

National Awareness Survey 2020



#### Table of Contents

lı	ntroduction	3
	Executive Summary	3
	Survey Methodology	3
	Key Findings	3
F	inal Report4	-24
	Question 1: Which of the following best describes your familiarity with pulmonary fibrosis (PF)?	4
	Question 2: How serious of a disease would you consider PF?	5
	Question 3: Of the following respiratory illnesses, which one do you consider the most serious?	6
	Question 4: Have you or anyone you know been affected by PF?	7
	Question 4a: Who in relation to you has been affected by PF?	7
	Question 5: Do you know the symptoms of PF?	8
	Question 6: To the best of your knowledge, which of the following are symptoms of PF?9	-10
	Question 7: If you had a lingering cough and fatigue, what would you do?	. 11
	Question 8: If you had a lingering cough and fatigue, how serious would you consider it?	. 12
	Question 9: If you had a lingering cough and fatigue, how long would you wait to visit a doctor?	. 13
	Question 10: Of the symptoms listed below, which would prompt you to see a doctor if the symptoms persisted for longer than a month?	. 14
	Question 11: Has your doctor ever talked to you about PF?	. 15
	Question 12: If recommended by your primary doctor, what factors might prevent you from visiting a specialist for PF?	-17
	Question 13: How important is finding a cure for PF?	. 18
	Question 14: Do you think there will be a cure for PF within your lifetime?	. 19
	Question 15: If you were diagnosed with PF, how concerned would you be?	. 20
	Question 16: If you were diagnosed with PF, what type of support would you want to receive?	. 21
	Question 17: If you wanted to learn more about PF, where would you go?	. 22
C	urrent/Former Smoker Population23	-24
	Question 18: Are you currently a smoker or have you been a smoker in the past?	. 23
	Question 18a: Of the following respiratory illnesses, which one do you consider the most serious?	. 23
	Question 18b: Do you know the symptoms of PF?	. 23
	Question 18c: Have you or anyone you know been affected by PF?	. 24
	Question 18d: Has your doctor ever talked to you about PF?	. 24



#### **Executive Summary**

The Pulmonary Fibrosis Foundation (PFF) commissioned a national survey online to determine public awareness of pulmonary fibrosis (PF). Since symptoms of PF are similar to other illnesses like the common cold, it can be difficult to diagnose and treat, leading to late stage diagnoses. The purpose of this survey was to identify how many people are familiar with PF, as well as levels of awareness and behaviors in relation to symptoms.

#### **Survey Methodology**

The survey was administered online to 2,013 adults in the United States. The margin of error is +/-2 percentage points with a confidence interval of 95 percent. The fieldwork was performed between January 9 and January 10, 2020 by Atomik Research, an independent creative market research agency.

#### **Key Findings**

The survey findings reveal awareness of PF is alarmingly low, especially when it comes to the symptoms associated with the disease.

#### **Awareness**

- A vast majority of Americans (86%) do not know the symptoms of PF.
- An overwhelming 90% of people report their doctors have never talked to them about PF.
- Of those age 60 and older, who are most at risk for PF, 91% do not know the symptoms of PF and 96% have never talked to their doctor about PF.
- Despite the overall lack of awareness of PF symptoms, 82% of Americans consider PF to be a serious disease.

#### Behavior

- 80% of Americans would see a doctor if they experienced shortness of breath for longer than a month.
- Nearly 4 in 5 (78%) Americans would go to the doctor if they had symptoms of a lingering cough and fatigue.
- 1 in 2 Americans would wait fewer than 3 weeks to visit a doctor if they had symptoms of a lingering cough and fatigue.

#### Finding a Cure

• About 1 in 2 Americans (49%) say that finding a cure for PF is very important, and 61% of Americans are unsure if there will be a cure for PF within their lifetime.

#### Current/Former Smoker Population

- Those who currently smoke or have smoked were almost 10% more likely than nonsmokers to know the symptoms of PF.
- Those who currently smoke or have smoked were 10% more likely to have suffered from PF or know someone affected by PF.
- Nearly 10% of smokers or former smokers say their doctor has talked to them about PF, compared to only 3% of non-smokers.
- Those with a history of smoking were more likely to consider COPD the most serious respiratory illness (37%), while those without a history of smoking consider cystic fibrosis the most serious (27%).

## Question 1 Which of the following best describes your familiarity with pulmonary fibrosis?



#### **Overall Results**

	Rank		
Total	2,013 (100%)		
Never heard of it	460 (23%)		
Only heard of the name	1,146 (57%)		
Somewhat familiar	331 (16%)		
Very familiar	76 (4%)		

Only 4% of people are <u>very</u> familiar with PF.

Results by Gender

	Male	Female
Total	1,002	1,011
Never heard of it	217 (22%)	243 (24%)
Only heard of the name	565 (56%)	581 (57%)
Somewhat familiar	166 (17%)	165 (16%)
Very familiar	54 (5%)	22 (2%)

Only 5% of men and 2% of women are very familiar with PF.

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Never heard of	72 (27%)	82 (21%)	111 (26%)	93 (26%)	22 (19%)	80 (17%)
it						
Only heard of	135 (51%)	206 (54%)	223 (53%)	192 (54%)	77 (66%)	313 (67%)
the name						
Somewhat	49 (18%)	76 (20%)	68 (16%)	55 (15%)	16 (14%)	67 (14%)
familiar						
Very familiar	9 (3%)	21 (5%)	22 (5%)	18 (5%)	2 (2%)	4 (1%)

Only 1% of 60-year-olds and older, who are most at risk, are very familiar with PF.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Never heard of it	127 (25%)	91 (23%)	162 (21%)	80 (23%)
Only heard of the name	284 (55%)	262 (56%)	396 (60%)	204 (58%)
Somewhat familiar	87 (17%)	69 (17%)	119 (16%)	56 (16%)
Very familiar	19 (4%)	14 (5%)	32 (3%)	11 (3%)

More people in the South (60%) have only heard of the name pulmonary fibrosis, compared to other regions.

