

**6. How would you define your gender?**

- Female  
 Male  
 I prefer not to say

I prefer to describe myself as:

**7. What is your age range?**

- 25 or under  
 26 – 35  
 36 – 45  
 46 – 55  
 56 – 65  
 66 – 75  
 76 and over  
 I prefer not to say

**8. What is your ethnic background?**

- Asian/ Asian British  
 Arab  
 Black/ African/Caribbean/Black British  
 White  
 Mixed/multiple ethnic groups  
 I prefer not to say  
 Other (please specify in box below)

**9. Where do you live?**

- England  
 Northern Ireland  
 Scotland  
 Wales  
 I prefer not to say  
 Other (please specify in box below)

**Would you like to help us with the next step?**

Once the survey has closed, we would like to get back in touch for your help with putting the research topics into order of importance or urgency.

If you would like to help with the next steps, please give your consent by providing your contact details below.

**Thank you for taking the time to complete this survey.**



✉ Please complete and return this survey to us before Monday 10 May 2021. To return your survey stamp-free and without charge, please address your envelope to: **'Freepost ACTION FOR PULMONARY FIBROSIS'** – please ensure you use capital letters and there is no need to include our full postal address.

To complete the survey online please visit:  
[www.actionpf.org/research/james-lind-alliance](http://www.actionpf.org/research/james-lind-alliance)



← Scan this QR code to view the online version of this survey.

For more information, please visit our website:  
[www.actionpf.org](http://www.actionpf.org)

🐦 @ActionPFcharity

📘 @ActionforPulmonaryFibrosis

You have been sent this survey by APF because you have told us you are happy to receive information from the charity by post. If you'd like to change how you receive information from us or stop postal communication you can let us know by email: [optout@actionpf.org](mailto:optout@actionpf.org) or write to us OPT OUT, FREEPOST ACTION FOR PULMONARY FIBROSIS with your full name and address so we can make sure we update your information.

Action for Pulmonary Fibrosis, Stuart House, East Wing, St Johns Street, Peterborough PE1 5DD. Registered charity 1152399 in England and Wales.

# Research priorities about progressive pulmonary fibrosis postal survey

James Lind Alliance:  
Feb 2021

Please complete and return this survey to us before Monday 10 May 2021. If you would like us to share the results with you, please leave your name and email address at the end of this survey. Many thanks in advance for your feedback. To complete the survey online please visit: [www.actionpf.org/research/james-lind-alliance](http://www.actionpf.org/research/james-lind-alliance)



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## Section A – Intro

**This is an exciting opportunity for anyone connected to pulmonary fibrosis to shape the future of research. If you have been diagnosed with pulmonary fibrosis, or you know anyone who has or has had it, or if you work with people with pulmonary fibrosis this important survey is for you.**

### The topic

The term progressive pulmonary fibrosis (PPF) describes many conditions characterised by inflammation and fibrosis (scarring) in the lungs. To date, we do not have a cure for pulmonary fibrosis, but we have treatments that can slow down the progress of the disease.

### Setting the research agenda

When the views of those affected by a condition are not considered, scientific research can fail to answer the most important questions. This survey is the first step to collect a broad range of unanswered questions from people affected by pulmonary fibrosis, their carers, and healthcare professionals.

### How you can help

We would like to invite you to complete the following survey. Please let us know about anything which is important to you, with a special focus on diagnosis, treatment, and care. You can report the concerns you have, or you had, before and after the diagnosis. Do not worry if you are not an expert, we want to hear about your experience.

### What we will do with the results

This survey is the first step to collect your views on research that is needed on progressive pulmonary fibrosis. We will check your responses against existing research. Responses that are not yet solved by research will be included in a second survey. Finally there will be a workshop to identify the top 10 research priorities.

### How we will store and use the information

We will keep the information you provide secure. You do not need to provide contact details, but if you do, we will store them securely in an encrypted format. Please only provide your contact details if you would like to take part in the next phase of the process. You will not be personally identifiable in any analysis of the survey results.

By completing this survey, you agree to participate in this project.

## Section B – Survey

We would like to identify any concerns of patients, caregivers, family members, and healthcare professionals, in relation to pulmonary fibrosis. (Please write in the boxes below or scan the QR code)



**1. What questions or concerns about the **diagnosis** of pulmonary fibrosis would you like to see answered by research?**

**2. What questions or concerns about the **treatment** of pulmonary fibrosis would you like to see answered by research?** (E.g. drug and non-drug therapies, pulmonary rehab, managing cough, breathlessness and other symptoms)

**3. What questions or concerns about the **care** of people affected by pulmonary fibrosis would you like to see answered by research?** (E.g. psychological assistance, support groups, carers' issues)

## Section C – Demographic

Please tell us a little about yourself. We will use this information to make sure we are reaching a wide range of people and to understand the needs of different groups better:

**1. Which of the following best describes you?**

- A person living with pulmonary fibrosis
- A carer or family member of someone who has or had pulmonary fibrosis
- A healthcare professional
- An organisation representing the interests of people with pulmonary fibrosis
- Other (please specify in box below)

**2. People living with pulmonary fibrosis or family member, what is your disease or that of the person you care/cared for?**

- Idiopathic pulmonary fibrosis – IPF
- Familial pulmonary fibrosis – FPF
- Non-specific interstitial pneumonia – NSIP
- Chronic hypersensitivity pneumonitis – cHP
- Unclassifiable interstitial lung disease – uILD
- Connective tissue disease-associated ILD (e.g. Rheumatoid Arthritis-ILD, Scleroderma ILD, dermatomyositis, polymyositis)
- Occupational disease related ILD (e.g. pneumoconiosis, silicosis, asbestosis)
- Sarcoidosis
- Other (please specify in box below)

**3. Healthcare professionals only. What is your specific profession?**

- GP
- Nurse
- Physician
- Physiotherapist
- Palliative care
- Oxygen technician
- Psychologist
- Pharmacist
- Dietician
- Other (please specify in box below)

**4. For healthcare professional only. Where do you work?**

- Primary care
- Secondary care
- Tertiary care
- Other (please specify in box below)

**5. For healthcare professionals only. How many years of experience do you have working with ILD patients?**

- None
- Less than 5 years
- 5- 10 years
- More than 10 years