

THE NEEDS OF PATIENTS AND CAREGIVERS

The Needs of Patients and Caregivers

EXPLORE IPF SURVEY FACT SHEET

The EXPLORE IPF survey investigated the needs, experiences, and feelings of patients living with idiopathic pulmonary fibrosis (IPF) and their caregivers. It was led by a multidisciplinary Advisory Committee that includes IPF thought leaders and advocates dedicated to addressing the unmet needs of the IPF community. The survey was conducted among 100 patients with IPF and 100 caregivers, all self-reported.

The survey showed that patients and caregivers experience a significant emotional burden and feel that more support and resources can help with the challenges associated with IPF. Raising awareness of the disease's impact can help address the needs of IPF patients and their caregivers, healthcare professionals, and advocates.

TAKING ACTION

Members of the EXPLORE IPF Advisory Committee recommend that the survey results be used to:

EDUCATE THE GENERAL PUBLIC ABOUT IPF TO:

- Know the signs and symptoms
- See a doctor when experiencing possible symptoms
- Decrease stigma associated with the disease
- Inform healthcare professionals, including primary care providers, to consider referral of patients to pulmonologists specialized in distinguishing IPF from other diseases
- Improve the dialogue between healthcare providers and patients/caregivers to speed diagnosis, provide understanding of IPF

upon diagnosis and continue ongoing support and comfort after diagnosis

- Create information, resources and support networks for patients and caregivers

KEY SURVEY FINDINGS

The road to an IPF diagnosis is long and frustrating. Patients who seek medical care for symptoms of IPF often see multiple doctors over many months before receiving the right diagnosis.

- Patients suffer, on average, for **1.9 years (23 months)** before being diagnosed with IPF
- Patients saw, on average, approximately **2 doctors (2-3)** before receiving an IPF diagnosis
- **Half of patients (52%) and caregivers (50%)** had difficulty finding a doctor who was knowledgeable about IPF
- **Nearly all patients (97%)** wished they knew what was causing their symptoms earlier (Figure 1)

FIGURE 1

Strongly agree:

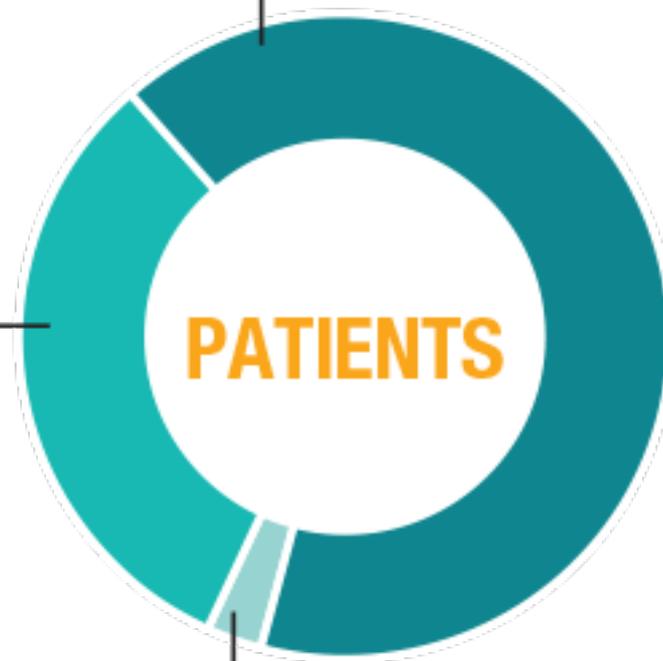
65%

Somewhat
agree:

32%

Somewhat
disagree:

3%



Strongly disagree: **0%**

- **9 in 10 patients (93%)** agreed better education of medical professionals could improve the time it takes to diagnose and manage IPF (Figure 2)

