online from August 14 to 26, 2015. The survey was recruited without gender quotas and the even distribution of men and women was coincidental. Median participant age was 63 years for women and 69 years for men, and most participants had been diagnosed within the past two to five years.

Survey Rationale

Each year, an estimated 175,000 to 200,000 patients in the United States and major European countries present with suspected ILDs.[1] These diseases are notoriously difficult to diagnose. Among the known forms of ILD, IPF is among the most common and the deadly; there is no known cure for IPF and patients have a median survival of 3.8 years[2] - worse than most forms of cancer.[3] In October 2014, the US Food and Drug Administration approved the first two drugs demonstrated to slow IPF progression among some patients - increasing the importance of accurate and timely diagnosis for all patients with suspected IPF.

Delayed Diagnoses Among Survey Respondents are Compounded by Significant Incidence of Misdiagnoses

ILD patients endure significant diagnostic delays

- Forty-two percent of survey respondents endured a year or more between the time they first experienced symptoms and the time they obtained a diagnosis; 25 percent endured two years or more; and 6 percent endured six years or more
- The median reported time to diagnosis was seven months
- The most common ILD symptoms experienced by survey participants were shortness of breath or breathlessness (77 percent), cough (53 percent), fatigue and weakness (38 percent) and chest discomfort (17 percent)
- Almost one-quarter of respondents (23 percent) waited more than one year to see a physician after noticing their first symptoms. Many doubted the importance of their initial symptoms, attributing them to "just getting older" (51 percent of total respondents)

Mis-diagnoses are common and not quickly rectified

- Fifty-five percent of respondents were misdiagnosed at least once; 38 percent were misdiagnosed at least twice over the course of diagnosing their disease
- The most common misdiagnoses were asthma (14 percent), pneumonia (13 percent) and bronchitis (12 percent)

- Among those who were misdiagnosed, the misdiagnoses persisted for nearly a year (median 11 months)

Accurate Diagnosis Requires Substantial Healthcare Resources

For INTENSITY survey respondents, an accurate diagnosis most typically required the involvement of three physicians and multiple diagnostic tests, including invasive diagnostic procedures. This diagnostic odyssey is time-consuming and can be clinically risky for patients.

Diagnosis requires three or more doctor visits

- Survey participants saw a median of three physicians before receiving a diagnosis; more than one-quarter (26 percent) saw five or more
- While most ILD diagnoses (88 percent) were ultimately provided by a pulmonologist, multiple primary care physician (PCP) visits were the norm: Seventy-five percent of patients saw their primary care physician more than once and 21 percent saw their PCP more than four times before seeing a specialist
- Approximately one-third of participants' diagnoses came from a dedicated ILD or pulmonary fibrosis center

Multiple diagnostic procedures are the norm

- On average, respondents endured six pulmonary lung function tests, five chest X-rays, two bronchoscopies and two to three CT scans before receiving a diagnosis
- Nearly half of survey participants (45 percent) underwent surgical lung biopsy – an invasive, expensive and potentially risky procedure - as part of their diagnostic process

Diagnostic Challenges Have Negative Emotional, Quality of Life and Financial Implications

Survey participants reported that the process of being diagnosed with an ILD takes an emotional and financial toll.

Respondents report feeling lonely, stressed and isolated by their lack of diagnoses and the obstacles they encountered

- Sixty-four percent of survey participants said they either mostly agreed or agreed that it was "very stressful not to know what was wrong with me"
- Forty-three percent of those surveyed mostly agreed or agreed that they did not feel that family/friends understood what they were going through in trying to get a diagnosis
- A full 85 percent mostly agreed or agreed that the process of trying to get their disease diagnosed took away from time with family/friends

Patients are also impacted financially

- Twenty-two percent mostly agreed or agreed that they had to go on disability or retire because of the time diagnosis was taking
- More than one-quarter of survey participants (28 percent) mostly agreed or agreed that getting their lung disease diagnosed was more expensive than they anticipated

Undiagnosed Patients Seek Information and Support

- Forty-nine percent of participants mostly agreed or agreed that they wished for a community of people to share their frustration and relate to their experiences while they were trying to obtain a diagnosis
- Survey respondents reported that the PFF (60 percent) and their personal physicians (52 percent) were the two most valuable sources of information about ILD during their diagnostic journey

Media Contacts:

Pulmonary Fibrosis Foundation
Michelle Michael
Vice President, Marketing and Communications
312.239.6628
mmichael@pulmonaryfibrosis.org

Veracyte, Inc.
Michele Parisi
925.429.1850
mparisi@forwardhealthinc.com

---

[1] Veracyte estimates.
[2] Raghu G, et. al. Idiopathic pulmonary fibrosis in US Medicare beneficiaries aged 65 years and older: incidence, prevalence, and survival, 2001-11. *Lancet Respir Med.* 2014 Jul;2(7):566-72.
[3] Hunninghake G.M., A New Hope for Idiopathic Pulmonary Fibrosis. *New Eng. J of Med.* May 29, 2014;370:2142.