## **Question 2**How serious of a disease would you consider pulmonary fibrosis?



**Overall Results** 

<u> </u>			
	Rank		
Total	2,013 (100%)		
Not serious	28 (1%)		
Somewhat serious	639 (32%)		
Very serious	1,006 (50%)		
Not sure	340 (17%)		

82% of respondents consider pulmonary fibrosis to be a serious disease.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Not serious	16 (2%)	12 (1%)
Somewhat serious	316 (32%)	323 (32%)
Very serious	495 (49%)	511 (51%)
Not sure	175 (17%)	165 (16%)

Women (83%) are slightly more likely to consider pulmonary fibrosis a serious disease than men (81%).

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Not serious	4 (2%)	3 (1%)	11 (3%)	4 (1%)	0 (0%)	6 (1%)
Somewhat	77 (29%)	124 (32%)	150 (35%)	118 (33%)	40 (34%)	130 (28%)
serious						
Very serious	132 (50%)	190 (49%)	193 (46%)	177 (49%)	59 (50%)	255 (55%)
Not sure	52 (20%)	68 (18%)	70 (17%)	59 (16%)	18 (15%)	73 (16%)

60-year-olds and older (55%), who are most at risk, are the most likely to consider PF to be a <u>very</u> serious disease.

**Results by Region** 

	Northeast	Midwest	South	West	
Total	517	436	709	351	
Not serious	7 (1%)	8 (2%)	11 (2%)	2 (1%)	
Somewhat serious	160 (31%)	138 (32%)	240 (34%)	101 (29%)	
Very serious	260 (50%)	211 (48%)	348 (49%)	187 (53%)	
Not sure	90 (17%)	79 (18%)	110 (16%)	61 (17%)	

Respondents in the South (83%) are more likely to consider PF to be a serious disease.

#### **Question 3**

### Of the following respiratory illnesses, which one do you consider the most serious?



**Overall Results** 

<u> </u>				
	Rank			
Total	2,013 (100%)			
Pneumonia	267 (13%)			
Cystic fibrosis	460 (23%)			
COPD/Chronic Obstructive	617 (31%)			
Pulmonary Disease				
Pulmonary fibrosis	135 (7%)			
I don't know	534 (27%)			

Only 7% of respondents consider PF to be the most serious disease when compared to other respiratory illnesses.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Pneumonia	166 (17%)	101 (10%)
Cystic fibrosis	195 (19%)	265 (26%)
COPD/Chronic Obstructive	313 (31%)	304 (30%)
Pulmonary Disease		
Pulmonary fibrosis	81 (8%)	54 (5%)
I don't know	247 (25%)	287 (28%)

More men (8%) than women (5%) consider PF to be the most serious.

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Pneumonia	38 (14%)	61 (16%)	53 (13%)	38 (11%)	10 (9%)	67 (14%)
Cystic fibrosis	68 (26%)	79 (21%)	105 (25%)	80 (22%)	25 (21%)	103 (22%)
COPD/Chronic	57 (22%)	118 (31%)	127 (30%)	132 (37%)	44 (38%)	139 (30%)
Obstructive						
Pulmonary						
Disease						
Pulmonary	20 (8%)	32 (8%)	27 (6%)	22 (6%)	5 (4%)	29 (6%)
fibrosis						
I don't know	82 (31%)	95 (25%)	112 (26%)	86 (24%)	33 (28%)	126 (27%)

Only 6% of 60year-olds and older consider PF to be the most serious disease.

Results by Region

	Northeast	Midwest	South	West
Total	517	436	709	351
Pneumonia	57 (11%)	53 (12%)	107 (15%)	50 (14%)
Cystic fibrosis	106 (21%)	121 (28%)	152 (21%)	81 (23%)
COPD/Chronic	169 (33%)	123 (28%)	217 (31%)	108 (31%)
Obstructive Pulmonary				
Disease				
Pulmonary fibrosis	34 (7%)	33 (8%)	47 (7%)	21 (6%)
I don't know	151 (29%)	106 (24%)	186 (26%)	91 (26%)

Respondents in the Northeast consider COPD (33%) as the most serious disease, and PF (7%) as the least serious.

#### **Pulmonary Fibrosis** FOUNDATION

### **National Awareness Survey**

### **Question 4**

#### Have you or anyone you know been affected by pulmonary fibrosis?

#### **Overall Results**

<u> </u>	
	Rank
Total	2,013 (100%)
Yes	147 (7%)
No	1,382 (69%)
Not sure	484 (24%)

69% of respondents report not knowing anyone affected by PF.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Yes	94 (9%)	53 (5%)
No	668 (67%)	714 (71%)
Not sure	240 (24%)	244 (24%)

Females (71%) are less likely to know anyone affected by PF than men (67%).

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Yes	19 (7%)	28 (7%)	38 (9%)	36 (10%)	3 (3%)	23 (5%)
No	173 (65%)	253 (66%)	280 (66%)	240 (67%)	82 (70%)	354 (76%)
Not sure	73 (28%)	104 (27%)	106 (25%)	82 (23%)	32 (27%)	87 (19%)

60-year-olds and older (76%) are less likely to know anyone affected by PF than 18-24-yearolds (65%).

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Yes	30 (6%)	39 (9%)	56 (8%)	22 (6%)
No	373 (72%)	294 (67%)	483 (68%)	232 (66%)
Not sure	114 (22%)	103 (24%)	170 (24%)	97 (28%)

A majority of respondents in the Northeast (72%) report not knowing anyone affected by PF.

