



Action for
Pulmonary
Fibrosis



Head of Research and Involvement

Charity Commission England & Wales Registered Charity Number: 1152399
Scottish Charity Regulator Number: SC050992

actionpf.org

Job description

Job title:	Head of Research and Involvement
Location:	Hybrid – regular travel across the UK, including at least one day per month at the charity’s Peterborough office
Salary:	£50,000 – £55,000 per annum (pro rata if part-time)
Hours:	Full-time, 37.5 hours per week. Part-time considered (minimum 4 days per week). Typically 9:00am–5:00pm, with flexibility to support work–life balance. Occasional out-of-hours work may be required, with time off in lieu.
Reports to:	Director of Policy, Research and Involvement
Direct Reports:	Involvement Officer
Directorate Area:	Policy, Research and Involvement

About Action for Pulmonary Fibrosis

Action for Pulmonary Fibrosis (APF) is a national charity dedicated to improving the lives of individuals and families affected by pulmonary fibrosis. We fund research into better treatments, provide essential support to patients, and campaign for better access to care. Our mission is underpinned by values of being compassionate, bold, expert, and collaborative. We believe in creating a supportive environment in which both our employees and beneficiaries can thrive.

Founded in 2013 by people affected by PF and clinicians, APF has grown into a respected national charity rooted in community and evidence.

We provide trusted information and support, help a growing network of support groups, campaign to improve access to care, and invest in research to bring hope of new treatments.

APF strives to be an organisation of equity and inclusion, welcoming people from all backgrounds. Our team and volunteers aim to reflect the diverse communities we serve. In 2026 we launched an ambitious five-year strategy, co-created with the PF community, focused on expanding support, transforming care, and accelerating research to ensure no one faces pulmonary fibrosis alone.



Role purpose

The Head of Research and Involvement is a senior leadership role responsible for shaping and delivering APF's research and involvement ambitions. The role will lead the development and delivery of a new research strategy, oversee APF's research funding portfolio, and embed meaningful involvement of people affected by pulmonary fibrosis across the organisation's work.

The postholder will provide strategic leadership across research, involvement and external partnerships, strengthening APF's influence within the UK and global research landscape.

This is a highly visible role, representing APF with researchers, clinicians, funders, industry partners and the third sector.

As a member of APF's Organisation Leadership Group, the Head of Research and Involvement will contribute to organisational leadership, supporting cross-team delivery of strategic priorities, organisational planning, risk management and continuous improvement.

Key responsibilities

Strategic Leadership

- Lead the development, delivery and evaluation of APF's research strategy in line with the organisation's five-year strategy, working closely with the Director of Policy, Research and Involvement and the Chief Executive.
- Lead the strategic direction for involvement, ensuring lived experience meaningfully informs APF's strategy, delivery and governance.
- Provide expert strategic advice to the Senior Leadership Team on research and involvement opportunities, risks and emerging developments.

Research Funding and Governance

- Lead and oversee APF's full research funding portfolio, including small travel grants, mid-level direct impact grants, and large multi-year awards (including fellowships and direct funding).
- Lead the development and continuous improvement of APF's research funding offer, ensuring schemes are competitive, impactful and aligned with organisational priorities.
- Develop and maintain robust research funding procedures, ensuring transparency, fairness and compliance with AMRC best practice and charity governance standards.
- Oversee research governance structures, including research funding and advisory committees, ensuring effective reporting, assurance and escalation to the Board.
- Monitor delivery, outputs and impact of funded research, ensuring effective grant management, learning and accountability.
- Work with former grant and fellowship recipients to establish and maintain an alumni network that supports collaboration, learning, advocacy and future funding opportunities.



Key responsibilities (continued)

Research Communications and Education

- Monitor national and international research developments relevant to pulmonary fibrosis and respiratory health, identifying emerging trends and opportunities.
- Translate complex research activity and findings into clear, accessible updates for internal and external audiences.
- Lead the development of public-facing research materials, including web content, leaflets, impact reports and other communications assets.
- Work closely with the Communications team to ensure research activity is regularly communicated through press releases, digital channels and social media.
- Act as an APF spokesperson on research matters where appropriate, supporting media engagement and public understanding.
- Support education and engagement activity for people affected by PF, including talks, presentations and events focused on research and innovation.
- Provide internal briefings and training for staff and volunteers on APF's research activity and wider PF research developments.

