Priority Setting Partnership Postal Survey

James Lind Alliance: April 2022

Have your say!

What are the most important questions for future research on progressive pulmonary fibrosis (PPF)?

Please complete and return this survey to us before Monday 9 May 2022.
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**

Action for Pulmonary Fibrosis

Imperial College London

James Lind Alliance
Priority Setting Partnerships

Section A – Intro

What is this survey for?

We recently ran a survey that asked patients, families and healthcare professionals to tell us their questions about Progressive Pulmonary Fibrosis (PSP). Thank you to the hundreds of people who took part.

We did this to make sure that future research in pulmonary fibrosis is focussed on answering questions that are important to patients, as well as to their families and to healthcare professionals. To date, we do not have a cure for pulmonary fibrosis, but we have treatments that can slow down the process.

We read all your questions, and put the ones that need more research into categories and have produced a list of 44 summary questions. These are set out in this survey and we are asking you to choose the ones that are most important to you. You can see more about the project here:

www.actionpf.org/research/james-lind-alliance

Who can take part in the survey?

We would like to hear from:

- People living with pulmonary fibrosis.
- A carer or family member of someone who has or had pulmonary fibrosis.
- A health or social care professional (including doctors, nurses, and others).
- An organisation representing interests of people of pulmonary fibrosis.

What are we asking you to do?

We have made a list of questions where people have suggested that more research on pulmonary fibrosis is needed.

Please read through the list and tick the questions (please choose up to 10) that you think it is most important for researchers to answer based on your own experiences and your own opinions.

Please ask others to complete this survey too. Once you have completed this survey, please share the link via your social media account and use #PFResearchSurvey.

How will my answers be used?

A summary of the results of this survey will be shared widely to influence the direction of research into pulmonary fibrosis, namely through reports and presentations. Your individual answers will be analysed confidentially and safely by Imperial College London.

We will ask for a little information about you. This is so we can understand who is completing the survey and whether we are hearing from a wide range of people. You do not have to put your name and address or email address on this form unless you want to hear from APF again. Your contact details will not be shared. You will not be identified in any of the survey results and we will keep the information you give us secure.

What will happen next?

After this survey has closed, we will use the survey responses to work out which questions are the most important to people. We will then hold an online workshop for people with experience of pulmonary fibrosis, and healthcare professionals. At the workshop they will discuss the most important questions in more detail and agree the top 10 questions that need researching.

Section B – Questions

SCAN ME

We would like you to read through the questions on this list and tick the ones that you think are the most important for researchers to answer. Please do this based on your own experiences and opinions. You don't need to know about research, and we don't need you to try to answer them. That's for researchers to do later.

Please restrict your selection to a **maximum of 10** questions.

I understand that by participating in this survey, I am agreeing to allow my anonymised answers to be published and shared as part of the survey results. The information we collect from you will help inform our research priorities. We will share demographic information and the results of this survey with funding bodies and research institutions to help guide their decisions about research that still needs to be done. The data we share will be anonymised, and your contact details will not be shared. All information you share with us will be stored securely. For more information on how we use and store data, please visit our privacy statement – https://www.actionpf.org/policies/privacy

I understand that by completing this survey, I consent to my data being used as outlined above. ☐ (Please tick box)

- ☐ What tests and tools (e.g. blood tests, lung function, imaging, virtual and artificial technology) can predict the progression of PPF?
- ☐ How many people live with different types of PPF in the UK?
- ☐ How can acute deteriorations of PPF be predicted in patients with PPF?
- ☐ Can new treatments for PPF be developed with reduced side effects? Does how the drug is delivered (e.g. oral, nebulised, through a vein) affect potential side effects of the drug in PPF?
- ☐ Can treatments halt or reverse PPF?
- ☐ What are the increased medical risks following a diagnosis of PPF during certain medical procedures (e.g. anaesthesia), and how can these be reduced or eliminated?
- ☐ How should exercise programmes and pulmonary rehabilitation be delivered to best improve symptoms and quality of life in PPF?
- ☐ How can the delivery of portable and home-based oxygen be improved (digital monitors, remote control, lighter weight, quieter, higher flow rates) for patients with PPF?
- ☐ What is the best time to refer to occupational therapy to benefit quality of life and improve planning for the future for patients with PPF and their carers?
- ☐ What are the biological changes in human cells that lead to the development of PPF?
- ☐ What can be done to improve the speed and accuracy of PPF diagnosis in primary care (e.g. training, integration of case-based studies in GP training, awareness campaigns)?

