



James  
Lind  
Alliance

Priority Setting Partnerships

**NIHR**

Nottingham Biomedical  
Research Centre



**Action for  
Pulmonary Fibrosis**

## **PROMOTION GUIDE & ASSETS FOR PPF RESEARCH PRIORITIES SURVEY**

**Survey open from Friday 12 February until Tuesday 10 May 2021**

Website and survey link: <https://www.actionpf.org/research/james-lind-alliance>  
Paper version available by emailing [info@actionpf.org.uk](mailto:info@actionpf.org.uk)

### **Social media guidance:**

- Include the link to the survey: <https://www.actionpf.org/research/james-lind-alliance>
- Please include the hashtag #EveryVoiceMatters where possible
- Encourage followers to share with 'please RT'
- Tag participating organisations as well as your own for credibility, such as @actionpfcharity @Lindalliance
- To use our social media assets on pages 3 & 4 please request files from: [info@actionpf.org.uk](mailto:info@actionpf.org.uk)

APF social media handles:

Twitter: <https://twitter.com/ActionPFcharity>

Facebook: <https://www.facebook.com/actionpulmonaryfibrosis>

Instagram: <https://www.instagram.com/actionpulmonaryfibrosis/>

LinkedIn: <https://www.linkedin.com/company/action-for-pulmonary-fibrosis>

## Example adverts survey launch – patients / carers / family members

“  
For most of us, this will be a once in a lifetime opportunity to put the diagnosis, treatment and care of this condition to the front of the queue...”

We are calling on **you** to be **pioneers** for the future of **pulmonary fibrosis research**

APF is delighted to be partnering with the **James Lind Alliance** and the **University of Nottingham** on this landmark survey which will identify the top ten priority areas for pulmonary fibrosis research. Your feedback in this survey will directly set the standard for researchers; not just in the UK but the world...

The **survey** will be open until **10th May 2021**, and in the words of APF's CEO Louise Wright **'every single view matters'**.

**Action for Pulmonary Fibrosis**  
**NIHR** Nottingham Biomedical Research Centre  
**James Lind Alliance** Priority Setting Partnerships

## Health professionals – Twitter / LinkedIn / external

“  
Your experience and influence would be invaluable to our brief survey to shape the future of pulmonary fibrosis research...”

We know you are passionate about your **patients**, we also understand you are stretched due to the pandemic. By taking **5 minutes** to complete our survey, you could **transform the future** of research for patients with lung scarring

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## Facebook / Instagram

**Action for Pulmonary Fibrosis**  
**NIHR** Nottingham Biomedical Research Centre  
**James Lind Alliance** Priority Setting Partnerships

A one-time opportunity for you to **shape future research** into pulmonary fibrosis across the world...

## Posts to encourage a chain-reaction



### Suggested tweets

Shape the future of research in progressive pulmonary fibrosis. Tell us the questions you want answered by research in @Actionpfcharity survey with @Lindalliance <https://www.actionpf.org/research/james-lind-alliance>

Help pulmonary fibrosis research to focus on what matters to you as a health care professional. Complete @Actionpfcharity & @Lindalliance survey: [www.actionpf.org](http://www.actionpf.org) <https://www.actionpf.org/research/james-lind-alliance>

What questions do you have about progressive pulmonary fibrosis? Have your say on #PFResearchPriorities in @ActionPFCharity survey with @Lindalliance. Take part <https://www.actionpf.org/research/james-lind-alliance>

Share @ActionPFcharity survey with your colleagues, service users & carers so their questions about pulmonary fibrosis are heard and represented in future <https://www.actionpf.org/research/james-lind-alliance>

## How to add JLA Survey email signature



(This applies to Outlook) Go to **new message / insert / signature** and click on “**signatures...**” option

Click **new**

Click photo and computer icon and insert the image above

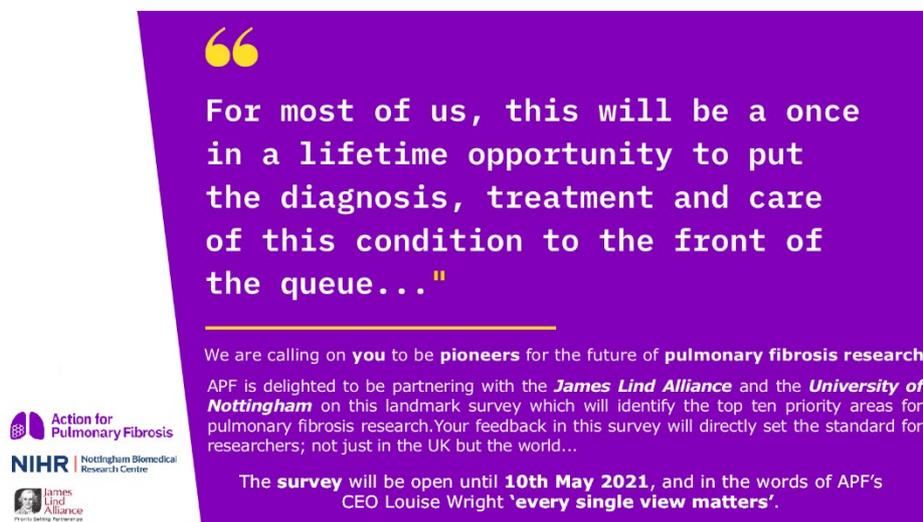
Once you have resized the image to your preference, right click and select “**link**” or “**hyperlink**”

Add the following URL: <https://www.actionpf.org/research/james-lind-alliance>

Save!