Involvement

- Champion involvement as a core organisational principle, ensuring lived experience shapes APF's strategy, delivery and decision-making at all levels.
- Lead the development, implementation and evaluation of systems, processes and standards that support high-quality involvement activity.
- Grow and develop the involvement function as a high-quality internal and external service, supporting APF teams and external research partners.
- Ensure staff are supported and trained to meaningfully and safely involve people affected by PF.
- Ensure involvement activity contributes to agreed income generation targets (where appropriate) and delivers demonstrable value and impact.

Partnerships, Pharma and Income Generation

- Build and sustain strategic relationships with UK and international research centres, study sites and academic institutions to strengthen the pulmonary fibrosis research ecosystem.
- Develop and maintain strong relationships with pharmaceutical and life sciences organisations, positioning APF as a credible and trusted research partner.
- Facilitate connections between researchers, study sites and industry partners to support high-quality PF research and collaboration.
- Work closely with the Fundraising team to support income generation for research and involvement activity, including partnership development and funding opportunities.

Leadership, Governance and Impact

- Lead, support and develop a high-performing Research and Involvement team, fostering a culture of collaboration, learning and continuous improvement.
- Provide clear leadership, objectives and performance management for direct reports, supporting wellbeing and professional development.
- Contribute to organisation-wide leadership, including resource planning, safeguarding, risk management and organisational change.
- Lead the development of robust impact reporting for research and involvement activity, tailored for the Board, funders, partners and the wider public.
- Ensure research impact evidence is used to inform strategy, funding decisions and future income generation opportunities.



Person Specification

Essential Experience and Knowledge

- Proven experience of developing and delivering organisational or departmental strategies.
- Significant experience leading or managing research programmes, including grant funding schemes.
- Strong knowledge of research governance, ethics and best practice.
- Experience engaging senior external stakeholders within research, healthcare, academic or industry environments.
- Knowledge of the UK research landscape and the role of the voluntary sector.
- Experience leading and developing teams, with a track record of building high-performing staff.
- Demonstrable commitment to ensuring lived experience and patient voice shape research and organisational practice.
- Strong understanding of equality, diversity and inclusion, including barriers faced by under-represented groups.

Essential Skills and Abilities

- Strategic thinker with the ability to translate vision into practical delivery.
- Excellent written and verbal communication skills, with the ability to adapt messages for different audiences.
- Strong interpersonal skills, with credibility and influence across a wide range of stakeholders.
- Sound judgement and ability to manage complexity, risk and competing priorities.

Desirable Experience

- Experience working within a medical research charity or health-related organisation.
- Experience managing budgets and resources to deliver value and impact.
- Knowledge of respiratory health, rare diseases or long-term conditions.
- Experience supporting income generation through research partnerships or funding activity.

Diversity & Inclusion

At Action for Pulmonary Fibrosis, we are committed to promoting equity and inclusion. Pulmonary fibrosis does not discriminate, and neither do we. We believe our team should reflect the diverse communities we serve, and we warmly welcome applications from all candidates regardless of age, disability, race, sex, pregnancy or maternity, gender reassignment, sexual orientation, religion or belief, or marital or civil partnership status.



Terms of appointment

Contract:	Permanent
Salary band:	£50,000 – £55,000 per annum (pro rata if part-time)
Pension:	Auto-enrolment (APF contributes 3%)
Holiday:	25 days plus 3 days at Christmas, plus bank holidays (pro rata). Buy/sell leave scheme available
Location:	Hybrid/remote with regular UK travel, including Peterborough office
Hours:	37.5 hours full-time; part-time considered (minimum 4 days per week)
Other benefits:	Flexible working policies, free gym membership at Peterborough office, life assurance
Probation:	Six-month probationary period
Notice periods:	Two weeks during probation; three months thereafter

How to apply

Please submit a CV and a covering letter (maximum of two pages) to HR@actionpf.org outlining your suitability for the role, with reference to the key responsibilities.

First stage interviews will be held virtually on **DATE**. Second stage interviews will be held at the Peterborough office on **DATE**.

Registered office:

Action for Pulmonary Fibrosis, Stuart House,
East Wing, St John's Street, Peterborough PE1 5DD



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