

# Virtual research studies feasible

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A new pilot study in Parkinson's disease suggests a new era of clinical research which removes the barrier of distance for both scientists and volunteers. The research, which appears in the journal *Digital Health*, could also enable researchers to leverage the rapid growth in personal genetic testing to better diagnose, and potentially treat, a wide range of diseases.

"These findings demonstrate that remote recruitment and conduct of research visits is feasible and well-received by participants," said Ray Dorsey, M.D., M.B.A., a neurologist at the University of Rochester and lead author of the study. "Direct-to-consumer [genetic testing](#), when paired with telemedicine, has the potential to involve more people in [clinical research](#) and accelerate the process of identifying the genetic

causes and variations in chronic diseases such as Parkinson's"

"Giving clinicians the ability to recruit and assess patients remotely for research and clinical trials is a game changer," said Emily Drabant Conley, Ph.D., a research scientist and director of business development with 23andMe, and co-author of the study. "Leveraging genetically-defined groups of patients through direct-to-consumer genetic testing combined with self-reported data and remote assessment opens up exciting frontiers in research and may allow us to do things at a scale and speed that was previously not possible."

Parkinson's is a complex multi-system disease with many known genetic "clues" and a wide range of patient experiences, both in terms of the severity and progression of symptoms and an individual patient's responsiveness to the several available forms of treatment. While researchers have been able to identify many of the different phenotypes of the disease, this variation makes the process of diagnosis and treatment a challenge.

The ideal solution would be to identify the genetic signature of the various phenotypes and understand more precisely how these different forms of the disease are manifested in terms of symptoms and what treatments, or combination of treatments, provide the most effective relief.

However, this has proven to be a highly difficult undertaking given the previous high cost of genetic testing and the logistical obstacle of having to recruit from a geographically diverse pool of volunteers in order to create a sample large enough to arrive at scientifically meaningful conclusions.

Two new technologies now make this task possible: direct-to-consumer genetic testing - and the recent rapid decline in the cost of genetic

sequencing - and telemedicine.

Researchers at the University of Rochester and Johns Hopkins University partnered with 23andMe, a personal genomics and biotechnology company based in California, to conduct a pilot study to determine if individuals with known genetic risk factors for Parkinson's disease could be diagnosed for the condition via telemedicine. The researchers also wanted to test the feasibility of conducting clinical research remotely.

Working with 23andMe and the Michael J. Fox Foundation for Parkinson's Research, the researchers were able to ultimately recruit 50 individuals in 23 states who agreed to undergo a remote assessment consisting of cognitive and motor tests via a secure video conferencing developed by [Vidyo](#). The participants also completed a survey.

Provided by University of Rochester Medical Center

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