

Accelerating research on Parkinson's disease and empowering patients through digital health technologies.



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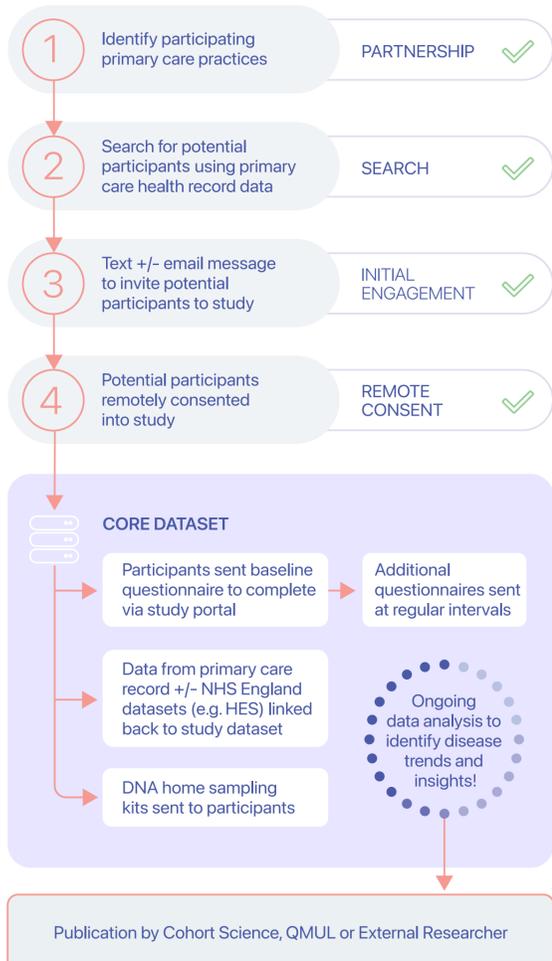
Background:

Parkinson's disease (PD) is a heterogeneous condition, both in terms of its clinical manifestations, progression and aetiological determinants.

This calls for individualised treatment approaches and clinical trials that are designed to take account of the heterogeneity of PD. One of the key challenges faced by current PD studies is the difficulty in recruiting participants from diverse backgrounds that are truly representative of the PD spectrum. Limited ability to travel to trial sites due to physical disability, geographical distance, or financial constraints could further deter patients from participating in research studies.

Aims & methods:

Access-PD is a fully remote, next-generation registry that is designed to tackle these challenges by incorporating digital solutions for identification and recruitment of patients, as well as collection of longitudinal data.



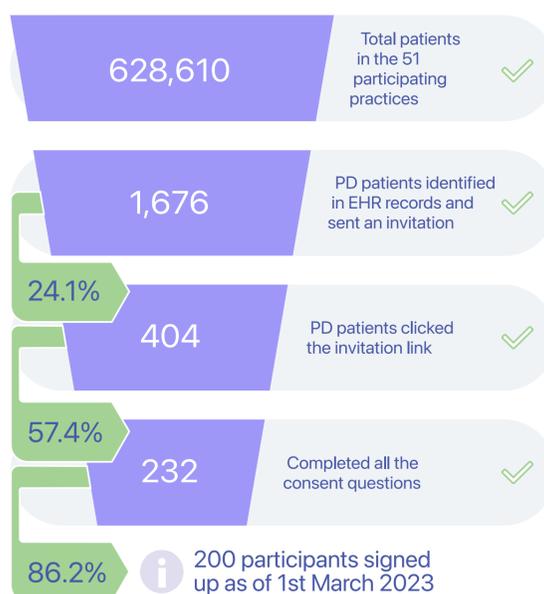
Potential participants with a coded diagnosis of PD are identified using data held in primary care electronic health records (EHR) and engaged via a text message that takes them to a website for consent and registration.

The process is simple and is supported by study nurses who act as the point of contact for any questions and issues related to participation. This approach ensures PD patients from different backgrounds can have equal opportunity to be invited to participate in the registry and those who are less familiar with remote research can be guided by a dedicated nurse.

Once consented to the registry, participants are sent further questionnaires and test kits (e.g. DNA or smell test kits) to collect additional data.

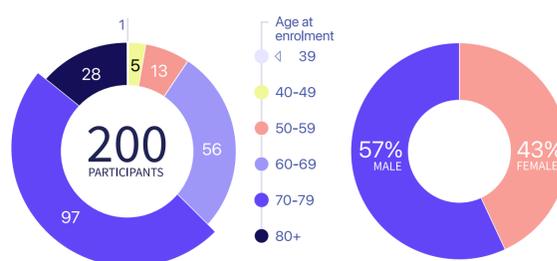
By combining routinely collected EHR data with patient-reported outcome measures and home testing, Access-PD aims to create a comprehensive database that allows researchers to effectively stratify patients into meaningful subgroups, perform analysis and identify patterns that can guide the directions of future research and trials.

Results:

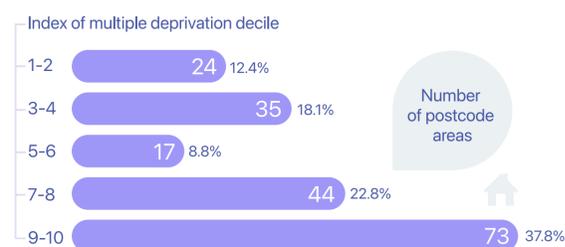


The first **200** participants were recruited within **6** months of launch from **51** primary care practices in England. **43%** are female and **57%** are male. In alignment with the higher prevalence of PD among elderly patients, **62.5%** of participants are over the age of **70**.

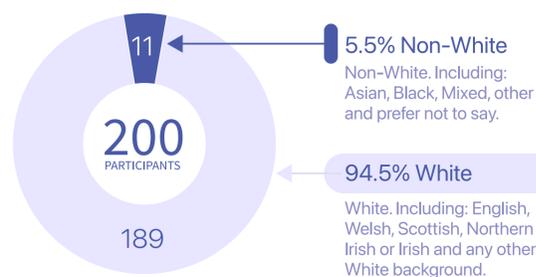
Demographic:



Participation deprivation scores



Cohort diversity



Conclusion:

The pilot project has been well received by PD patients who feel empowered by an initiative that allows their voice to be heard. The high percentage of elderly participants demonstrates that advanced age is not a barrier to taking part in Access-PD.

More work needs to be done to increase participation of PD patients from ethnic minorities.

