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Remote DNA Collection for Parkinson's Research: Insights from AccessPD

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Objectives

Established in 2022, the AccessPD registry aims to create a comprehensive database integrating electronic health records, self-reported outcomes, and genetic data from Parkinson's disease (PD) patients.

This report outlines our experiences with remotely collecting DNA samples to analyze genetic variants and risk factors associated with PD.

Background

PD is associated with known genetic factors, notably the GBA1 genetic mutation, which is present in approximately 5% of patients and varies by ancestry. Additionally, about 15% of PD patients report a family history of the disease among first-degree relatives.

Our sub-study employed a non-invasive saliva DNA collection kit to gather genetic information.

Methods

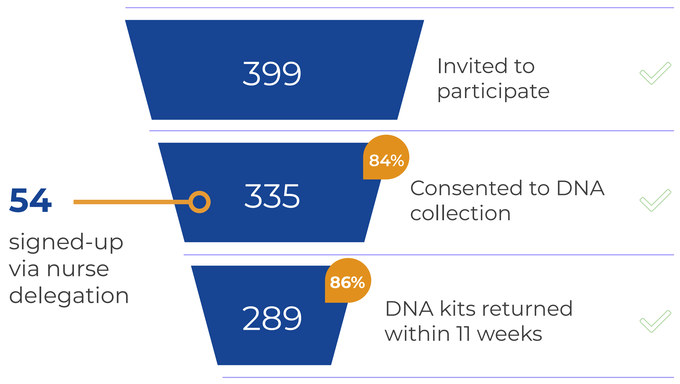
We invited existing AccessPD participants to join the DNA collection study through letters and SMS. The study facilitated remote participation by sending DNA collection kits to participants' homes.

Kits included pre-paid return envelopes, and participants could delegate consent tasks to nurses if necessary. We monitored engagement outcomes and DNA sample collection metrics.

Results

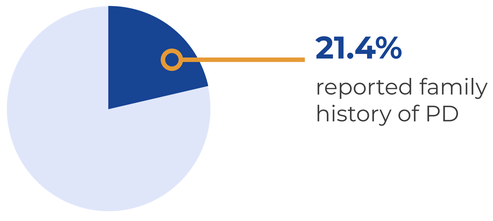
Out of 399 invited participants, 335 (84%) consented to the DNA collection sub-study.

SMS invitations achieved a 68% click-through rate. Support calls and nurse interventions helped engage participants unresponsive to digital prompts, particularly those with limited technology access. 54 patients signed-up via nurse delegation.



Following outreach, **289 DNA kits** were returned within 11 weeks of the first engagement.

It's worth noting that **21.4%** of AccessPD participants reported having a family history of PD.



Conclusion

The high consent rate and rapid engagement in the DNA study highlight the effectiveness of our approach, which included prompt re-engagement, varied outreach methods, and accommodations for remote participation. These strategies contributed significantly to the study's success

The findings from this study are expected to enhance understanding of genetic factors in PD, support the design of genetically-stratified clinical trials, and inform future research within the AccessPD registry.

Next Steps

Conduct Genetic Analysis: We will analyze the collected DNA samples to identify genetic markers associated with PD. This genetic data will be integrated with other data modalities currently available in the registry, such as electronic health records and patient-reported outcome measures.

Genetically-Stratified Clinical Trials: Leveraging the genetic data, we aim to support clinical trials that stratify participants by genetic profiles. This approach will facilitate the exploration of targeted treatments and interventions for PD.

Enhanced Participant Engagement: We will continue to enhance our outreach strategies and digital engagement tools to ensure better support and accessibility for participants, thereby expanding our sample size.

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