Patient and public involvement (PPI) role description

Project title	UCB Patient Engagement Council for Parkinson's Research (PECPR)
PPI role title	PECPR member

Project background
In November 2021, Parkinson's UK, Parkinson's Foundation in the U.S., and pharmaceutical company UCB joined forces to establish a Patient Engagement Council for Parkinson's Research (PECPR), building upon existing work the three organisations had done previously over several years. The aim of the council is to ensure that patient insights are central to the overall strategy and activities across UCB's Parkinson's research and early clinical development programme. Through this collaborative partnership, the council aims to embed patient involvement in the earliest stages and throughout each step of UCB's Parkinson's drug development programme to improve outcomes for people living with Parkinson's. Since the council was launched, the group has made great strides in focusing on areas they consider will have the greatest impact and value for people living with Parkinson's. Topics currently being explored by the PECPR include Equality, Diversity & Inclusion, disease modification therapy, and patient involvement in early medicines development. We currently have three people with Parkinson's from the US, UK and the Netherlands sitting on the PECPR. Each of them have a very personal Parkinson's story. To learn more about our current members and why they wanted to be involved with the group, please click the link here. The consortium is looking to increase diversity within the PECPR and is aiming to recruit two 2 members (1 person from the US and 1 person from the UK).

What does the role involve?

The role will involve attending regular virtual meetings alongside fellow PECPR members as well as members of the UCB, Parkinson's UK and Parkinson's Foundation Patient Involvement teams. We are particularly interested in someone who is from an ethnic minority group who can help the council embed the views of people living with Parkinson's from diverse communities.

Role description:

- Someone living with Parkinson's or a family member, partner or carer of someone living with Parkinson's
- From a non white background
- Interested in Research
- Ability to build connections with the wider Parkinson's community to gather broader community insights
- Motivated to work in partnership to achieve successful results
- Confident to express views in a group
- Able to think broadly across challenges and solutions

Since this opportunity involves working with a pharmaceutical company, there are some regulatory processes that need to be followed and you will be asked to sign a contract with the company. The company is offering an optional honorarium for those taking part.

What support will there be for PECPR members?

There will be an induction for new members which will include an online meeting with Nikul Bakshi, the Research Involvement Manager at Parkinson's UK and some reading material about UCB and the PECPR. Nikul will also be attending all PECPR/pre-planning meetings, so will be on hand to answer any questions and support you during or outside of the meetings.

What is the time commitment?

Anticipated time commitment in 2023

- On average attend 4 PECPR meetings each lasting approximately 2 hours.
- Attend 4 x 2 hour Pre planning meetings
- 4 hours review of meeting materials

All meetings will take into consideration PECPR members availability prior to establishing the exact meeting dates.