

Job Role and Person Specification: Research and Advocacy Officer

Salary Range:	£30,000 - £32,000
Location:	100% Remote Working
Travel:	You will be required to attend face-to-face meetings and events approximately 3–4 times per year. This may include team strategy days, clinical conferences, or patient events within the UK. Travel expenses will be reimbursed in line with our employee policy.
Term:	Full Time (flexible working 37 hours per week) Fixed-term, 2 years to support project work. Possible extension based on available funding. 6-month probation
Annual Leave:	28 days + bank holidays
Pension:	5% employer contribution

All candidates must have the right to work in the UK. We are unable to provide sponsorship for this role.

Main Purposes of Role

The Research and Advocacy Officer is a pivotal role designed to bridge the gap between clinical research and the PSC community. You will be responsible for the seamless delivery of our research grant programme and the growth of our Patient and Public Involvement and Engagement (PPIE) activities.

Reporting to and working closely with the Head of Research and Policy, you will ensure that the voices of those living with PSC are at the heart of everything we do, from influencing national care standards and advocacy to the creation of high-quality educational resources for clinicians and patients alike. This is an ideal role for an organised, empathetic professional looking to make a tangible impact on the lives of people affected by primary sclerosing cholangitis.

Key Tasks

1. Research Programme and Grant Administration

- **Programme Coordination:** Support the Head of Research and Policy (HoRP) in the end-to-end management of the PSC Support Research Programme.
- **Committee and Review Management:** Organise meetings for the Scientific Review Committee (SRC) and act as the primary liaison for external peer reviewers.
- **Grant Lifecycle and Payments:** Use grant management software to monitor awardee progress; send research reports to the SRC for approval and liaise with the HoRP to confirm when grant instalments can be released.
- **Stakeholder Correspondence:** Manage professional communications with all grant applicants and awardees regarding their applications and reporting requirements.

2. Patient and Public Involvement and Engagement (PPIE)

- **Activity Leadership:** Take the lead in organising and running online PPIE meetings and engagement activities for our community.
- **Researcher Liaison:** Work with HoRP and researchers to understand their specific PPIE needs to help them involve patients effectively in their work.
- **Insight Sharing:** Collate views from the Patient Panel activities and share these insights with relevant researchers and the HoRP to ensure they inform both individual projects and wider organisational strategy.
- **Financial Administration:** Work with the team to develop and manage the process for PPIE participant payments and expenses.

3. Education and Resource Development

- **Resource Project Management:** Lead the development of PSC-specific resources across various formats, including digital, print, video, and e-learning.
- **Collaborative Creation:** Liaise with a mix of patient and medical reviewers to update existing resources or create new information materials.
- **Stakeholder Management:** Coordinate inputs from medical writers, healthcare professionals, patients and families to ensure all resources are accurate and meet the needs of the audience.

4. Advocacy and External Representation

- **Patient Advocacy:** Attend external meetings to represent people with PSC and their interests, ensuring their unmet needs are highlighted to stakeholders.
- **Care Improvement:** Support the HoRP in the delivery of projects aimed at improving clinical care and services for those affected by PSC.

5. Communications and Operations

- **Digital Maintenance:** Update the PSC Support website with news, research breakthroughs, and programme updates (utilising content provided by the wider team).
- **Content Collaboration:** Work alongside the team to provide and format high-quality content for external communications including our newsletters, social media channels, and the website.
- **Impact Reporting:** Support the HoRP to write professional reports for internal and external stakeholders and provide regular project progress updates to the wider PSC Support team.
- **Administrative Excellence:** Maintain organised systems to ensure smooth daily operations and accurate impact reporting.

6. Other Duties

- Any other duties as may reasonably be required by PSC Support that are commensurate with the nature and grade of the post.

Key Objectives

- Support the end-to-end administration of the PSC Support Research Programme, managing the grant lifecycle, SRC reviews, and payment milestones.
- Drive our PPIE strategy by leading the Patient Panel and representing patient interests at external meetings to influence care and research.
- Project manage the creation of multi-format educational resources and showcase our impact through website, newsletter, and social updates.

Reporting

Line Manager: Head of Research and Policy (Work and Performance)

HR Reporting: Head of Operations and Finance (Policies and Leave)

This role may be subject to a DBS Check.

Person Specification

About You:

Experience	Essential/ Desirable	Evidence <i>Application (A)</i> <i>Interview (I)</i> <i>Test/ Presentation (T)</i> <i>Documentary (D)</i>
<p>Experience of working in a research or advocacy role</p> <p>Experience in project or programme coordination within the charity, healthcare, or research sectors</p> <p>Experience using grant management software or updating website CMS (e.g., WordPress).</p> <p>Proven track record of managing administrative processes (e.g., grant cycles, committee servicing, or complex scheduling).</p> <p>Experience in coordinating meetings or events, particularly for patient groups or clinical stakeholders.</p>	<p>Essential</p> <p>Desirable</p> <p>Desirable</p> <p>Essential</p> <p>Essential</p>	<p>A, I</p> <p>A, I</p> <p>A, I</p> <p>A, I</p> <p>A, I</p>
<h3>Knowledge, Skills and Abilities</h3>		
<p>Educated to A-level (including one science-based qualification) or equivalent experience</p> <p>Advanced Microsoft or Google Workspace skills</p> <p>The ability to adapt your style to speak clearly with patients and families, as well as professionally with clinicians and researchers.</p>	<p>Essential</p> <p>Essential</p> <p>Essential</p>	<p>A, D</p> <p>A, I</p> <p>A, I</p>

Highly organised with the ability to manage multiple deadlines across different workstreams (Research, PPIE, Advocacy and Education).	Essential	A, I
Ability to review complex information and ensure it is formatted appropriately for different audiences.	Essential	A, I
Empathetic to our cause and beneficiaries	Desirable	A, I
Ability to work autonomously without daily supervision	Desirable	A,I
Proficiency in remote collaboration tools (e.g. Google Workspace, Zoom, MS Teams)	Essential	A, I
Knowledge of PPIE (Patient and Public Involvement and Engagement) principles and why they matter in research.	Essential	I
<h3>Values and Behaviours</h3>		
Commitment - a demonstrable commitment to PSC Support's mission, vision and values.	Essential	A, I
Integrity - acts with integrity, building trust, openness and collaboration with staff, Trustees, volunteers and key stakeholders.	Essential	A, I
Transparency - works in a transparent way; is accountable for actions; respects and maintains confidentiality in course of work.	Essential	A, I
Curious - takes initiative, has a natural curiosity and willingness to learn and improve and work to the highest standards	Essential	A, I