FIGURE 1

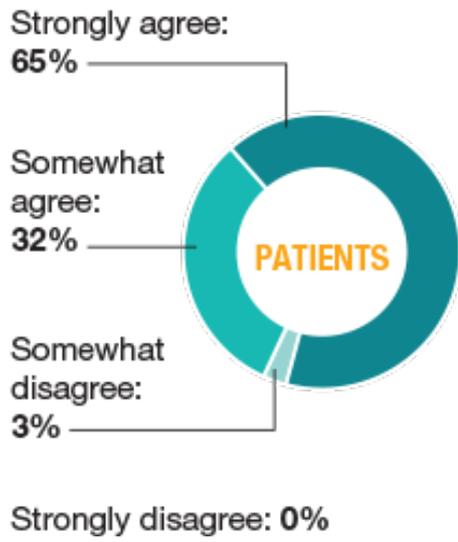


FIGURE 2

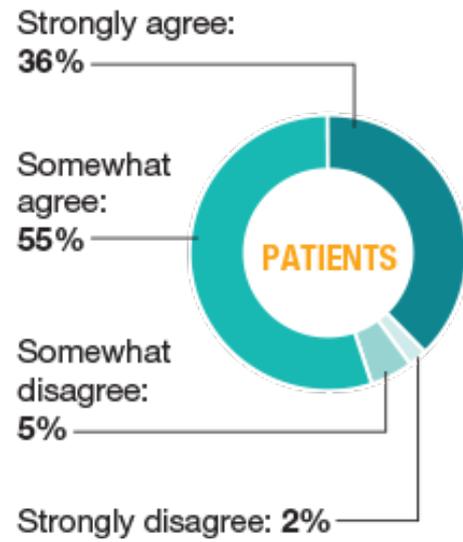


FIGURE 2

Strongly agree:

36%

Somewhat agree:

55%

Somewhat disagree:

5%

Strongly disagree: **2%**



Most People Do Not Understand IPF or How It Will Impact Their Lives

Patients and caregivers often begin the IPF journey with low understanding about the disease and the impact it will have on their lives, both physically and emotionally.

- **9 in 10 patients (89%)** had never heard of IPF before being diagnosed

(Figure 3)

FIGURE 3

PATIENTS



- **79% of patients** did not initially understand the severity of their diagnosis (Figure 4)

FIGURE 4

PATIENTS



- **Nearly three-quarters of patients (73%) and caregivers (82%) did**

not understand the emotional toll IPF would have on them (Figure 5)

FIGURE 5



Patients Feel Isolated, Stigmatized and Embarrassed

Even as patients begin to understand the complexity of IPF after their diagnosis, other challenges begin to emerge.

BEFORE EXPERIENCING IPF SYMPTOMS

- **2 out of 3 patients** were satisfied with their life, particularly their spirituality/religious faith and ability to travel
- **Less than one in three patients** reported experiencing negative emotions

After Being Diagnosed with IPF

- **Nearly 7 in 10 (67%)** felt powerless because there is nothing they can do
- **More than half of patients (52%)** believed they had become a burden on family and friends
- **More than 7 in 10 (77%)** reported difficulty finding other IPF sufferers with whom they could connect
- **More than 9 in 10 (93%)** patients who experienced coughing reported that they are embarrassed by not being able to control their coughing (Figure 6)

FIGURE 6

Embarrassed by coughing

Strongly agree:

41%

Somewhat
agree:

52%

Somewhat
disagree:

5%

Strongly
disagree:

2%



- More than 7 in 10 (76%) patients who experienced coughing believed that people often keep a distance because of their coughing (Figure 7)

FIGURE 7

Believe people keep their distance

Strongly agree:

37%

Somewhat agree:

39%

Somewhat disagree:

10%

Strongly disagree:

14%



- Nearly 7 in 10 (69%) patients who tried supplemental oxygen felt embarrassed by it (Figure 8)

FIGURE 8

Embarrassed by supplemental oxygen

Strongly agree:

46%

Somewhat agree:

23%

Somewhat disagree:

19%

Strongly disagree:

