

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



Welcome to the Winter edition of the AccessPD update!

In this final newsletter of 2023, you'll find an update on the QMUL DNA research project, a latest roundup of the baseline data collected from all participants in AccessPD, a patient story from an AccessPD participant, and Parkinson's research news that's been hitting the headlines.

We are also excited to share that there are now 503 **participants** in AccessPD, and **146 GP practices** from across the UK have now signed-up.

We hope you enjoy this update and as always if you have any questions about the content of this newsletter or about your participation in AccessPD please don't hesitate to get in touch.

Happy holidays from the uMed team!

Hear from the AccessPD Community

We've been speaking to AccessPD participants about their experiences of living with Parkinson's and why they chose to take part in research. You can read our latest patient story on page 3.

if you'd like to share your experiences with the rest of the AccessPD community, or if you'd like to provide your feedback based on your participation so far, please email us at patientservices@accesspd.org and our nurse team will arrange to call you back.

Research Update QMUL DNA

A huge thank you to the 335 AccessPD participants that have taken part in the QMUL DNA project! The data you have provided will be invaluable to the researchers at QMUL who are aiming to develop a better understanding of the genetic variants and genetic risk factors that might be associated with Parkinson's Disease.

So far we've received 268 collection kits back for analysis; just a gentle reminder to return any outstanding test kits as soon as you can.

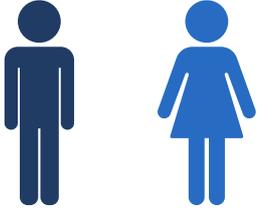
Contact support

If you have questions about AccessPD, please contact our support team at:
patientservices@accesspd.org.
Alternatively you can contact our helpdesk number on +1 888 454 5580 (US) or +44 (0) 20 3481 8905 (UK).

AccessPD baseline data roundup

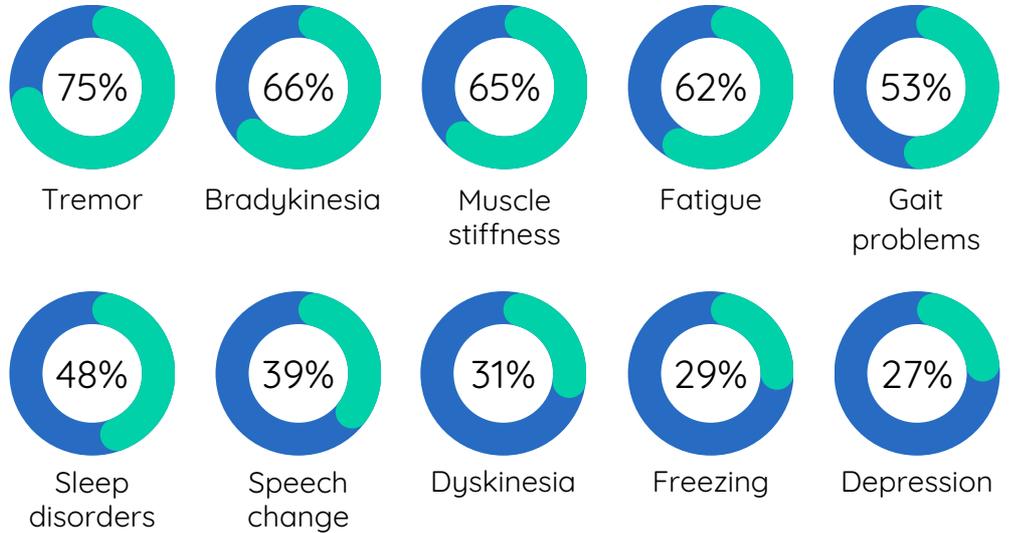
71.1

Average age

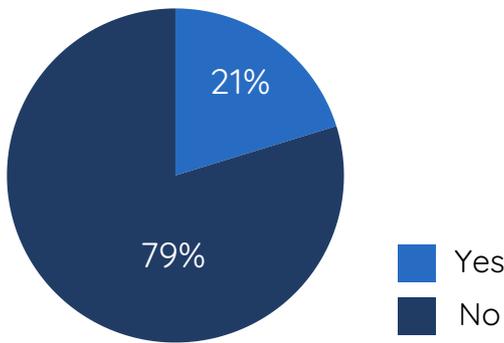


Male **62%** Female **38%**

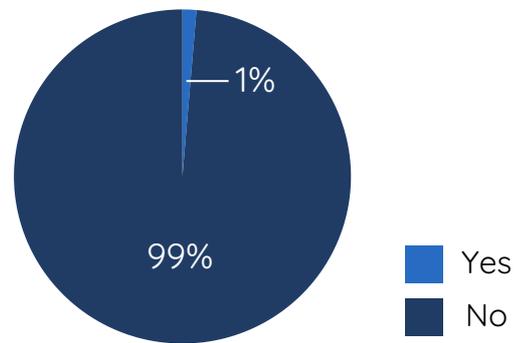
Symptoms experienced by AccessPD participants