#### Question 4a

Who in relation to you has been affected by pulmonary fibrosis? Note: Small sample size of respondents

#### Overall Results

	Rank
Total	147
Myself	45 (31%)
Immediate family	49 (33%)
Extended family	33 (22%)
Friend or acquaintance	46 (31%)

### **Question 5 Do you know the symptoms of pulmonary fibrosis?**



**Overall Results** 

	Rank
Total	2,013 (100%)
Yes	282 (14%)
No	1,731 (86%)

86% of people do not know the symptoms of PF.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Yes	167 (17%)	115 (11%)
No	835 (83%)	896 (89%)

More men (17%) know the symptoms of PF than women (11%).

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Yes	46 (17%)	66 (17%)	67 (16%)	52 (15%)	8 (7%)	43 (9%)
No	219 (83%)	319 (83%)	357 (84%)	306 (85%)	109 (93%)	421 (91%)

91% of 60year-olds and older, who are most at risk, do not know the symptoms of PF.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Yes	76 (15%)	58 (13%)	102 (14%)	46 (13%)
No	441 (85%)	378 (87%)	607 (86%)	305 (87%)

87% of respondents in the Midwest and West regions do not know the symptoms of PF.



### **Question 6**

#### To the best of your knowledge, which of the following are symptoms of pulmonary fibrosis?

#### **Overall Results**

	Rank
Total	2,013 (100%)
Shortness of breath	985 (49%)
Fatigue	775 (38%)
Persistent, dry cough	693 (34%)
Rapid/irregular heartbeat	414 (21%)
Swelling in legs, ankles, and feet	311 (15%)
Aching muscles and joints	299 (15%)
Water retention/bloating	253 (13%)
Numbness or weakness in face, arm or leg	235 (12%)
Unexplained weight loss	214 (11%)
Widening and rounding of the tips of the fingers or toes (clubbing)	201 (10%)
Difficulty concentrating	129 (6%)
None of these	67 (3%)
I'm not sure	708 (35%)

When prompted, respondents are most likely to identify the symptoms of PF, including shortness of breath (49%), fatigue (38%) and persistent, dry cough (34%).

**Results by Gender** 

Male	Female
1,002	1,011
471 (47%)	514 (51%)
394 (39%)	381 (38%)
338 (34%)	355 (35%)
224 (22%)	190 (19%)
146 (15%)	165 (16%)
160 (16%)	139 (14%)
118 (12%)	135 (13%)
128 (13%)	107 (11%)
120 (12%)	94 (9%)
106 (11%)	95 (9%)
78 (8%)	51 (5%)
36 (4%)	31 (3%)
350 (35%)	358 (35%)
	471 (47%) 394 (39%) 338 (34%) 224 (22%) 146 (15%) 160 (16%) 118 (12%) 128 (13%) 120 (12%) 106 (11%)  78 (8%) 36 (4%)

More women (51%) identified shortness of breath as a symptom of PF than men (47%).



#### **Results by Age Group**

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Aching muscles and joints	47 (18%)	74 (19%)	54 (13%)	62 (17%)	13 (11%)	49 (11%)
Difficulty concentrating	25 (9%)	23 (6%)	27 (6%)	26 (7%)	7 (6%)	21 (5%)
Fatigue	90 (34%)	139 (36%)	170 (40%)	163 (46%)	38 (32%)	175 (38%)
Numbness or weakness in	39 (15%)	56 (15%)	56 (13%)	35 (10%)	9 (8%)	40 (9%)
face, arm or leg						
Persistent, dry cough	76 (29%)	125 (32%)	154 (36%)	136 (38%)	35 (30%)	167 (36%)
Rapid/irregular heartbeat	57 (22%)	90 (23%)	104 (25%)	89 (25%)	14 (12%)	60 (13%)
Shortness of breath	108 (41%)	188 (49%)	212 (50%)	187 (52%)	51 (44%)	239 (52%)
Swelling in legs, ankles, and	29 (11%)	65 (17%)	70 (17%)	57 (16%)	20 (17%)	70 (15%)
feet						
Unexplained weight loss	33 (12%)	52 (14%)	39 (9%)	37 (10%)	11 (9%)	42 (9%)
Water retention/bloating	25 (9%)	38 (10%)	62 (15%)	44 (12%)	8 (7%)	76 (16%)
Widening and rounding of	27 (10%)	43 (11%)	47 (11%)	33 (9%)	9 (8%)	42 (9%)
the tips of the fingers or toes						
(clubbing)						
None of these	14 (5%)	18 (5%)	11 (3%)	8 (2%)	4 (3%)	12 (3%)
I'm not sure	93 (35%)	122 (32%)	139 (33%)	117 (33%)	52 (44%)	185 (40%)

45-54-year-olds (46%) are more likely to identify fatigue as a PF symptom than 60-year-olds and older (38%), who are most at risk.

