

Keeping you up-to-date with AccessPD & Parkinson's Disease research opportunities.



Welcome to the Autumn edition of the AccessPD update!

Great news! AccessPD has now reached **938 participants**, and **222 healthcare providers** from across the UK have now signed up to provide their patients access to the study.

This update brings you details of a new study opportunity available to AccessPD participants on specific medications. You'll also find an invitation to a free virtual event hosted by Parkinson's UK this October, along with important information about the surveys you may have received as part of AccessPD. Additionally, we've included an updated analysis of the latest anonymised data from participants.

As always, thank you for being part of AccessPD, the information you are contributing as a participant is vital to support the development of new PD therapies and treatments.

Helpdesk

If you have any questions about your participation in AccessPD or the content of this newsletter please don't hesitate to email our support team at patientservices@accesspd.org, or speak to us on **+44 (0) 808 304 9869**.



Shumina



Katy

Upcoming Study Opportunity

*Are you currently being prescribed **Opicapone** or **Entacapone**?*

We want to hear from you!

We are preparing to launch a study aimed at understanding the experiences of patients who have been prescribed Opicapone or Entacapone to help manage their motor fluctuations with Parkinson's Disease.

Eligible participants will be selected based on the information we have, and you may receive an invitation to join the study via text, email, or phone call. The study will involve completing a simple survey from the comfort of your home.

Keep an eye out for the invitation, and feel free to contact our patient support team at patientservices@accesspd.org or call us on **+44 (0) 808 304 9869** if you have any questions.

Baseline data roundup

*Change since April 2024 analysis



846

completions of the
baseline questionnaire



37.1%
Female



62.9%
Male

(↓9.9%*)



20.4%

report a family history
of PD

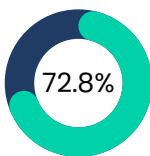


5.6

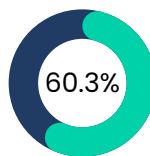
(↓3.4yrs*)

average number of years
since diagnosis

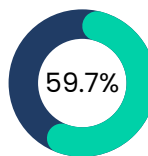
Top symptoms



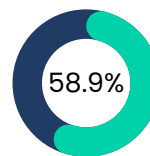
Tremor



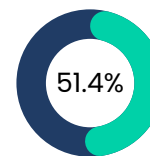
Bradykinesia



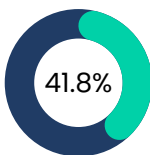
Muscle
stiffness



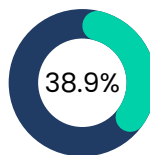
Fatigue



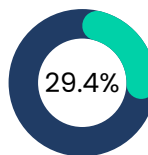
Gait
problems



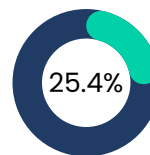
Sleep
disorders



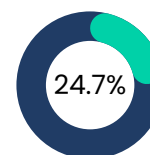
Speech
change



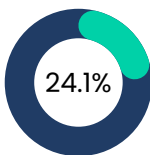
Dyskinesia



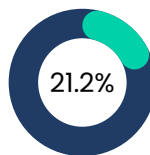
Freezing



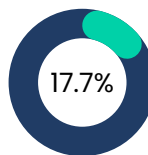
Depression



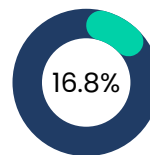
Impaired
handwriting



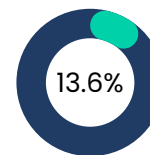
Impaired
balance



Loss of
smell

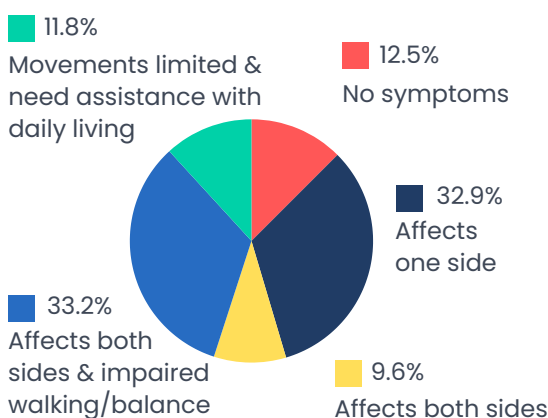


Constipation

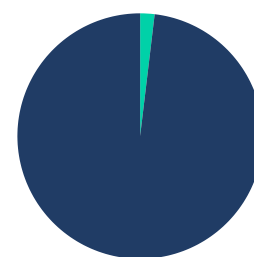


Impaired
posture

Impact of Parkinson's Disease on movement



Received Deep Brain Stimulation (DBS)



A reminder to complete the baseline questionnaire

A huge thank you to all the participants who have already completed our baseline questionnaire. Your insights are shaping our path forward. To those who haven't had a chance yet, we'd love to include your voice too. You will have received a text message and an email with a link to the questionnaire which will only take a few minutes to complete.

Our Patient Services team will be routinely calling to offer assistance to those that have not yet completed the baseline questionnaire, however please don't hesitate to reach out to the team with any questions in the meantime.

You are invited to Par-Con 2024!

A FREE online event organised by Parkinson's UK

We are working with Parkinson's UK to share and promote their abundance of free resources, events and news that are available to support those living with Parkinson's Disease.

Next month Parkinson's UK are inviting you to Par-Con, a free online, 2-day event for the Parkinson's community. [Join the event](#) on the 11th and 12th of October and hear directly from expert speakers, connect with others and learn more about living well with Parkinson's.

2024 PAR-CON

When? 11 – 12 October

Where? Online

Cost? Free to attend!

Register now!

