

Pulmonary Fibrosis Trust Patient and Carer Survey

Thank you for taking the time to participate in our survey. Your voice is important and will provide us with facts to push for greater awareness and patient care for pulmonary fibrosis sufferers.

The survey will last approximately 10 minutes.

About the Pulmonary Fibrosis Trust

The Pulmonary Fibrosis Trust (charity no. 1149901) is the only charity to offer practical support to people living with pulmonary fibrosis (PF) by providing access to medical equipment and aids wherever they live in the UK.

As a charity, and particularly in these difficult times, we want to understand what matters to you - particularly about your experiences regarding treatment and access to support and care - as well as the physical and emotional impact of this cruel disease.

Important information

This survey adheres to the market research code of conduct.

This online questionnaire will be conducted in accordance with the Data Protection Act and Market Research Society.

The aim of this research is to gain your views for market research purposes. Anything you see or read during this research should be treated as confidential. The identity of respondents is confidential and none of your details will be passed on to any 3rd party.

Any information you disclose will be treated in the strictest confidence and the results of the research aggregated to provide an overall picture of attitudes to the areas being covered in this survey. No answers will be attributable to you as an individual.

The outputs of this research may be used by the Pulmonary Fibrosis Trust in a promotional context (at an aggregated level or using anonymised quotes), for example, to educate people and their caregivers and families, raise awareness among the general public (via the media) regarding the burden of pulmonary fibrosis and idiopathic pulmonary fibrosis.

You have the right to withdraw from the research at any time and to withhold information as you see fit.

Please [click here](#) to read our full Privacy Policy.

Thank you again for your time.

Contact details:

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Pulmonary Fibrosis Trust Patient and Carer Survey

About you

1. Which of the following statements most closely describes you?

- I am living with pulmonary fibrosis (PF)
- I am living with idiopathic pulmonary fibrosis (IPF)
- I care for someone living with PF / IPF
- I cared for someone with PF/IPF who has now passed away
- Other (please specify)

2. How long have you, or the person you care/cared for, been diagnosed with IPF/PF?

- | | |
|--|---|
| <input type="radio"/> Less than 3 months | <input type="radio"/> 18-24 months |
| <input type="radio"/> 3-6 months | <input type="radio"/> 24 months - 5 years |
| <input type="radio"/> 6-12 months | <input type="radio"/> More than 5 years |
| <input type="radio"/> 12-18 months | <input type="radio"/> Don't know |

3. What was the cause of your, or the person you care/cared for, condition?

(Please select all that apply then press "OK")

- Acid reflux
- Medication
- Allergen
- Dust
- Virus
- Rheumatoid Arthritis
- Exposure to asbestos
- UNKNOWN
- Other (please specify)

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Being diagnosed

1. After first seeing a doctor about the symptoms causing you, or the person you care/cared for PF/IPF, how long did it take to be diagnosed?

- Less than a month
- 1 to 3 months
- 3 to 6 months
- 6 months to a year
- More than a year
- Don't know/can't remember

2. Was the diagnosis for you, or the person you care/cared for, correct at every point during this time?

- Yes, the diagnosis was correct from the start
- No, PF/IPF was initially diagnosed as something different
- No, PF/IPF was diagnosed as something different a number of times
- Don't know / can't remember

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Wrongful diagnosis

1. If you, or the person you care/cared for, diagnosis was wrong prior to being diagnosed with PF/IPF, please enter what diagnosis was given.

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About treatment and care

1. What health professionals are currently involved in your, or the person you care/cared for, care?

(Please select all that apply then press "OK")

- Respiratory consultant
- GP
- Surgeon
- Respiratory/ILD nurse
- Mental health professional
- Occupational Therapist
- Physiotherapist
- Other (please specify)

2. The way that PF is treated will depend on the cause of the fibrosis. Which of the following types of treatment did you, or the person you care/cared for, receive?

(Please select all that apply and press "OK")

- Antifibrotic therapy e.g. pirfenidone and nintedanib
- Anti-acid therapy
- Immunosuppressant drugs
- Pulmonary rehabilitation (PR)
- Oxygen therapy
- Stop smoking advice
- Other (please specify)

3. Which of the following best describes you, or the person you care/cared for, with regards to lung transplantation?

- Not referred for lung transplant assessment
- Awaiting lung transplant assessment
- Currently being assessed for lung transplant
- Any additional comments
- Post transplant assessment - not accepted
- Currently on lung transplant waiting list
- Received a lung transplant

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About practical support and rehabilitation

1. Have you, or the person you care/cared for, ever been referred to an occupational therapist via the NHS (e.g. from a GP, consultant or following a hospital admission) for practical support? Examples of such support include: stairlifts, grab rails, oxygen at home etc.

- Yes
- No
- Not sure

2. If YES, how long did you, or the person you care/cared for, wait before you received help from an occupational therapist via the NHS?

- Not applicable
- 3-4 weeks
- 1 week
- 6-8 weeks
- 2 weeks
- More than 8 weeks (please specify how long)

3. Have you, or the person you care/cared for, ever been referred to an occupational therapist via the local authority (social care) to receive an assessment for practical support in the home?