**Results by Region** 

The state of the s	Northeast	Midwest	South	West
Total	517	436	709	351
Aching muscles and joints	80 (15%)	54 (12%)	117 (17%)	48 (14%)
Difficulty concentrating	31 (6%)	25 (6%)	48 (7%)	25 (7%)
Fatigue	199 (38%)	162 (37%)	292 (41%)	122 (35%)
Numbness or weakness in face, arm or leg	68 (13%)	46 (11%)	84 (12%)	37 (11%)
Persistent, dry cough	191 (37%)	141 (32%)	243 (34%)	118 (34%)
Rapid/irregular heartbeat	100 (19%)	87 (20%)	160 (23%)	67 (19%)
Shortness of breath	264 (51%)	204 (47%)	351 (50%)	166 (47%)
Swelling in legs, ankles, and feet	84 (16%)	59 (14%)	113 (16%)	55 (16%)
Unexplained weight loss	50 (10%)	36 (8%)	90 (13%)	38 (11%)
Water retention/bloating	82 (16%)	51 (12%)	74 (10%)	46 (13%)
Widening and rounding of the tips of the fingers or toes	50 (10%)	32 (7%)	73 (10%)	46 (13%)
(clubbing)				
None of these	20 (4%)	14 (3%)	21 (3%)	12 (3%)
I'm not sure	172 (33%)	159 (36%)	243 (34%)	134 (38%)

More respondents in the Northeast identified shortness of breath (51%) and persistent, dry cough (37%) as PF symptoms compared to other regions.

### Question 7 If you had a lingering cough and fatigue, what would you do?



**Overall Results** 

	Rank
Total	2,013 (100%)
Go to the doctor	1,567 (78%)
Search symptoms online	546 (27%)
Nothing, wait for it to	212 (11%)
get better	
Talk to a friend	159 (8%)

78% of people would go to the doctor if they had a lingering cough and fatigue.

Results by Gender

	Male	Female
Total	1,002	1,011
Go to the doctor	771 (77%)	796 (79%)
Search symptoms online	279 (28%)	267 (26%)
Nothing, wait for it to	107 (11%)	105 (10%)
get better		
Talk to a friend	80 (8%)	79 (8%)

More females (79%) would go to the doctor if they had a lingering cough and fatigue, compared to men (77%).

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Search	89 (34%)	128 (33%)	135 (32%)	101 (28%)	28 (24%)	65 (14%)
symptoms						
online						
Talk to a friend	24 (9%)	50 (13%)	36 (8%)	33 (9%)	6 (5%)	10 (2%)
Go to the	184 (69%)	267 (69%)	326 (77%)	292 (82%)	97 (83%)	401 (86%)
doctor						
Nothing, wait	36 (14%)	51 (13%)	46 (11%)	31 (9%)	10 (9%)	38 (8%)
for it to get						
better						

60-year-olds and older (86%), who are most at risk, are most likely to go to a doctor if they had a lingering cough and fatigue.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Search symptoms online	137 (26%)	107 (25%)	198 (28%)	104 (30%)
Talk to a friend	41 (8%)	36 (8%)	62 (9%)	20 (6%)
Go to the doctor	408 (79%)	333 (76%)	551 (78%)	275 (78%)
Nothing, wait for it to	51 (10%)	47 (11%)	76 (11%)	38 (11%)
get better				

Respondents in the Northeast (79%) are the most likely to go to a doctor for a lingering cough and fatigue.

## Question 8 If you had a lingering cough and fatigue, how serious would you consider it?



**Overall Results** 

	Rank
Total	2,013 (100%)
Somewhat serious	1,342 (67%)
Very serious	362 (18%)
Not serious	309 (15%)

85% of people consider a lingering cough and fatigue to be serious.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Not serious	143 (14%)	166 (16%)
Somewhat serious	653 (65%)	689 (68%)
Very serious	206 (21%)	156 (15%)

More men (86%) consider a lingering cough and fatigue to be serious than women (83%).

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Not serious	51 (19%)	76 (20%)	72 (17%)	45 (13%)	14 (12%)	51 (11%)
Somewhat	182 (69%)	231 (60%)	277 (65%)	245 (68%)	84 (72%)	323 (70%)
serious						
Very serious	32 (12%)	78 (20%)	75 (18%)	68 (19%)	19 (16%)	90 (19%)

Only 19% of 60-year-olds and older consider a lingering cough and fatigue to be very serious.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Not serious	75 (15%)	82 (19%)	100 (14%)	52 (15%)
Somewhat serious	351 (68%)	278 (64%)	479 (68%)	234 (67%)
Very serious	91 (18%)	76 (17%)	130 (18%)	65 (19%)

Respondents in the Midwest (81%) are least likely to consider a lingering cough and fatigue to be serious compared to other regions (86%).

### **Question 9**If you had a lingering cough and fatigue, how long would you wait to visit a doctor?

**Overall Results** 

O VOI all' I COOdito	
	Rank
Total	2,013 (100%)
Less than 3 weeks	1,020 (51%)
3-4 weeks	633 (31%)
1-5 months	267 (13%)
6-12 months	45 (2%)
1-2 years	15 (1%)
More than 2 years	33 (2%)

51% of people would wait fewer than three weeks to visit a doctor for a lingering cough and fatigue.

Results by Gender

	Male	Female
Total	1,002	1,011
Less than 3 weeks	540 (54%)	480 (47%)
3-4 weeks	296 (30%)	337 (33%)
1-5 months	114 (11%)	153 (15%)
6-12 months	27 (3%)	18 (2%)
1-2 years	8 (1%)	7 (1%)
More than 2 years	17 (2%)	16 (2%)

More men (54%) would wait fewer than three weeks to visit a doctor for a lingering cough and fatigue than women (47%).

**Results by Age Group** 

Troounce by rigo	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Less than 3	139 (52%)	182 (47%)	191 (45%)	168 (47%)	68 (58%)	272 (59%)
weeks						
3-4 weeks	82 (31%)	137 (36%)	128 (30%)	124 (35%)	32 (27%)	130 (28%)
1-5 months	33 (12%)	46 (12%)	73 (17%)	54 (15%)	16 (14%)	45 (10%)
6-12 months	4 (2%)	10 (3%)	18 (4%)	5 (1%)	1 (1%)	7 (2%)
1-2 years	1 (<1%)	2 (1%)	7 (2%)	4 (1%)	0 (0%)	1 (<1%)
More than 2	6 (2%)	8 (2%)	7 (2%)	3 (1%)	0 (0%)	9 (2%)
years						

60-year-olds and older (59%) are most likely to wait fewer than three weeks to visit a doctor for a lingering cough and fatigue.

