

PEPP: Connecting patient preferences with clinical and genetic data

Customised patient data collection through uMed's AccessPD cohort.

About the Study

The Patient Endpoint Preference Project (PEPP) investigated which symptoms matter most to people with early Parkinson's disease and what delay in progression they consider meaningful. Answering these questions required direct patient input beyond existing clinical records, to inform endpoint selection in future trials.

Through its AccessPD cohort, uMed enabled remote questionnaires and at-home saliva collection, connecting newly collected patient-preference, quality-of-life and genetic data with existing clinical information. This created a study-specific dataset for examining patient priorities alongside disease history and genetic characteristics.

Key Outcomes



511

UK participants
consented to the study



457

DNA kits returned through
remote saliva collection



407

Participants with complete
questionnaire and genetic
data after validation



9

Data inputs leveraged for
multiintegrated analysis



Evidence built around the research question.

PEPP combined existing clinical information with bespoke patient questionnaires, standardised quality-of-life measures and newly collected genetic data.

Through uMed’s AccessPD cohort, these components formed a connected research pathway—from remote participation to integrated analysis—with interim findings informing further preference research.



Research need	How PEPP addressed it	Value for evidence teams
Generate evidence missing from existing datasets	Combined a bespoke adaptive symptom questionnaire, a discrete choice experiment and standardised quality-of-life assessment with at-home saliva collection for genotyping.	Collect complementary patient-reported and biological evidence tailored to the research question.
Understand patient priorities in clinical context	Linked prospective responses and genetic data with existing AccessPD demographic, disease-history and medication information, supporting demographic, clinical and exploratory genetic subgroup analyses.	Investigate whether priorities vary between patient groups using connected evidence rather than isolated survey responses.
Translate patient insight into evidence-design decisions	Interim symptom priorities informed a subsequent preference experiment. Analyses quantified preferences for delaying symptoms and assessed how established outcome measures captured patient-prioritised symptoms.	Inform endpoint selection and identify measurement gaps through quantitative preference evidence and structured outcome-measure assessment.

Rigour across the study pathway

Remote eligibility screening and participant support; adaptive allocation across eight preference-questionnaire versions; component-specific response validation and genetic quality control; explicitly defined analysis populations.