12%



FIGURE 6

Embarrassed by coughing

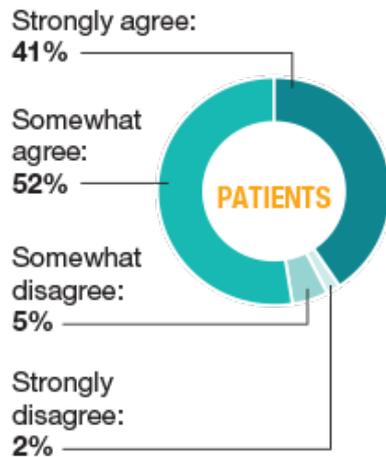


FIGURE 7

Believe people keep their distance

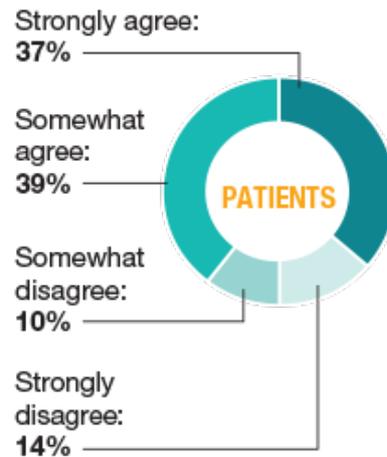
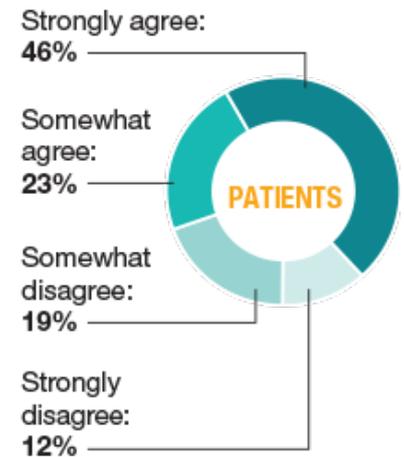


FIGURE 8

Embarrassed by supplemental oxygen



The Lives of Caregivers Change After a Diagnosis

While IPF takes a significant toll on patients, it also affects caregivers, who experience a more dramatic emotional shift following their loved one's diagnosis of IPF.

- Most caregivers were satisfied with their sense of **independence (84%)** and their **social life (85%)** before an IPF diagnosis (Figure 9) — following diagnosis less than four out of 10 caregivers reported feeling satisfied with their sense of **independence (39%)** and their **social life (38%)** (Figure 10)

FIGURE 9 *Before diagnosis*

SENSE OF INDEPENDENCE **SOCIAL LIFE**

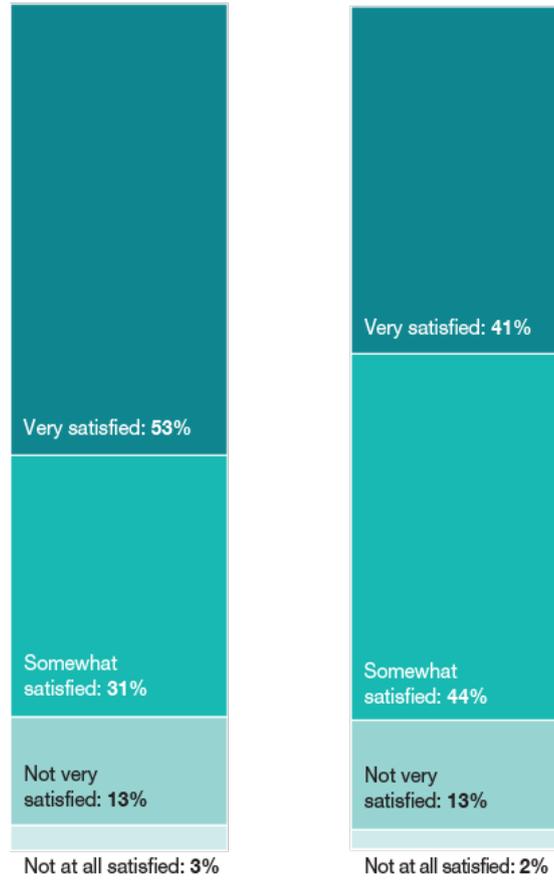
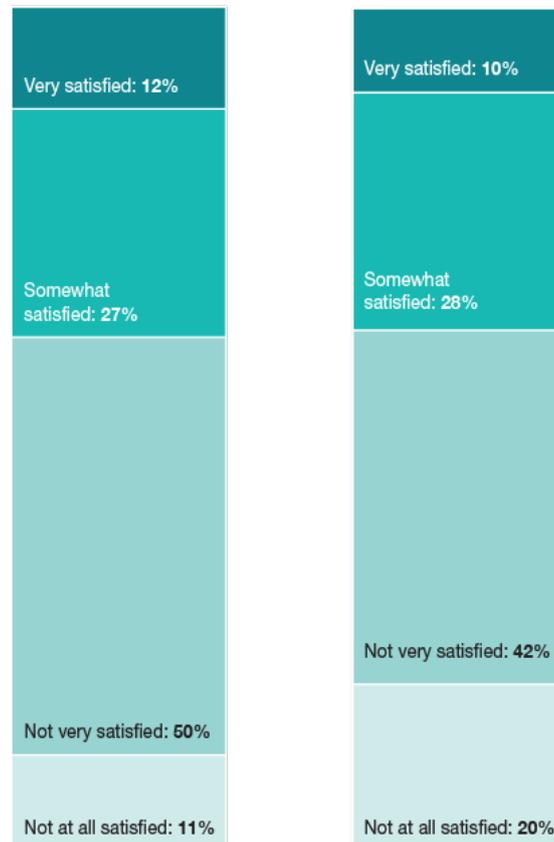