Results by Region

	Northeast	Midwest	South	West
Total	517	436	709	351
Less than 3 weeks	270 (52%)	207 (47%)	385 (54%)	158 (45%)
3-4 weeks	172 (33%)	147 (34%)	206 (29%)	108 (31%)
1-5 months	54 (10%)	59 (14%)	86 (12%)	68 (19%)
6-12 months	10 (2%)	9 (2%)	18 (3%)	8 (2%)
1-2 years	5 (1%)	4 (1%)	3 (<1%)	3 (1%)
More than 2 years	6 (1%)	10 (2%)	11 (2%)	6 (2%)

Respondents in the South (54%) are more likely to wait fewer than three weeks to see a doctor for a lingering cough and fatigue.

#### **Question 10**



Of the symptoms listed below, which would prompt you to see a doctor if the symptoms persisted for longer than a month?

**Overall Results** 

	Rank
Total	2,013 (100%)
Shortness of breath	1,618 (80%)
Dizziness	1,472 (73%)
Nausea	1,254 (62%)
Cough	1,136 (56%)
Headaches	1,088 (54%)
Fatigue	973 (48%)
None of the above	84 (4%)

80% of people would see a doctor if experiencing shortness of breath for longer than a month.

Results by Gender

	Male	Female
Total	1,002	1,011
Shortness of breath	770 (77%)	848 (84%)
Dizziness	724 (72%)	748 (74%)
Nausea	620 (62%)	634 (63%)
Cough	559 (56%)	577 (57%)
Headaches	553 (55%)	535 (53%)
Fatigue	493 (49%)	480 (47%)
None of the above	48 (5%)	36 (4%)

More women (84%) than men (77%) would see a doctor if experiencing shortness of breath for longer than a month.

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Headaches	137 (52%)	221 (57%)	221 (52%)	196 (55%)	32 (53%)	251 (54%)
Cough	110 (42%)	197 (51%)	216 (51%)	210 (59%)	82 (70%)	321 (69%)
Fatigue	128 (48%)	166 (43%)	183 (43%)	184 (51%)	54 (46%)	258 (56%)
Shortness of breath	187 (71%)	306 (79%)	328 (77%)	300 (84%)	104 (89%)	393 (85%)
Dizziness	185 (70%)	279 (72%)	296 (70%)	276 (77%)	91 (78%)	345 (74%)
Nausea	165 (62%)	236 (61%)	262 (62%)	221 (62%)	80 (68%)	290 (63%)
None of the above	18 (7%)	14 (4%)	24 (6%)	6 (2%)	2 (2%)	20 (4%)

55-59-yearolds (89%) are most likely to see a doctor if experiencing shortness of breath for longer than a month.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Headaches	288 (56%)	222 (51%)	402 (57%)	176 (50%)
Cough	274 (53%)	251 (58%)	410 (58%)	201 (57%)
Fatigue	260 (50%)	198 (45%)	365 (51%)	150 (43%)
Shortness of breath	418 (81%)	352 (81%)	569 (80%)	279 (79%)
Dizziness	380 (74%)	324 (74%)	525 (74%)	243 (69%)
Nausea	315 (61%)	267 (61%)	451 (64%)	221 (63%)
None of the above	25 (5%)	15 (3%)	25 (4%)	19 (5%)

Respondents in the West (43%) are least likely to see a doctor if experiencing fatigue for longer than a month.

### **Question 11**Has your doctor ever talked to you about pulmonary fibrosis?



**Overall Results** 

	Rank
Total	2,013 (100%)
Yes	112 (6%)
No	1,821 (90%)
Not sure	80 (4%)

90% of people report never talking to their doctor about PF.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Yes	84 (8%)	28 (3%)
No	877 (88%)	944 (93%)
Not sure	41 (4%)	39 (4%)

Men, who are more at risk than women, are more likely to report talking to their doctor about PF than women.

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Yes	25 (9%)	22 (6%)	33 (8%)	21 (6%)	2 (2%)	9 (2%)
No	216 (82%)	346 (90%)	377 (89%)	326 (91%)	112 (96%)	444 (96%)
Not sure	24 (9%)	17 (4%)	14 (3%)	11 (3%)	3 (3%)	11 (2%)

96% of 60year-olds and older, who are most at risk, report never talking to their doctor about PF.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Yes	31 (6%)	24 (6%)	36 (5%)	21 (6%)
No	458 (89%)	400 (92%)	645 (91%)	318 (91%)
Not sure	28 (5%)	12 (3%)	28 (4%)	12 (3%)

92% of respondents in the Midwest report never talking to their doctor about PF.



#### **Question 12**

If recommended by your primary doctor, what factors might prevent you from visiting a specialist for pulmonary fibrosis?

#### **Overall Results**

	Rank
Total	2,013 (100%)
Lack of knowledge	419 (21%)
Financial concerns	749 (37%)
Health insurance limitations	776 (39%)
Fear	414 (21%)
Stigma	51 (3%)
Limited access where I live	312 (15%)
None of the above	627 (31%)
Other (Please Specify)	8 (<1%)

Health insurance limitations (39%) and financial concerns (37%) are the main factors preventing people from visiting a specialist for PF.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Lack of knowledge	222 (22%)	197 (19%)
Financial concerns	356 (36%)	393 (39%)
Health insurance limitations	368 (37%)	408 (40%)
Fear	195 (19%)	219 (22%)
Stigma	31 (3%)	20 (2%)
Limited access where I live	142 (14%)	170 (17%)
None of the above	331 (33%)	296 (29%)
Other (Please Specify)	5 (<1%)	3 (<1%)

Women (40%) are more likely to report health insurance limitations as a factor that might prevent them from seeing a specialist for PF than men (37%).

