AccessPD Registry Update: Accelerating Parkinson's Disease Research Through Integrated Digital Solutions

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Objectives

To update on AccessPD's progress, emphasising the growth in patient recruitment, data integration, and the preliminary analysis aimed at advancing Parkinson's disease (PD) research.

Background

Launched in September 2022, AccessPD aims to address the challenges of PD research by leveraging electronic health records and electronic patient-reported outcomes within a fully remote, integrated platform.

By facilitating diverse and representative participant recruitment and enabling comprehensive data collection, AccessPD seeks to support the development of individualised treatment approaches and informs clinical trial design reflective of PD's heterogeneity.

Initial insights, based on data from the first 200 participants, have been published, demonstrating AccessPD's potential as a next-generation registry to accelerate PD research (Chang, YH., Periñan, M.T., Wilson, M., Noyce, A.J. et al. *AccessPD as a next generation registry to accelerate Parkinson's disease research. npj Parkinson's Dis.* 10, 66 (2024). https://doi.org/10.1038/s41531-024-00651-z).

Methods

AccessPD continues to expand by involving an increased number of General Practitioner practices across England, growing from 51 to 167 in 12 months. Potential participants are invited to sign up to the registry via SMS.

By the end of 2023, DNA sample collection kits were dispatched to participants who consented for the collection of genetic data. Additional validated questionnaires, including the 8-item Parkinson's Disease Questionnaire (PDQ-8) and the EuroQol 5-Dimension 5-Level questionnaire (EQ-5D-5L), have been distributed since March 2024.

Methods

Table 1. Data routinely collected from participants in AccessPD. EQ-5D-5L and PDQ-8 assessments have been dispatched, with RBDSQ and HADS scheduled for future distribution.

Patient profile	Treatment journey	Quality of Life
EHR & ePROs	**EHR & ePROs**	**ePROs**
· Demographics (incl. ethnicity) · Date of Diagnosis · First symptoms and onset · Current symptoms · Vital signs · Caregiver arrangements · Family and social history	· PD medication codes · Current and previous medications · Medication duration & switching	· HRQoL (EQ-5D-5L) · Parkinson's Disease Questionnaire (PDQ-8) · Sleep (RBD Screening Questionnaire (RBDSQ) · Hospital Anxiety Depression Scale (HADS)

Additional outcome measures can be incorporated based on the needs of the research. If you are interested in collaborating or contributing to further data collection, please feel free to contact us to discuss potential opportunities.

Results

Since the last report, the registry grew to 932 participants as of September 1. The SMS click-through rate for AccessPD invitations rose to 35%, showing that 1 in 3 invited patients actively engaged by completing all questions.

The participant demographics and disease profiles indicate that the average age at enrollment is 71, while the average age at disease onset is 65. The gender split is 62.9% male and 37.1% female.

Disease stage reveals 12.5% who do not recognise impairment of movement, 32.9% with unilateral motor symptoms, 9.6% with bilateral symptoms, 45% with bilateral impact and walking/ balance impairment, or needing daily living assistance.

A total of 289 DNA test kits were collected to analyse genetic risk factors associated with PD. (See our poster 'Remote DNA Collection for Parkinson's Research: Insights from AccessPD' (Abstract Number: 1632) on 30/09, 13:00–15:00 in Exhibit Hall A, for insights into DNA collection and genetic risk factors in PD.)

Results

Figure 1. Disease stage reported by participants within AccessPD.

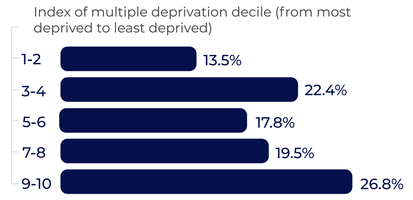

Figure 2. Distribution of GP practice postcode areas by Index of Multiple Deprivation (IMD) decile. IMD deciles range from 1 (most deprived) to 10 (least deprived). GP practice postcodes were used as a proxy for participants' social deprivation, showing broad recruitment across socioeconomic areas. IMD scores are based on the English Indices of Deprivation 2019.

Conclusion

Having surpassed 900 consented participants and begun data analysis, the registry is set to offer key insights into PD heterogeneity, patient needs, and potential therapeutic avenues. Initial exploration of the dataset has established its capability to identify early-stage PD patients, pinpoint individuals with specific symptoms such as dyskinesia, and support rapid, customised trial recruitment for interventions such as device-aided therapy. These applications, while yet to be utilised, demonstrate the dataset's potential to significantly impact PD research.

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