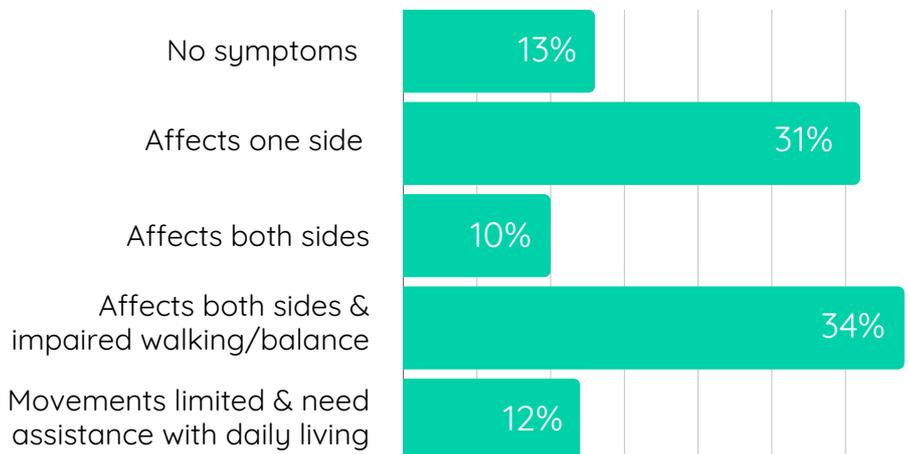
Family history of Parkinson’s Disease



Received Deep Brain Stimulation (DBS)



Impact of Parkinson’s Disease on movement



5.4

Average number of years since diagnosis

If you have any questions about the data presented in this update please don’t hesitate to contact us at patientservices@accesspd.org.

Patient story: Carole Henrickson



Carole Henrickson from Hull in the UK

was diagnosed with Parkinson's Disease 5 years ago at the age of 75. She joined AccessPD earlier this year having never previously participated in any Parkinson's research.

We caught up with Carole to ask her about her experiences of living with Parkinson's Disease and why she decided to participate in Parkinson's research.

“ I have lived with a diagnosis of Parkinson's for 5 years, but I believe my symptoms were present up to 6 years prior to this. I was experiencing multiple falls, in particular when trying to turn to the left when standing stationary. I also found that I froze in doorways when mobilising. ”

Carole told us that despite raising her concerns about her symptoms with her GP, they initially did not investigate her condition. However, when Carole was finally unable to mobilise, she was taken to hospital where she was diagnosed with Parkinson's on the ward.

Since this diagnosis she has been medicated and has regular physiotherapy to manage her symptoms.

“ I have been significantly impacted because I have poor mobility secondary to Parkinson's, but I am able to walk with assistance and a stroller, and I work hard to improve my ability with regular physiotherapy. When leaving the house I use a wheelchair and a wheelchair taxi. ”

Carole told us that she currently has a good relationship with her carers that support her 4 times a day. Previously she has suffered with anxiety which was exacerbated by changes in carer, but this is now well managed.

Carole told us that falling asleep is an issue for her but that she finds reading before bed for an hour helps overcome this.

When we asked Carole why she chose to join AccessPD she told us that she'd never taken part in research before, but being able to participate remotely in AccessPD was attractive due to her poor mobility.

“ I received the SMS but I was unable to follow the link as I have no internet access, so I was pleased when the nurse called to follow-up and was able to sign me up by phone. This was simple and easy! Being able to take part despite having no internet is a big positive, and your nurses make this possible. ”

Want to share your experiences of living with Parkinson's Disease with the AccessPD community? Email us patientservices@accesspd.org to organise a chat with one of our team.

In case you missed it...

Here are some recent exciting research developments external to AccessPD that are supporting the advancement of better treatments and cures for Parkinson's Disease.

Shared from: Parkinson's UK

More research shows potential benefits of vitamin B3 for Parkinson's

Researchers add to existing evidence that vitamin B3 may help slow down the progression of Parkinson's. A new clinical trial has published promising signs that taking a high dose of vitamin B3 is safe, and can reduce some symptoms for people with Parkinson's.

[Read more +](#)



Shared from: Cure Parkinson's

A new potential biomarker for Parkinson's

Researchers at Duke University have recently presented data on a new potential biomarker for Parkinson's that could be useful in clinical trials targeting the LRRK2 gene in people with Parkinson's.

[Read more +](#)

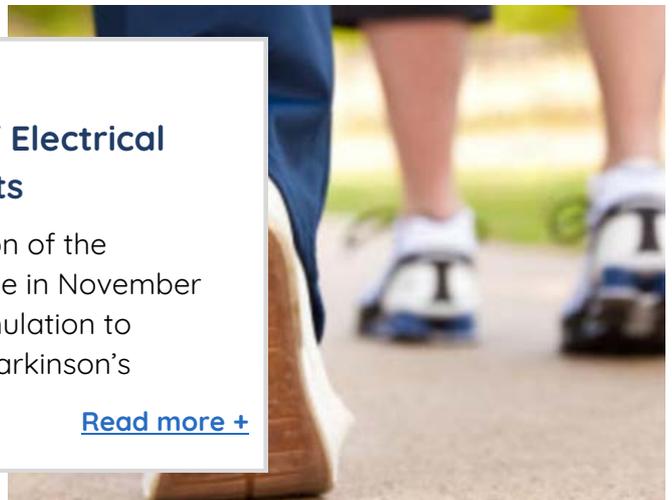


Shared from: The Michael J Fox Foundation

News in Context: Early Positive Results of Electrical Spinal Stimulation for Parkinson's Patients

A global team of researchers captured the attention of the scientific world with a publication in Nature Medicine in November outlining success in using electrical spinal cord stimulation to address gait and balance issues in a patient with Parkinson's disease (PD).

[Read more +](#)



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