**Results by Age Group** 

recente by rige ereap						
	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Lack of knowledge	91 (34%)	122 (32%)	84 (20%)	57 (16%)	14 (12%)	51 (11%)
Financial concerns	118 (45%)	186 (48%)	177 (42%)	122 (34%)	34 (29%)	112 (24%)
Health insurance limitations	112 (42%)	174 (45%)	184 (43%)	134 (37%)	53 (45%)	119 (26%)
Fear	74 (28%)	102 (26%)	96 (23%)	73 (20%)	23 (20%)	46 (10%)
Stigma	17 (6%)	9 (2%)	11 (3%)	11 (3%)	0 (0%)	3 (1%)
Limited access where I live	66 (25%)	64 (17%)	66 (16%)	50 (14%)	15 (13%)	51 (11%)
None of the above	48 (18%)	65 (17%)	101 (24%)	116 (32%)	43 (37%)	254 (55%)
Other (Please Specify)	0 (0%)	3 (1%)	1 (<1%)	2 (1%)	0 (0%)	2 (<1%)

60-year-olds and older are the least likely to consider health insurance as factor that might prevent them from seeing a doctor for PF.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Lack of knowledge	114 (22%)	84 (19%)	157 (22%)	64 (18%)
Financial concerns	159 (31%)	176 (40%)	289 (41%)	125 (36%)
Health insurance	197 (38%)	171 (39%)	284 (40%)	124 (35%)
limitations				
Fear	117 (23%)	82 (19%)	166 (23%)	49 (14%)
Stigma	15 (3%)	12 (3%)	16 (2%)	8 (2%)
Limited access where I	64 (12%)	76 (17%)	119 (17%)	53 (15%)
live				
None of the above	165 (32%)	134 (31%)	194 (27%)	134 (38%)
Other (Please Specify)	1 (<1%)	3 (1%)	1 (<1%)	3 (1%)

81% of respondents in the South are most likely to consider financial concerns and health insurance limitations as factors that might prevent them from seeing a doctor for PF.

### **Question 13**How important is finding a cure for pulmonary fibrosis?

**Overall Results** 

	Rank
Total	2,013 (100%)
Very unimportant	188 (9%)
Somewhat unimportant	53 (3%)
No opinion	323 (16%)
Somewhat important	461 (23%)
Very important	988 (49%)

72% of people think that finding a cure for PF is important.

Results by Gender

	Male	Female
Total	1,002	1,011
Very unimportant	95 (9%)	93 (9%)
Somewhat unimportant	28 (3%)	25 (2%)
No opinion	159 (16%)	164 (16%)
Somewhat important	233 (23%)	228 (23%)
Very important	487 (49%)	501 (50%)

Slightly more women (73%) then men (72%) think that finding a cure for PF is important.

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Very	22 (8%)	33 (9%)	35 (8%)	27 (8%)	12 (10%)	59 (13%)
unimportant						
Somewhat	16 (6%)	12 (3%)	9 (2%)	6 (2%)	2 (2%)	8 (2%)
unimportant						
No opinion	42 (16%)	71 (18%)	88 (21%)	44 (12%)	12 (10%)	66 (14%)
Somewhat	62 (23%)	96 (25%)	106 (25%)	74 (21%)	33 (28%)	90 (19%)
important						
Very important	123 (46%)	173 (45%)	186 (44%)	207 (58%)	58 (50%)	241 (52%)

71% of 60year-olds and older think that finding a cure for PF is important.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Very unimportant	52 (10%)	47 (11%)	58 (8%)	31 (9%)
Somewhat unimportant	14 (3%)	15 (3%)	17 (2%)	7 (2%)
No opinion	86 (17%)	67 (15%)	112 (16%)	58 (17%)
Somewhat important	119 (23%)	111 (25%)	151 (21%)	80 (23%)
Very important	246 (48%)	196 (45%)	371 (52%)	175 (50%)

Respondents in the South (52%) are more likely to consider a cure for PF as <u>very</u> important than those in the Midwest (45%).

#### **Question 14**

#### Do you think there will be a cure for pulmonary fibrosis within your lifetime?



**Overall Results** 

	Rank	
Total	2,013 (100	%)
Yes	544 (27%)	
No	232 (12%)	
Unsure	1,237 (61%	<u>ś)</u>

Only 27% of people think there will be a cure for PF in their lifetime.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Yes	319 (32%)	225 (22%)
No	115 (11%)	117 (12%)
Unsure	568 (57%)	669 (66%)

Men (32%) are more likely to think there will be a cure in their lifetime than women (22%).

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Yes	121 (46%)	145 (38%)	129 (30%)	82 (23%)	12 (10%)	55 (12%)
No	23 (9%)	45 (12%)	33 (8%)	43 (12%)	15 (13%)	73 (16%)
Unsure	121 (46%)	195 (51%)	262 (62%)	233 (65%)	90 (77%)	336 (72%)

Only 9% of 18-24-year-olds report that there will not be a cure for PF in their lifetime.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Yes	156 (30%)	111 (25%)	198 (28%)	79 (23%)
No	61 (12%)	52 (12%)	83 (12%)	36 (10%)
Unsure	300 (58%)	273 (63%)	428 (60%)	236 (67%)

Respondents in the Northeast (30%) are most likely to think there will be a cure for PF in their lifetime.

