

Introduction to UCB's Patient Engagement Council for Parkinson's Research

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

 **Parkinson's**
Foundation



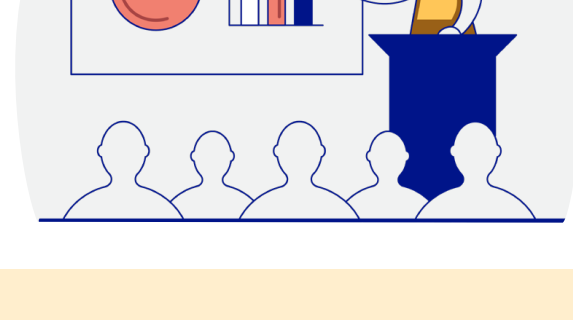
Patients and caregivers are the true experts, which is why at UCB we believe that it's vital to work with the patient community, involving them at every stage of our research and development, to help ensure better treatments that result in stronger outcomes for patients.

It has become common for patients to be involved in various steps of the drug development process. However, patient communities are often not invited to participate in early research and clinical development. In order to address this, UCB set up the Patient Engagement Council for Parkinson's Research (PECPR).

What is the Patient Engagement Council for Parkinson's Research? (PECPR)

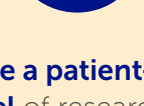
The PECPR is a strategic steering group created in 2021 by UCB, The Parkinson's Foundation, and Parkinson's UK, with **the overall goal to partner consistently with the patient community** to improve early research and clinical development.

Integral to the PECPR are **five people living with Parkinson's who represent the wider Parkinson's community and their perspectives**, with a keen interest in early research and development.



The PECPR aims to:

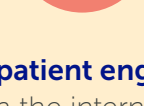
Improve patient outcomes by working together strategically to:



Co-create a patient-centered model of research and development, leading to more **efficient and higher quality research that meets the needs and priorities** of people living with Parkinson's.



Embed patient involvement into the earliest stages and throughout each step of UCB's Parkinson's drug development portfolio, ensuring that **decision-making is driven by the priorities of people affected by Parkinson's**.



Elevate patient engagement within the international Parkinson's research community, **enabling increased opportunities for collaboration and shared learning** to advance Parkinson's research.

What has the PECPR achieved so far?

Since its inaugural meeting in September 2021, the PECPR has **gathered many invaluable insights from its members**. A set of key focus areas to drive impact and value for patient communities was suggested by all the members of the PECPR group.

These were then ranked using the Clinical Trials Transformation Initiative (CTTI) to determine the expected impact and resource requirements. After further qualitative exercises, a consensus was reached on three priorities to be built and worked upon:



Model for target product profiles (TPP) co-creation:

Building a transparent and robust playbook for use at UCB, clearly setting out **where and how patients should be involved and embedded into this process** to inform and co-create the development of TPPs.

This template also acts as a guiding tool to capture everything we jointly know about the medicine we are investigating, sets out its potential value proposition, and **ensures the patient voice** is captured.

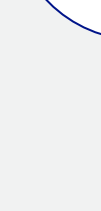
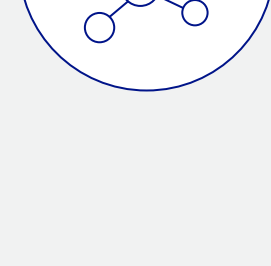
Guidance has also been developed for the patient community to help understand **how people living with Parkinson's can meaningfully contribute** to the early drug development process.

To increase further awareness, we also want this work to be **shared with the wider research community** to encourage others to follow in our footsteps and put the **patient at the heart of everything**.

Diversity, equity and inclusion; moving our thinking to take action on our ambitions:

Working to ensure that **research opportunities are accessible for everyone**, including communities that are often underrepresented in clinical research. We jointly held a workshop with people living with Parkinson's who were from ethnic minority communities to **secure further data and insights to help bolster our research efforts**.

By learning about the lived experiences of people from **across different communities**, we can help to ensure that clinical research and treatments for Parkinson's are designed in a way that is **inclusive of everyone's needs**.



Disease-modifying treatment:

As research is moving at a fast pace, we need to **bring the Parkinson's community along with us**. UCB and Novartis have partnered on a Parkinson's drug development project, combining our expertise, and aiming to bring **disease-modifying therapies** to people living with Parkinson's disease.

Together we are building a narrative to **enhance understanding** about the potential of this **new treatment approach**. We are currently researching how much is known about disease-modifying therapies in the Parkinson's community, how we can best explain what they entail, and the potential of this treatment.

We hope disease-modifying therapies can **transform the disease landscape**, from symptom management to slowing and eventually stopping the disease.