- Yes
- No
- Not sure

4. If YES, how long did you, or the person you care/cared for, wait before you received an assessment?

- Not applicable
- Up to 1 week
- up to 1 month
- More than 6 months - how long did you wait?
- Up to 3 months
- Up to 6 months

5. Were you, or the person you care/cared for, successful in receiving practical support following an assessment via an NHS or Social Care Occupational Therapist?

- Yes
- No

6. If you answered "yes", what type of support was received?

(Please select all that apply and press "OK")

- Education/advice to help you manage your condition
- Rehabilitation
- Equipment to help with your independence at home
- Adaptations to your property such as grab rails, stairlift, level access shower etc.

7. Do you, or the person you care/cared for, belong to a local PF/IPF support group?

- Yes
- No

8. Have you, or the person you care/cared for, ever received practical support or help from the Pulmonary Fibrosis Trust?

Yes

No

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About awareness

1. Do you think there is enough understanding / awareness about PF/IPF among the general public?

Yes

No

2. Did you, or the person you care/cared for, ever hear of PF/IPF before diagnosis?

Yes

No

Pulmonary Fibrosis Trust Patient and Carer Survey About COVID-19

1. Have you, or the person you care for, felt safe enough to leave your home since shielding ended?

- Very safe
- Safe
- Not safe
- Not applicable

2. Since shielding ended, have you, or the person you care for, felt safe enough to meet with/have visitors from people outside of your household e.g. family, friends, neighbours?

- Very safe
- Safe
- Not safe
- Not applicable

3. Have you/the person you care/cared for had any appointments cancelled due to COVID-19?

- Yes
- No
- Not applicable

4. If you answered "Yes", do you, or the person you care/cared for, feel your/their health worsened due to missing any appointment/s and the possibility of tests and/or medicine changes?

- Yes
- No
- Don't know
- Not applicable

5. If you, or the person you care/cared for, started pulmonary rehabilitation (PR) prior to lockdown, how has this continued?

- Cancelled due to COVID-19 and no further pulmonary rehabilitation offered
- Continued pulmonary rehabilitation in person in a COVID secure facility
- Online pulmonary rehabilitation (e.g. via Zoom) offered but unable access
- Have never received pulmonary rehabilitation
- Accessed online pulmonary rehabilitation (e.g. via Zoom)
- Not applicable
- Found alternative resources

6. Are you happy with the Government's guidance with regard to shielding and PF/IPF patients?

- Yes
- No

7. There are early indications of a link between COVID-19 and developing pulmonary fibrosis. Are you aware of this link?

- Yes
- No

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Demographics

1. In which age bracket are you? If you are or were a carer please tick the age of the person you care or cared for with pulmonary fibrosis/idiopathic pulmonary fibrosis.

- | | |
|-----------------------------|--------------------------------------|
| <input type="radio"/> 16-24 | <input type="radio"/> 60-69 |
| <input type="radio"/> 25-29 | <input type="radio"/> 70-79 |
| <input type="radio"/> 30-39 | <input type="radio"/> 80-89 |
| <input type="radio"/> 40-49 | <input type="radio"/> 90+ |
| <input type="radio"/> 50-59 | <input type="radio"/> Rather not say |

2. Which gender do you currently identify as? If you are a carer, please tick the gender of the person you care or cared for.

- Male
- Female
- Other
- Rather not say

3. Which ethnicity are you? If you are a carer, please tick the ethnicity of the person you care or cared for.

- | | |
|---|--|
| <input type="radio"/> White (British, Irish or other white) | <input type="radio"/> Mixed background |
| <input type="radio"/> Asian or Asian British | <input type="radio"/> Rather not say |
| <input type="radio"/> Black or Black British | |
| <input type="radio"/> Other (please specify) | |

4. In which part of the UK do you/the person you care/cared for live?

- East Midlands (*Derbyshire, Leicestershire, Nottinghamshire, Northamptonshire, Rutland*)
- East of England (*Bedfordshire, Cambridge, Essex, Hertfordshire, Norfolk, Suffolk, Lincolnshire*)
- Greater London
- North East (*County Durham, Northumberland, Teesside, Tyne & Wear*)
- North West (*Cumbria, Lancashire, Greater Manchester, Cheshire, Merseyside*)
- South East (*Berkshire, Buckinghamshire, Hampshire, Isle of Wight, Kent, Oxfordshire, Surrey, Sussex*)
- South West (*Bristol, Cornwall, Devon, Dorset, Gloucestershire, Somerset, Wiltshire*)
- West Midlands (*Birmingham and West Midlands, Herefordshire, Shropshire, Staffordshire, Warwickshire, Worcestershire*)
- Yorkshire and the Humber (*North Yorkshire, West Yorkshire, South Yorkshire, East Riding and Humberside*)
- Northern Ireland
- Scotland
- Wales
- Rather not say

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Contact

1. Sharing patient and carer stories raises awareness and supports others affected by PF/IPF. Would you/your family consider sharing your personal story?

We will never share or sell your email address and will only use it for the purpose of contacting you regarding your story. Please read our [Privacy Policy](#) for more information).

- No
- Yes (please enter your email address)

2. Would you like to be added to the Pulmonary Fibrosis Newsletter Mailing list?

We will never share or sell your email address and will only use it for the purpose of sending you updates such as the Newsletter. Please read our [Privacy Policy](#) for more information).

- No thank you
- Yes please (please enter your email address)