#### **Question 15**

#### If you were diagnosed with pulmonary fibrosis, how concerned would you be?



**Overall Results** 

O TOTALI I TOOGITO	
	Rank
Total	2,013 (100%)
Not concerned	32 (2%)
Somewhat concerned	455 (23%)
Very concerned	1,328 (66%)
Not sure	198 (10%)

89% of people would be concerned if diagnosed with PF.

Results by Gender

recurs by serias.	Male	Female
Total	1,002	1,011
Not concerned	17 (2%)	15 (1%)
Somewhat concerned	222 (22%)	233 (23%)
Very concerned	670 (67%)	658 (65%)
Not sure	93 (9%)	105 (10%)

Men (67%) are slightly more likely to be very concerned if diagnosed with PF than women (65%).

**Results by Age Group** 

18-24	25-34	35-44	45-54	55-59	60+
265	385	424	358	117	464
6 (2%)	6 (2%)	11 (3%)	2 (1%)	0 (0%)	7 (2%)
63 (24%)	86 (22%)	107 (25%)	73 (20%)	32 (27%)	94 (20%)
163 (62%)	256 (66%)	259 (61%)	249 (70%)	74 (63%)	327 (70%)
33 (12%)	37 (10%)	47 (11%)	34 (9%)	11 (9%)	36 (8%)
	265 6 (2%) 63 (24%) 163 (62%)	265     385       6 (2%)     6 (2%)       63 (24%)     86 (22%)       163 (62%)     256 (66%)	265         385         424           6 (2%)         6 (2%)         11 (3%)           63 (24%)         86 (22%)         107 (25%)           163 (62%)         256 (66%)         259 (61%)	265         385         424         358           6 (2%)         6 (2%)         11 (3%)         2 (1%)           63 (24%)         86 (22%)         107 (25%)         73 (20%)           163 (62%)         256 (66%)         259 (61%)         249 (70%)	265         385         424         358         117           6 (2%)         6 (2%)         11 (3%)         2 (1%)         0 (0%)           63 (24%)         86 (22%)         107 (25%)         73 (20%)         32 (27%)           163 (62%)         256 (66%)         259 (61%)         249 (70%)         74 (63%)

90% of respondents age 45 and older are more likely to be concerned if diagnosed with PF.

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Not concerned	6 (1%)	10 (2%)	8 (1%)	8 (2%)
Somewhat concerned	111 (21%)	111 (25%)	153 (22%)	80 (23%)
Very concerned	347 (67%)	266 (61%)	485 (68%)	230 (66%)
Not sure	53 (10%)	49 (11%)	63 (9%)	33 (9%)

Respondents in the South (90%) are most likely to be concerned if diagnosed with PF.



#### **Question 16** If you were diagnosed with pulmonary fibrosis, what type of support would you want to receive?

#### **Overall Results**

	Rank
Total	2,013 (100%)
Family	1,565 (78%)
Friends	1,143 (57%)
In-person support group	588 (29%)
Phone support group	169 (8%)
Online support group (i.e. forums, social media group, chat rooms, etc.)	560 (28%)
None of the above	167 (8%)

78% of respondents would want to receive support from family if diagnosed with PF.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Family	771 (77%)	794 (79%)
Friends	544 (54%)	599 (59%)
In-person support group	304 (30%)	284 (28%)
Phone support group	89 (9%)	80 (8%)
Online support group (i.e. forums, social media group, chat	239 (24%)	321 (32%)
rooms, etc.)		
None of the above	93 (9%)	74 (7%)

Women (68%) are more likely to use a support group if diagnosed with PF than men (63%).

Results by Age Group

Results by Age Group	10 24	25.24	25 44	45 54	55 <b>5</b> 0	60.
	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Family	211 (80%)	299 (78%)	319 (75%)	279 (78%)	91 (78%)	366 (79%)
Friends	168 (63%)	243 (63%)	246 (58%)	195 (54%)	59 (50%)	232 (50%)
In-person support group	78 (29%)	105 (27%)	121 (29%)	113 (32%)	38 (32%)	133 (29%)
Phone support group	18 (7%)	36 (9%)	36 (8%)	36 (10%)	9 (8%)	34 (7%)
Online support group (i.e. forums, social media group, chat rooms,	60 (23%)	109 (28%)	131 (31%)	107 (30%)	34 (29%)	119 (26%)
etc.)						
None of the above	16 (6%)	25 (6%)	45 (11%)	28 (8%)	8 (7%)	45 (10%)

Results by Region

	Northeast	Midwest	South	West
Total	517	436	709	351
Family	406 (79%)	329 (75%)	555 (78%)	275 (78%)
Friends	276 (53%)	262 (60%)	411 (58%)	194 (55%)
In-person support group	158 (31%)	125 (29%)	207 (29%)	98 (28%)
Phone support group	41 (8%)	31 (7%)	75 (11%)	22 (6%)
Online support group (i.e.	135 (26%)	125 (29%)	198 (28%)	102 (29%)
forums, social media				
group, chat rooms, etc.)				
None of the above	39 (8%)	42 (10%)	59 (8%)	27 (8%)

79% of 60-year-olds and older would want to receive support from family.

> Respondents in the South (68%) are most likely to use a support group.

### **Question 17**If you wanted to learn more about pulmonary fibrosis, where would you go?

**Overall Results** 

<u> </u>	
	Rank
Total	2,013 (100%)
Online	1,501 (75%)
Doctor/health provider	1,182 (59%)
Health organization/foundation	442 (22%)
Friend or family member	193 (10%)
Other (please specify)	7 (<1%)

75% of respondents would search online to learn more about PF.

**Results by Gender** 

	Male	Female
Total	1,002	1,011
Online	737 (74%)	764 (76%)
Doctor/health provider	615 (61%)	567 (56%)
Health organization/foundation	213 (21%)	229 (23%)
Friend or family member	113 (11%)	80 (8%)
Other (please specify)	2 (<1%)	5 (<1%)

Males (61%) are more likely to go to their doctor to learn more about PF than women (56%).

