Role profile

Information Guidance Group

Help us provide information for everyone affected by pulmonary fibrosis

Context

Action for Pulmonary Fibrosis (APF) create information resources for people affected by pulmonary fibrosis (PF). These resources include booklets, leaflets, web pages, and online documents. The information we produce covers different topics, from travel to medications. We also produce information for carers, friends, and family members.

Our information aims to help people learn more about PF and how they can manage their disease to live well.

Why?

It’s crucial that people affected by PF are involved in producing our information. This helps to make sure our information:

- Answers the questions people affected by PF would have.
- Is relevant to people’s experiences.
- Is easy to read and understand.
- Gets to the people who need it, when they need it.

By helping us produce information, you’re helping us to ensure people affected by PF have the knowledge and support they need to live well.

In this role, you will be expected to...

- **Attend a brief introduction phone or video call.** This is a chance for you to ask any questions about the role and for us to get to know you.
- **Read and give feedback on resources.** We’ll email resources to you to give feedback on, usually with some specific questions to prompt your thinking.
- **Let staff know if you need further information or if things change for you.**

We’re looking for people who...

Are or have been **affected by any type of pulmonary fibrosis** (including people with a diagnosis, friends, family members, or carers)

AND

- Are able to read and give feedback on resources.
- Have an interest in shaping high-quality pulmonary fibrosis information.
You do **not** need to have:

- An understanding of pulmonary fibrosis or related topics
- Any previous experience of creating information resources
- Any prior knowledge of Action for Pulmonary Fibrosis

**Time commitment:**

- The Information Guidance Group is a fixed-term, one-year group, so we will look to renew the group members each year.
- We’ll email you approximately once per month with a resource to feedback on.
- The size of the resource will vary. It might be a single paragraph, or up to a few thousand words.
- You can give as much or as little feedback as you like.
- You’ll usually have two weeks to send your feedback via email.

We value the unique insight that people affected by PF share with us and appreciate that commitments may be impacted by your health or the person you care for. We would always encourage you to prioritise your physical and mental wellbeing and are grateful if you can let the relevant staff member know if things change for you.

**Interested?**
Please email [involvement@actionpf.org](mailto:involvement@actionpf.org) to request a short expression of interest form for the Information Guidance Group. Please send your expression of interest forms to us by **Wednesday 5th June.**