- [ ] How can we use new technology (e.g. artificial intelligence) to help inform diagnosis and prognosis of PPF?
- [ ] What is the best time for drug and non-drug interventions (pulmonary rehab, oxygen therapy, psychological support) to start to preserve quality and length of life for patients with PPF?
- [ ] To what extent do different interventions (medication, pulmonary rehab, oxygen therapy, psychological support) impact length of life in patients with PPF?
- [ ] What is the best management of acute deterioration in PPF?
- [ ] How can treatments be tailored for individual patients with PPF?
- [ ] What forms of education and training for Health Care Professionals could improve the way patients and families are informed of the diagnosis of PPF?
- [ ] Can non-drug interventions (e.g. yoga, singing, relaxation techniques, acupuncture, herbal remedies etc) improve wellbeing, symptoms management, and survival in PPF?
- [ ] Does diet help with the management of PPF symptoms?
- [ ] What treatments (drug, non-drug and aids) can reduce breathlessness and phlegm production in PPF?
- [ ] Does psychological wellbeing affect PPF disease progression?
- [ ] What type of support (psychological, peer, drug) is most effective at reducing feelings of isolation, depression and anxiety in patients, carers and families affected by PPF?
- [ ] Are there health inequalities in access to care for PPF (e.g. ethnic minorities or gender differences)? If so how can these be reduced?
- [ ] What tests and tools (e.g. blood tests, lung function, imaging, virtual and artificial technology) should be used to monitor progression of PPF
- [ ] What are the most effective ways to reduce or manage side effects from medications used to treat PPF?
- [ ] How can other co-existing medical conditions (comorbidities) be managed in people living with PPF?
- [ ] How can the diagnosis of PPF be improved in terms of accuracy and the time taken (screening programme, early signs and symptoms that could be detected in primary care, blood markers, imaging, biopsy, artificial intelligence, etc.)?
- [ ] What is the optimum timing for lung transplantation in PPF?
- [ ] What treatments (drug, non-drug and aids) can treat cough in PPF?
- [ ] Would early treatment delay progression, lung function decline, and improve survival in PPF?
- [ ] Which therapies will improve survival in PPF?
- [ ] How can palliative care support be more acceptable for people living with PPF, and when should this be proposed?
- [ ] Can the likelihood of developing PPF be predicted through genetic screening?
- [ ] How does geography impact on the quality of care that a person with PPF receives?
- [ ] What is the most effective multidisciplinary team structure and function to support patients and families affected by PPF?
- [ ] What are the psychological consequences of a diagnosis of PPF for patients, their families, and carers?
- [ ] Can oxygen improve quality of life and outcomes in PPF?
- [ ] How can the discussion and management of end of life in PPF be improved so that patients and families feel better prepared and supported?
- [ ] How can peer support (support groups, befrienders, friends) impact disease management for PPF patients and their carers?
- [ ] What support (e.g. information and training, financial, psychological etc) would enable carers of PPF patients to feel empowered in their role?
- [ ] To what extent can different interventions (medication, pulmonary rehab, oxygen therapy, psychological support) impact quality of life in patients with PPF?
- [ ] How effective are different treatments at treating different types of PPF?
- [ ] Can drugs used to treat other diseases be effective in treating PPF?
- [ ] Can treatments other than pirfenidone and nintedanib slow the progression of PPF?

Please restrict your selection to a **maximum of 10** questions.

#PFResearchSurvey

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? (Please select one only)

- ☐ 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
- ☐ I'd prefer to be identified as...

2. People living with pulmonary fibrosis or family member, what was your diagnosis 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

6. How would you define your gender?

- ☐ Female
- ☐ Male
- ☐ I prefer not to say

I prefer to describe myself as:

7. What is your ethnic background?

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

8. 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

9. Where do you live?

- ☐ England
- ☐ Northern Ireland
- ☐ Scotland
- ☐ Wales
- ☐ Other (please specify in box below)

Would you like to help us with the next step?

The final stage of this project is an online workshop via Zoom involving a series of facilitated group discussions between people with lived experience of PF and healthcare professionals. Participants will work to agree the top 10 questions for future research on PF. It is a chance for people who do not normally influence the research agenda to have their say.

The workshop will be conducted over two mornings (11am-2.30pm on Thursday 16 June, then 11am-1.30pm on Friday 17 June, with breaks). You will need to be able to connect to an online Zoom meeting, via a tablet or computer. We can show you how to use Zoom if you have not used it before. Selected patient and carer participants will be offered an involvement honorarium for their participation.

Please fill in the following information if you are interested in being involved...

Full name:

Email address:

Do you have experience of using Zoom (not essential as we can provide help) and access to a computer or tablet?

- ☐ Yes
- ☐ No

Please tell us why you are interested in taking part in the workshop and what personal/professional experience of PF you bring (max 100 characters)...

Action for Pulmonary Fibrosis

Thank you for taking the time to complete this survey.

Please complete and return this survey to us before Monday 9 May 2022. 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

SCAN ME

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

For more information, please visit our website:
www.actionpf.org

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Action for Pulmonary Fibrosis, Stuart House, East Wing, St Johns Street, Peterborough PE1 5DD.
Registered Charity 1152399 in England and Wales. Registered Charity SC050992 in Scotland.