FIGURE 10 *After diagnosis*

SENSE OF INDEPENDENCE **SOCIAL LIFE**



- **64% of caregivers** said it was difficult to find other IPF caregivers to talk to or connect with
- When asked to describe their lives today (post-diagnosis) in one word, caregivers most often cited **'hectic' or 'stressful'**

FIGURE 9 Before diagnosis

SENSE OF INDEPENDENCE



SOCIAL LIFE

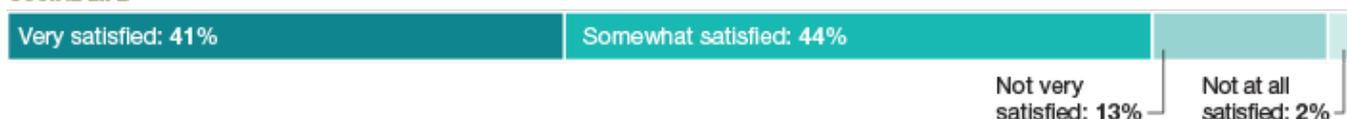
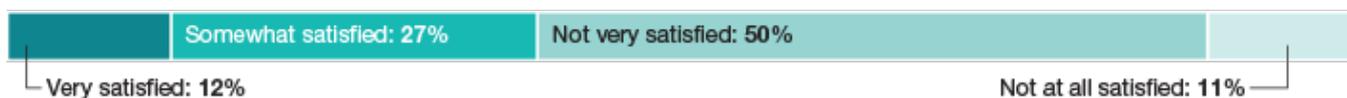
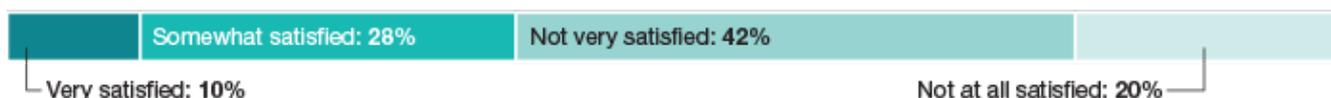


FIGURE 10 After diagnosis

SENSE OF INDEPENDENCE



SOCIAL LIFE



People Need Information on How to Manage Their Disease

In addition to the psychosocial support, patients and caregivers suffer from a lack of information on disease management. This type of information may help better equip them to face their condition and engage their families and friends for ongoing support.

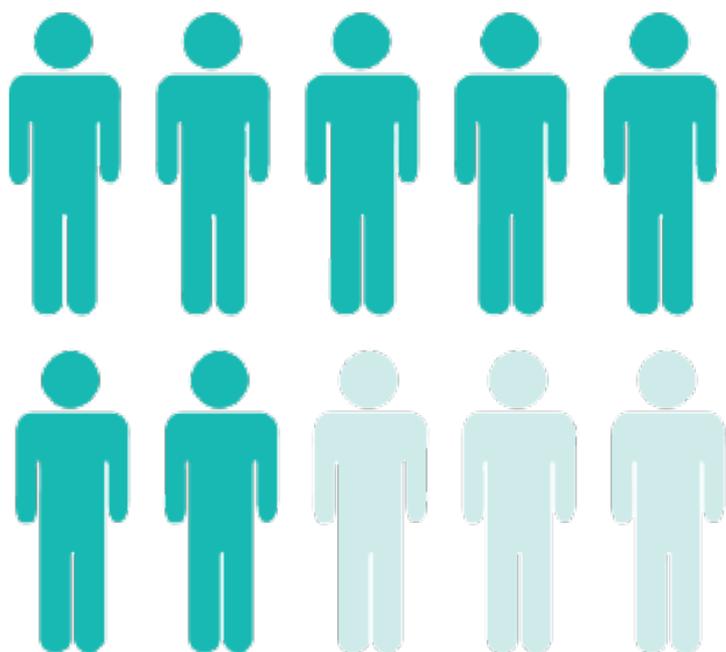
- **7 in 10 patients (72%)** agreed that better disease management can help improve overall well-being
- **Over half of patients (53%) and caregivers (55%)** indicated that a better understanding of the steps they can take to help manage IPF

