

Research Engagement Manager

Line manager	Head of Research Operations, and liaising with Community and Advocacy Manager
Location	London, 120 New Cavendish Street, W1W 6XX minimum of 3 days/week in the office
Time:	Full time (35 hours/week)
Salary:	£35-40K (dependent on experience)

Main Purpose of the Role:

The Research Team at Cure Parkinson's (CP) is a group of ~10 individuals who are responsible for achieving the charity's main objective of facilitating and funding research to slow, stop or reverse Parkinson's. These activities include research grant management, public communication of new findings and research, convening of internal and external events, and engaging with individuals within the Parkinson's research and patient communities.

The Research Engagement Manager will be responsible for ensuring that the lived experience and perspective of people with Parkinson's (PwP) is embedded across CP research activities. This role will include managing our international Research Advocate Council, supporting public and patient involvement and engagement (PPIE) initiatives, and contributing to the development and dissemination of accessible research communications and outputs.

Key Responsibilities:

- Maintain CP's PPIE strategy, and work with members of the Research and Advocacy Teams to align PwP perspectives across programmes.
- Maintain the Terms of Reference for Research Advocate Council to deliver impactful PPIE around disease modifying research
- Manage and coordinate the international Research Advocate Council, including:
 - Taking responsibility for the governance of and running of the Council.
 - Scheduling meetings, managing membership (with an annual recruitment round of patients from diverse backgrounds), and facilitating meaningful engagement across CP research activities.
- Represent CP externally in collaborations focused on PPIE-related research activities.
- Support PPIE efforts by designing and delivering focus groups and surveys focused on research-related topics. This will include:
 - Developing and providing briefing materials to enable international PwP to participate in defined PPIE and research activities.
 - Implementing strategies to evaluate impact of these sessions
 - Analysing previous surveys and other activities capturing patient perspectives and priorities in line with CP's core priority of disease modification.
 - Developing and contributing to presentations and conference materials, such as posters that showcase patient involvement and research engagement practice
 - Co-create content with patient advocates to ensure their perspective is central and visible in all communications.

Additional duties:

- Work to ensure that CP PPIE initiatives reflect the diversity of the PwP community – developing methods to expand the diversity of perspectives in the RAC and grow the involvement of underrepresented groups.
- Work with external collaborators and stakeholders to identify ground rules for PPIE-related activities (e.g. Horizon 2020 calls, industry patient panels, and reimbursement).
- Support the Community and Advocacy Manager in drafting research engagement opportunities for advocacy newsletters and related communications.
- Identify appropriate PwP peer reviewers for the CP grant evaluation process.
- Review and provide advice on PPIE elements of research projects and grant applications to ensure adequate PPIE is incorporated, providing advice and support to researchers where needed.
- Evaluate communications as needed with PPIE input working with the Communications and Research Teams
- Explore existing data around the benefits of research participation, PwP's experiences of trial participation, and how we understand people with Parkinson's views on data sharing and consent with insights from previous surveys and focus groups.
- Organise events or initiatives to engage the Parkinson's community in CP strategy: including review of written materials, taking part in focus groups, helping to improve trial recruitment strategies, and all aspects of PPIE, to reflect the real priorities of people with Parkinson's. Support for the Research Update Meetings.
- Respond to patient enquiries that come into the Research Team email account.
- Prepare management reports on PwP engagement activities, outcomes and viewpoints.

The Research Engagement Lead must have:

- A University degree in life sciences, public engagement or related field
- Experience supporting or leading PPIE in research, ideally in health or clinical trials
- Experience of working in a patient facing role, including with diverse and underrepresented communities.
- Experience managing or facilitating patient advisory councils or similar groups
- Strong communication skills, with experience speaking to and writing for both lay and academic audiences
- Experience conducting or supporting focus groups, interviews or surveys
- The ability to work well independently but also acts as a team player.
- A high degree of integrity and the ability to maintain confidentiality regarding privacy guidelines, patient matters and other sensitive information.
- High motivation and willingness to embrace change
- Willingness to travel overnight and represent CP at external meetings, occasionally internationally



Things we all do

- Support CP events and activities as required, which will include occasional evening and weekend work.
- Ensure the identification of risk, both physical and financial, relating to fundraising activities and to ensure that they follow COVID-19 guidelines and GDPR and Data Protection regulations.
- Work with fundraising colleagues to ensure the team is up to date on administrative and financial processes, including updating Donorfy.
- Work collaboratively across the organisation, providing support, advice and guidance where necessary.
- Be an effective ambassador for the charity.
- Develop an in-depth understanding of our work.
- Take on other reasonable tasks, as required.

This job description is not exhaustive. It merely acts as a guide and may be amended to meet the changing requirements of the charity at any time after discussion with the post holder

Hours of work and holidays:

This is a full-time role. However, it should be noted that some events will take place over weekends and Bank Holidays when your presence will be required, which will be compensated with time in lieu (agreed in advance). We give 28 days' holiday three of which must be taken over Christmas, plus bank holidays.

Pension scheme:

After three months you will be entitled to join CP auto-enrolment pension scheme to which the charity contributes 3%.

Location:

Cure Parkinson's, 120 New Cavendish St, London, W1W 6XX

Diversity:

CP recognises the importance of diversity and encourages people from any background to apply for this role, provided they have suitable experience and ability as indicated in this specification.