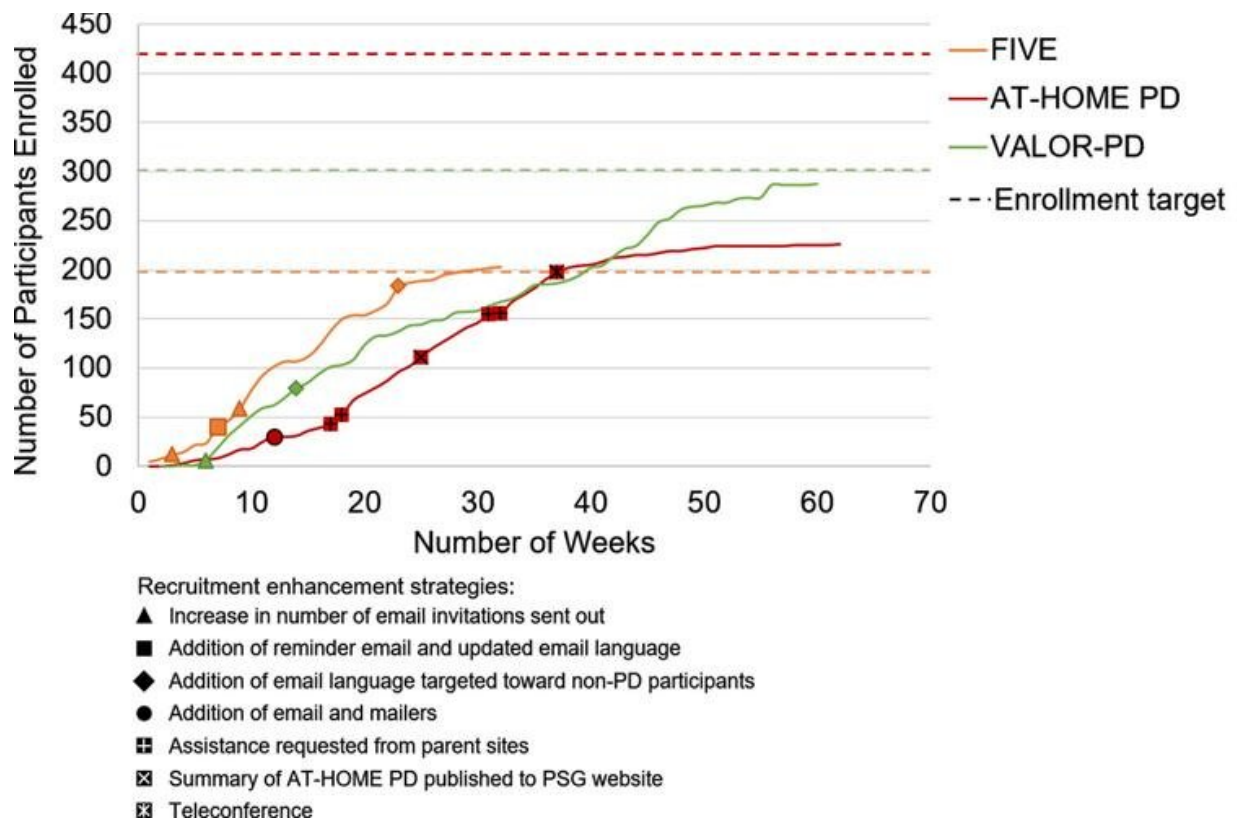


# Study details lessons learned from remote clinical studies

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Enrollment timeline, by study. Credit: DOI: 10.3233/jpd-212935

Traditional, in-person clinical research studies have long been plagued by slow and often unsuccessful recruitment. The limits of site location, which sometimes requires participants to travel long distances, and the reliance on busy clinicians to help with recruitment, are factors that

create barriers to study enrollment. These challenges were exacerbated at the start of the pandemic.

A new study by researchers with the University of Rochester Center for Health + Technology (CHeT) details the experience with three large remote clinical trials in Parkinson's [disease](#) and the lessons that can be learned for future studies.

The CHeT team are pioneers in the field of remote care and first created a telemedicine platform 12 years ago to provide care to Parkinson's disease patients at home and in long-term care settings, effectively demonstrating that geography could be minimized as a barrier to specialized care. The researchers have since built academic and industry partnerships in medicine and technology to create new tools that could extend the reach and impact of remote clinical care and research.

Researchers have long been excited about the potential of remote clinical trials. The ability to recruit participants regardless of their proximity to a study site vastly expands the pool of potential participants, which is particularly important for studies that involve rare or disabling diseases. Coupled with other remote technologies that measure walking and movement, researchers can develop a better understanding of the daily lived experience of patients and how they are responding to therapies in real time, as opposed to a snapshot every several months during a clinic visit. Remote studies also allow clinical trials to be conducted from a single location, which reduces cost, complexity, and enrollment time.

The pandemic accelerated the shift to remote clinical studies, as researchers were essentially forced to rethink how to conduct ongoing studies and design new ones. However, the concept is still novel. New research—led by University of Rochester neurologist Ruth Schneider, M.D., and appearing in the *Journal of Parkinson's Disease*—examines the recruitment process and outcomes for three remote decentralized

[clinical studies](#) in Parkinson's disease:

- FIVE—study that recruited participants through the Michael J. Fox Foundation for Parkinson's Research Fox Insight database of 45,000 individuals both with and without Parkinson's disease to assess motor function, quality of life;
- VALOR-PD—longitudinal study that recruited participants with the LRRK2 gene variant, a genetic variant that increases the risk of Parkinson's disease, from a pool of individuals who received genetic testing through 23andMe and opted in to receive information on clinical research; and
- AT-HOME PD—a follow-up study with participants from two Parkinson's disease clinical trials who were recruited via phone, mail, and email.

Despite being conducted from Rochester, all three studies recruited from a broad geographic area, with participants from between 34 and 40 states, territories, and Canadian provinces in each study. Similar large in-person Parkinson's disease clinical research studies might require dozens of sites to achieve the same geographic diversities.

The researchers note that the pandemic forced the transition of many aspects of daily life online, including work and education, potentially lowering barriers to participation in medical research if done in the comfort of one's home. At the same time, the pandemic also exposed the digital divide and the need to invest in affordable high speed internet in many areas of the country. This was observed in the studies, as all three struggled to recruit Black, Latino, and rural participants.

The studies hold lessons for future remote clinical trials. Recruitment was more effective when it came from trusted sources and was accompanied by large-scale outreach. Online recruitment tools are effective, but should supplement rather than replace traditional outreach.

**More information:** Taylor L. Myers et al, Recruitment for Remote Decentralized Studies in Parkinson's Disease, *Journal of Parkinson's Disease* (2021). [DOI: 10.3233/jpd-212935](https://doi.org/10.3233/jpd-212935)

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