## E-newsletters and website

Please promote the survey either by featuring the advert banner or by using the text provided in your e-newsletters and on your website. An example of the advert is shown below. If possible include a link to the survey and a clear call-to-action, asking people to take part. Alongside the banner advert, you can use the website text template to communicate the survey to your networks. Alternatively, you can use information about the survey from APF's website: <https://www.actionpf.org/research/james-lind-alliance>



“

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## Text for websites

### Action for Pulmonary Fibrosis Priority Setting Partnership

A survey has been launched by Action for Pulmonary Fibrosis (APF) to start to identify the top 10 research priorities for progressive pulmonary fibrosis in the UK. APF are looking for questions that research could answer to offer life-changing differences to anyone affected by pulmonary fibrosis. We / **[INSERT ORGANISATION'S NAME]** are supporting the project to ensure as many different perspectives as possible are represented in the survey responses.

APF would like to hear from patients, their carers or family, and from people with different experiences of pulmonary fibrosis, including others working in the health and care environment.

We invite you to take part in the survey. It takes about 5 minutes and can be completed here [www.actionpf.org/research/james-lind-alliance](http://www.actionpf.org/research/james-lind-alliance).

We also encourage you to circulate the survey to your colleagues and the people you work with who are connected with pulmonary fibrosis. APF is working with the James Lind Alliance in a Priority Setting Partnership (PSP) to identify the top 10 research priorities for progressive pulmonary fibrosis. More information can be found the APF website: [www.actionpf.org/research/james-lind-alliance](http://www.actionpf.org/research/james-lind-alliance)

### Email template

Here are two template emails to send to healthcare professionals and others working in the area of pulmonary fibrosis. You can insert your company/organisation's name and tailor accordingly, adapting language to suit your audience. Before circulating the survey by email, please make sure you are **complying with GDPR**. See GDPR guidance at the end of this document for more information. These email templates can also be used and amended where necessary for e-newsletters and websites.

### Email text to send to healthcare professionals and others working in the health and care environment.

#### Your experiences and influence matters

A chance to influence future research into pulmonary fibrosis.

A survey has been launched by the Action for Pulmonary Fibrosis (APF) to identify the top 10 research priorities for progressive pulmonary fibrosis. APF are looking for questions that research could answer to offer life-changing differences to anyone affected by pulmonary fibrosis. We / **[INSERT ORGANISATION'S NAME]** are supporting the project to ensure as many different perspectives as possible are represented in the survey responses.

As someone working in the healthcare environment, we invite you to take part in the survey. It takes about 5 minutes and can be completed here: [www.actionpf.org/research/james-lind-alliance](http://www.actionpf.org/research/james-lind-alliance)

We also encourage you to circulate the survey to your colleagues and the people you work with.

APF is working with the James Lind Alliance in a Priority Setting Partnership (PSP) to identify the top 10 research priorities for progressive pulmonary fibrosis.

Together we can support pulmonary fibrosis to have a life-changing impact on the quality of people's lives.

Thank you for your assistance.

## **Email text for partners and organisations working in the field of pulmonary fibrosis**

Dear

### **Your experiences and influence matters**

A chance to influence future research into progressive pulmonary fibrosis.

A survey has been launched by Action for Pulmonary Fibrosis (APF) to identify the top 10 research priorities for pulmonary fibrosis. APF are looking for questions that research could answer to make life-changing differences to people affected by pulmonary fibrosis. We / **[PARTNER'S NAME]** are supporting the project to ensure as many different perspectives as possible are represented in the survey responses.

### **Why we need you**

You may have some unanswered questions about progressive pulmonary fibrosis. We encourage you to take part in the survey and share your questions about pulmonary fibrosis to help guide future research. It will take about 5 minutes to complete and is open to anyone with a personal or work-related connection pulmonary fibrosis.

**You can complete the survey here:** [www.actionpf.org/research/james-lind-alliance](http://www.actionpf.org/research/james-lind-alliance)

### **Who we are working with**

APF is working with the James Lind Alliance in a Priority Setting Partnership (PSP) to identify the top 10 research priorities for progressive pulmonary fibrosis.

Your real life experience and questions about progressive pulmonary fibrosis are at the heart of APF's project. Thank you for your help.

### **GDPR and circulating the survey**

Action for Pulmonary Fibrosis appreciates your contribution to the success of this project by distributing the link to the online survey through your network. Action for Pulmonary Fibrosis and the James Lind Alliance take their data protection responsibilities under the General Data Protection Regulation (GDPR) seriously. Before distributing the survey link via direct email to anyone in your network, please ensure that people have actively consented to receive emails inviting them to participate in consultation exercises of this nature. This is your responsibility under GDPR, more information is available on this legislation on the Information Commissioner's Office (ICO) website at: <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/> Including information about the project and the link within other means of communication i.e. in newsletters or on social media, does not require consent.