symptoms can help improve overall well-being

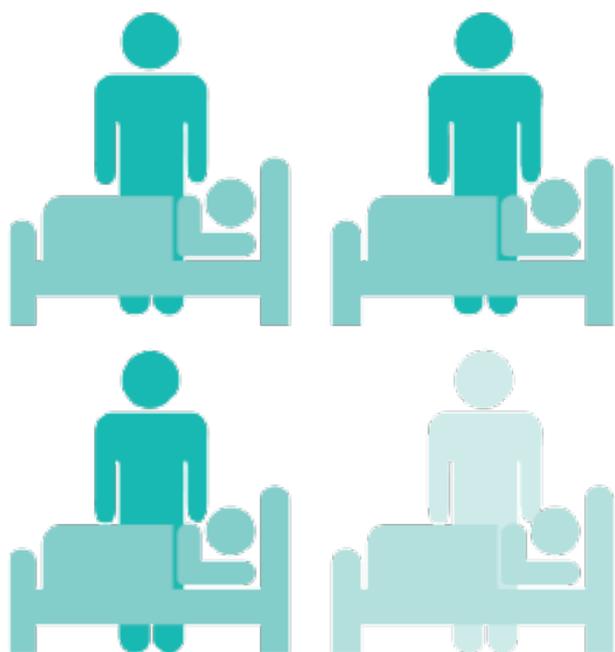
- **7 in 10 patients (70%) and 3 in 4 caregivers (75%)** agreed that in-person and online support groups would be helpful (Figure 11)

FIGURE 11

PATIENTS



CAREGIVERS



- **7 in 10 patients (68%)** reported that it was a struggle telling friends and family about their IPF, suggesting that support materials would be an important resource for patients

ABOUT THE EXPLORE IPF SURVEY

The Advisory Committee, which was responsible for the development and contextualization of the survey, include:

- **Jeffrey James Swigris, DO, MS**, associate professor of medicine,

Autoimmune Lung Center and Interstitial Lung Disease Program,
National Jewish Health

- **Richard Kradin, MD**, pulmonologist and psychiatrist, Pulmonary and Critical Care Unit, Massachusetts General Hospital
- **Dolly Kervitsky, RCP, CCRC**, nationally recognized patient advocate
- **Carolyn Spada, RN, BSN**, interstitial lung disease nurse coordinator, The Center for Interstitial Lung Disease, University of Washington Medical Center
- **Jennifer Hayes, RN, BSN**, interstitial lung disease nurse coordinator, The Center for Interstitial Lung Disease, University of Washington Medical Center
- **John Morthanos**, New Haven, CT, IPF patient
- **Craig Conoscenti, MD, FCCP**, Director, Idiopathic Pulmonary Fibrosis Program Lead, Clinical Development and Medical Affairs, Respiratory, Boehringer Ingelheim Pharmaceuticals, Inc.
- **Dale Baird**, Associate Director, Pipeline Market Research, Boehringer Ingelheim Pharmaceuticals, Inc

EXPLORE IPF is a national survey examining the emotional burden facing patients and caregivers living with IPF through the phases of diagnosis.

The survey was conducted by research company Taylor Nelson Sofres (TNS) and sponsored by Boehringer Ingelheim. The survey was conducted between April 14, 2014 and May 15, 2014 among 100 patients with IPF and 100 caregivers, all self-reported and age 18 and over in the United States. Respondents completed a 15-minute online survey exploring their IPF journey, retrospectively.

Results were weighted by gender, race and region to provide representative IPF population sampling.

REFERENCE

BI data on file. EXPLORE IPF Survey Results.

THIS INFORMATION IS FOR U.S. RESIDENTS ONLY.

COPYRIGHT © 2015, BOEHRINGER INGELHEIM PHARMACEUTICALS, INC. ALL RIGHTS RESERVED.

