

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



Welcome to the Spring edition of the AccessPD update

We are delighted to share that there are now **725 participants** within AccessPD, and **174 healthcare providers** from across the UK have now signed up to provide their patients access to the study. As the number of participants grows, so does the opportunity for researchers to discover biomarkers that could lead to the development of new treatments and cures. So as always, thank you for being part of AccessPD!

In this update we've included an analysis of the latest anonymised data collected from AccessPD participants, and we're also excited to share with you our first AccessPD manuscript published from the data that you've been providing as a participant.

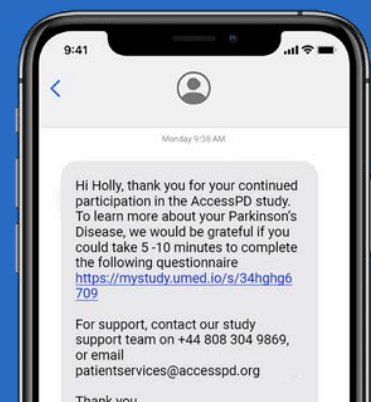
Furthermore, in honour of **Parkinson's Awareness Month this April** we want to celebrate the incredible research taking place globally that is working towards finding a cure and helping to improve the quality of life for those living with Parkinson's. So we're sharing some of the recent PD research and news that's been hitting the headlines.

Helpdesk update

Please note that we have updated our helpdesk contact details. You can now email our study support team at patientservices@accesspd.org, or speak to us on **+44 (0) 808 304 9869**.

Reminder to complete the Baseline Questionnaire

Just a gentle reminder to complete the baseline questionnaire if you haven't done so already. You will have received a text message and an email with a link to the questionnaire. The information you provide within this questionnaire will be combined with data from other participants in the study and will be anonymised, meaning you will not be identifiable from this information.



If you have any questions or require support with the completion of the questionnaire, please contact our study support team.

Baseline data roundup

538
 completions of the
 baseline questionnaire

47%
 Female
 (↑9%*)

53%
 Male

22%
 report a family
 history of PD

9
 (↑3.6yrs*)
 average number of
 years since diagnosis

Top symptoms

Symptom	Percentage
Tremor	75%
Bradykinesia	66%
Muscle stiffness	64%
Fatigue	63%
Gait problems	53%
Sleep disorders	48%
Depression	27%
Speech change	40%
Dyskinesia	32%
Freezing	28%

Impact of Parkinson's Disease on movement

Category	Count
Movements limited & need assistance with daily living	58
No symptoms	69
Affects both sides & impaired walking/balance	182
Affects one side	167
Affects both sides	62

Received Deep Brain Stimulation (DBS)

Response	Count
Yes	10
No	528

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. Filling out the questionnaire only takes a few minutes, but your feedback can make a lasting impact. Join us in reaching our goal of 100% participation!

*Change since December 2023 analysis

Announcing the first AccessPD publication!

npj | parkinson's disease

Great news! Our first manuscript from AccessPD has now been published in the Nature Journal - NPJ Parkinson's Disease.

From the data provided by AccessPD participants, we demonstrated how the registry enables researchers to perform analysis and identify patterns guiding future research directions.

The paper describes the demographics of study participants and ranks the most common symptoms, and identified participants who could potentially benefit from device-aided therapies using consensus criteria.

Access the full publication [here](#).

Share your story

Our mission is to provide every patient with the opportunity to participate in studies that could change the lives of future generations.

Therefore we'd value hearing about your experiences of living with Parkinson's Disease and your reasons for participating in AccessPD, so that we can share with the PD community and encourage more involvement in research.

Interested to share your experiences?

Contact our patient services team at patientservices@accesspd.org, or speak to us on **+44 (0) 808 304 9869**.

In the news: research round-up

As April is Parkinson's Awareness Month, we want to celebrate 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.

More research news on page 4 



England

Shared from: [NHS England](#)

NHS rolls out 'wearable' 24-hour infusion for advanced Parkinson's

Hundreds of NHS patients with advanced Parkinson's disease are set to benefit from a portable drug infusion that is gradually released around-the-clock to help better control their symptoms.

The treatment, called foslevodopa-foscarbidopa, will now offer an additional option for certain patients experiencing movement-related symptoms and whose condition is no longer responding to their oral medicines.

[Read more +](#)

In the news: research round-up



Shared from: [apda](#)

New Parkinson's Medication on the Horizon

The development of potential new medications remains very active, with multiple new medications that are aiming to treat and slow down PD in various stages of development. Here are additional medications to keep an eye on in 2024.

[Read more +](#)



Shared from: [The Guardian](#)

Diabetes Drug may slow progression of Parkinson's

Researchers have found that the type 2 diabetes medication exenatide, can help to slow the progression of motor symptoms in a small group of people with Parkinson's.

[Read more +](#)

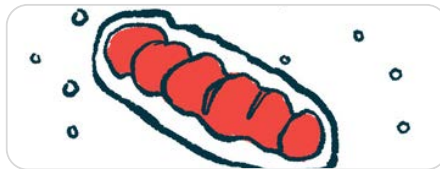


Shared from: [Parkinson's UK](#)

New research study shows impact of delirium for people with Parkinson's in hospital

Parkinson's UK funded research shows that people with Parkinson's are more likely to experience delirium while in hospital. Often leading to a quicker loss of independence.

[Read more +](#)



Shared from: [Parkinson's News Today](#)

Mitochondrial DNA damage evident before Parkinson's: Study

People with REM sleep behaviour disorder, a condition that often precedes Parkinson's disease, frequently have mitochondrial DNA (mtDNA) damage, a study found.

[Read more +](#)



Shared from: [BBC News](#)

Virtual reality helping people with Parkinson's

Virtual reality headsets are helping alleviate the symptoms of people with Parkinson's, a charity has said. The stimulus from the virtual activity produces adrenaline and dopamine in the body, both of which alleviate symptoms.

[Read more +](#)



Shared from: [NIH](#)

Skin test detects evidence of Parkinson's and related disorders

A study has shown that a simple skin biopsy could identify people who had Parkinson's disease or similar disorders with a high degree of accuracy.

[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**.