For more information and to secure your place, please register on the Par-Con webpage:

[Register here](#) 

Par-Con has been planned in collaboration with a team of people living with and affected by the condition and will cover the topics that matter to you. There will be sessions on the latest research, hidden symptoms and cutting-edge technology.

This year, Par-Con 2024 will include the Community Awards, an opportunity to celebrate the everyday heroes of the Parkinson's community.

Whether you are newly diagnosed, have lived with Parkinson's for many years or know someone who is affected by the condition, this event gives you the chance to hear directly from experts, learn about the latest research, and connect with others.

[Register your place here.](#)

If you have any questions about the event, please contact the Parkinson's UK Research Team at:

researchevents@parkinsons.org.uk or on **020 7963 9253**.

Speakers



Professor Camille Carroll

Professor of Clinical Neuroscience at Newcastle University



Professor David Dexter

Director of Research at Parkinson's UK



Professor Bas Bloem

Consultant neurologist, Radboud University Medical Centre, Nijmegen



Kuhan Pushparatnam

Co-host of the '2 Parkies in a Pod' podcast and creator of the Parkinson's ON app

View the full speaker list on the Par-Con website [here](#).

Knowledge hub: Health surveys

As a participant of AccessPD you will receive ongoing surveys and questionnaires related to your health condition and experience of living with Parkinson's Disease. The information collected is aggregated and anonymised, and used to build a rich source of data that researchers can analyse to better understand this disease.

In these newsletters, we will be providing you with more information about each of the surveys you'll receive, and how the information will be used by researchers.

You may have already received the EQ-5D-5L and the PDQ-8 surveys which are used to measure health-related quality of life. These surveys will be sent again in 6 months time, so keep an eye out!

EQ-5D-5L

EQ-5D-5L is a standardised measure of health-related quality of life. The questionnaire is used to assess health status in terms of five dimensions of health – mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each question has five levels of response, indicating the severity of problems in that dimension, ranging from no problems to extreme problems.

Additionally, there is a visual analog scale (VAS) at the end of the questionnaire, where patients rate their overall health on a scale from 0 to 100, with 0 being the worst health imaginable and 100 being the best. Questions are not specific to any one patient group or health condition.

The survey is referred to as a patient-reported outcome (PRO) measure, because patients can complete the questionnaire by themselves to provide information about their current health status and how this changes over time.



In research, EQ-5D-5L is used to:

- provide a patient health status profile
- monitor the health status of patient groups at particular times
- measure changes in health status over time such as before and after health interventions and treatments.
- assist in providing evidence about effectiveness in processes where drugs or procedures require approval

PDQ-8

The PDQ-8 is a short and simple survey that helps us understand how Parkinson's disease affects your daily life. As a study registry, we collect important information over time to gain a deeper understanding of how the condition impacts individuals with PD.

The survey asks eight questions covering different areas of your life, such as:

- **Mobility:** How easy it is for you to move around.
- **Activities of daily living:** How well you can manage everyday tasks like dressing or eating.
- **Emotional well-being:** How Parkinson's is affecting your mood and feelings.
- **Stigma:** How your condition might make you feel about yourself or others.
- **Social support:** The level of support you get from friends and family.
- **Cognition:** Whether Parkinson's affects your memory or thinking abilities.
- **Communication:** How easily you can communicate with others.
- **Bodily discomfort:** Any pain or physical discomfort you may experience.

By completing the PDQ-8, you are helping us gather valuable data that contributes to research aimed at improving the understanding of Parkinson's disease. Your participation may help enhance future care and treatment options for others.

If you have any questions about the surveys and questionnaires received please don't hesitate to contact our help desk: patientservices@accesspd.org, or speak to us on +44 (0) 808 304 9869.

Knowledge hub: Treatments & Therapies

Deep Brain Stimulation (DBS)

AccessPD participants that have already completed the baseline questionnaire will be aware of a question about Deep Brain Stimulation (DBS). Interestingly less than 2% of participants within AccessPD have received DBS, so, for those that may be unfamiliar, we're sharing this [resource from Parkinson's UK](#) that provides more information on the treatment.

DBS is a surgical treatment used to help manage movement symptoms in Parkinson's Disease, such as tremors, stiffness, and slow movement. It involves a surgery where tiny wires (electrodes) are placed in the brain to send electrical signals to areas that control movement. These wires are connected to a small device, like a pacemaker, that sits under the skin in your chest.

DBS doesn't cure Parkinson's, but it can help reduce symptoms and allow you to take fewer medications, which may also help reduce the side effects of some drugs. For more information on DBS, visit [Parkinson's UK](#).

Please note personal advice on therapies and treatments should only be provided by your healthcare provider.

In the news: research round-up

We're celebrating the incredible PD research that is taking place globally. Here's a roundup of the latest research news from the past couple of months that's working towards finding a cure and improving the quality of life for those living with Parkinson's.



Shared from: [Parkinson's UK](#)

Progress towards a form of adaptable deep brain stimulation

A small study shows that adaptive deep brain stimulation is better than the standard version at controlling movement symptoms day and night for people with Parkinson's.

[Read more +](#)



Shared from: [Parkinson's news today](#)

Study finds large-scale disruptions in Parkinson's gut microbiome

The gut microbiome of people with PD exhibits substantial compositional and functional shifts relative to that of healthy individuals, with some of these changes linked to a faster progression of motor issues over time.

[Read more +](#)



Shared from: [BBC](#)

Parkinson's blood test gives early-diagnosis hope

A simple blood test using artificial intelligence to predict Parkinson's disease years before symptoms begin has been developed by researchers.

[Read more +](#)

If you have any questions about any of the information presented in this update please don't hesitate to contact us at patientservices@accesspd.org or helpdesk number on **+44 (0) 808 304 9869**.