**Results by Age Group** 

	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Online	183 (69%)	288 (75%)	325 (77%)	281 (78%)	91 (78%)	333 (72%)
Doctor/health provider	153 (58%)	222 (58%)	238 (56%)	202 (56%)	76 (65%)	291 (63%)
Health	83 (31%)	104 (27%)	85 (20%)	66 (18%)	22 (19%)	82 (18%)
organization/foundation						
Friend or family	41 (15%)	54 (14%)	36 (8%)	30 (8%)	8 (7%)	24 (5%)
member						
Other (please specify)	1 (<1%)	1 (<1%)	0 (0%)	0 (0%)	0 (0%)	5 (1%)

18-24year-olds
are more
likely to
go to a
health
org. for
more info
about PF
than
those age
60 and
older
(18%).

**Results by Region** 

	Northeast	Midwest	South	West
Total	517	436	709	351
Online	393 (76%)	328 (75%)	508 (72%)	272 (77%)
Doctor/health provider	304 (59%)	245 (56%)	418 (59%)	215 (61%)
Health	107 (21%)	90 (21%)	160 (23%)	85 (24%)
organization/foundation				
Friend or family	53 (10%)	51 (12%)	59 (8%)	30 (9%)
member				
Other (please specify)	1 (<1%)	3 (1%)	2 (<1%)	1 (<1%)

Respondents in the West (61%) are most likely to visit a doctor to learn more about PF.

#### **Question 18**

### Are you currently a smoker or have you been a smoker in the past?



#### **Overall Results**

	Rank			
Total	2,013 (100%)			
Yes	799 (40%)			
No	1,214 (60%)			

40% of respondents are currently smokers or have been smokers in the past.

#### **Results by Gender**

	Male	Female
Total	1,002	1,011
Yes	438 (44%)	361 (36%)
No	564 (56%)	650 (64%)

More men (44%) report being smokers than women (36%).

#### **Results by Age Group**

, , , , , , , , , , , , , , , , , , ,	18-24	25-34	35-44	45-54	55-59	60+
Total	265	385	424	358	117	464
Yes	78 (29%)	152 (39%)	174 (41%)	147 (41%)	45 (38%)	203 (44%)
No	187(71%)	233 (61%)	250 (59%)	211 (59%)	72 62%)	261 (56%)

60-year-olds and older (44%) are the most likely to be/have been smokers, compared to 18-24-year-olds (29%).

#### **Results by Region**

	Northeast	Midwest	South	West
Total	517	436	709	351
Yes	208 (40%)	173 (40%)	296 (42%)	122 (35%)
No	309 (60%)	263 (60%)	413 (58%)	229 (65%)

There are more smokers in the South (42%) compared to other regions.

#### **Question 18a**

Of the following respiratory illnesses, which one do you consider the most serious?

Results by Non-Smoker/Smoker Population

	Smoker	Non-Smoker
Total	799	1,214
Pneumonia	111 (14%)	156 (13%)
Cystic fibrosis	136 (17%)	324 (27%)
COPD/ Chronic Obstructive	297 (37%)	320 (26%)
Pulmonary Disease		
Pulmonary fibrosis	54 (7%)	81 (7%)
I don't know	201 (25%)	333 (27%)

Those with a history of smoking are more likely to consider COPD the most serious respiratory illness (37%), while those without a history of smoking consider cystic fibrosis the most serious (27%).

#### **Question 18b**

Do you know the symptoms of pulmonary fibrosis?

**Results by Non-Smoker/Smoker Population** 

	Smoker	Non-Smoker
Total	799	1,214
Yes	153 (19%)	129 (11%)
No	646 (81%)	1,085 (89%)

Those who currently smoke or have smoked are almost 10% more likely than nonsmokers to know the symptoms of PF.

#### **Question 18c**

Have you or anyone you know been affected by pulmonary fibrosis?

**Results by Non-Smoker/Smoker Population** 

	Smoker	Non-Smoker
Total	799	1,214
Yes	93 (12%)	54 (4%)
No	500 (63%)	882 (73%)
Not sure	206 (26%)	278 (23%)

Those who currently smoke or have smoked are almost 10% more likely to have suffered from PF or know someone affected by PF.

#### Question 18d

Has your doctor ever talked to you about pulmonary fibrosis?

Results by Non-Smoker/Smoker Population

	Smoker	Non-Smoker
Total	799	1,214
Yes	75 (9%)	37 (3%)
No	694 (87%)	1,127 (93%)
Not sure	30 (4%)	50 (4%)

Nearly 10% of smokers or former smokers say their doctor has talked to them about PF, compared to only 3% of non-smokers.

#### **About the Pulmonary Fibrosis Foundation**

The Pulmonary Fibrosis Foundation (PFF) mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live longer, healthier lives. The PFF collaborates with physicians, organizations, patients, and caregivers worldwide. The PFF has a three-star rating from Charity Navigator and is a Better Business Bureau accredited charity. For more information, visit pulmonaryfibrosis.org or call 844.TalkPFF (844.825.5733) or 312.587.9272 from outside the U.S.

#### **About Atomik Research**

Atomik Research is a globally recognized market research firm that leverages Focus Vision's Decipher Platform to create powerful custom surveys for some of today's most recognized brands and associations. The Decipher survey tool tracks campaign stats in real-time through a centralized hub, allowing data to be filtered and split to easily discover target segment opinions and story headlines. The online surveys are mobile-friendly and optimized to create a turnkey user experience that results in a comprehensive understanding of consumers' thoughts and feelings towards the survey topics.