What are the key learnings from the PECPR so far?



Including people with Parkinson's strategically and early in research and development will ultimately lead to better patient outcomes.



Further support is needed to help people with Parkinson's represent the input of the wider Parkinson's community. And because of this, we want to urge others within the research community to join us on this important journey.



The principles of transparent, bi-directional communication have been key to the PECPRs success.



Tools such as the Clinical Trials Transformation Initiative (CTTI) and the Patient Focused Medicines Development (PFMD) Patient Engagement Quality Guidance, help to prioritize initial areas of importance and guide ways of working to ensure interactions with patients are respectful and meaningful.



The bonds created through trust and the ultimate shared goal, allow us to continue to co-develop a patient engagement model that works for all.

What has been the impact of the PECPR?

The PECPR has **helped all parties work together more strategically** with a bird's eye view of priorities.

This more holistic perspective has helped us look at key research and development topics through a long-term lens. This has ensured the projects and priorities UCB invests in are **fast-tracked to bring the most benefit to people living with Parkinson's**, whilst also sharing the outputs with the wider Parkinson's research and development community.



What is next for the PECPR?

The PECPR is currently evaluating what can be improved upon, such as; **enhanced communications and engagement** with the wider research community, **better utilizing the networks of the PECPR members** to gather wider insights into all aspects of our work and publishing more lay papers.

We are also evaluating the next topic areas we want to focus on, making sure they address our core needs:



What is our overall purpose?
And which specific actions achieve this?



Why is it important to focus on this area? How does this help us achieve our overall purpose?

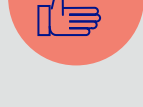


What specific results will deliver against our purpose?

Potential future topic areas include:



Exploring and embedding patient engagement in regulatory and funding discussions.



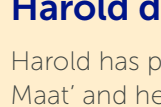
Reviewing the possibility of starting patient engagement even earlier in the drug development process.



Investigating ways the PECPR members can become more proactive when inputting into the drug development process.

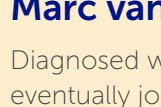
Who is part of the PECPR?

The PECPR is made up of seven people from UCB, The Parkinson's Foundation and Parkinson's UK as well as five people (included below) living with Parkinson's.



Harold de Wit – Netherlands

Harold has participated in a two-year trial 'Parkinson op Maat' and he is active in several Parkinson's Forums via social media (e.g. Health Unlocked, Reddit, Instagram and Facebook groups). Harold is also the founder of the Facebook group Parkinson's Silver Linings, which has over 5,000 members worldwide. He is also active on the board of the Driessen Foundation which aims to create happiness at work for people with a labour market disadvantage. Together with the Parkinson Center of Radboud UMC the Driessen Foundation will start a project that will support people still working with Parkinson's staying active in work. The Driessen Foundation also hosts several 'Parkinson's Cafés', meetings with sufferers who get together on a regular basis to share their experiences of getting information about the disease.



Marc van Grieken – UK

Diagnosed with early onset Parkinson's in 2006, Marc eventually joined the Research Support Network (RSN) of Parkinson's UK and the Dundee Research Interest Group (DRIG). He 'graduated' as an EUPATI Fellow in 2021 and has since participated in establishing UCB's Patient Engagement Council Parkinson's Research (PECPR). He represented EUPATI on PFMD – PEOF's steering committee for Fair Market Value (FMV) remuneration of patients and until recently he chaired the PD Avengers Research Committee. Throughout he has focused on active involvement of people with Parkinson's in all stages of research and in the design of clinical trials.



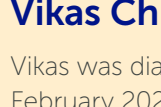
Carol Schulte – USA

Carol was diagnosed with Parkinson's over 20 years ago and has participated in more than 20 research studies, as well as having Deep Brain Stimulation. Carol has completed the Parkinson's Foundation Learning Institute Training. As well as serving as a research advocate for the Parkinson's Foundation for over 10 years, Carol has also served on the AGING Initiative Patient/Caregiver Advisory Council and contributed to two years of grant review with the Patient-Centered Outcomes Research Institute.



Shariah Karimi – UK

Shariah has been a member of Parkinson's UK Patient and Public Involvement (PPI) network since July 2018, following his diagnosis in 2015. Shariah has good connections with fellow Iranians who live with Parkinson's and spends much of his time advocating for the community.



Vikas Chinnan – USA

Vikas was diagnosed with early onset Parkinson's in February 2022. Since then he has focused on Parkinson's advocacy and promoting awareness within and outside of his community. Vikas is a member of the Parkinson's Foundation People with Parkinson's Advisory Council. He lives in San Carlos with his wife, Preeti, and his sons, Bailey and Sammy.

