

Leveraging videoconferencing supports the continuity of Alzheimer research during the COVID-19 pandemic and beyond

Francelethia S Johnson^{1,2} | Faina C Lacroix^{1,2} | Maricarmen Contreras¹ |
Penelope Baez³ | Temitope Ayodele^{3,4} | Izri Martinez^{3,4} | Sandra Fonseca³ |
Larry D Adams^{1,5} | Jacob Welch⁶ | Melissa N Jean-Francois⁷ | Pedro Ramon Mena^{1,8} |
Christiane Reitz⁹ | Jeffery M Vance¹ | Margaret A Pericak-Vance^{1,8} |
Michael L Cuccaro^{1,8} | Gary W Beecham^{1,8}

¹ John P. Hussman Institute for Human Genomics, University of Miami Miller School of Medicine, Miami, FL, USA

² University of Miami, Miami, FL, USA

³ Columbia University, New York, NY, USA

⁴ Columbia University Medical Center, New York, NY, USA

⁵ Dr. John Macdonald Foundation Department of Human Genetics, University of Miami Miller School of Medicine, Miami, FL, USA

⁶ John P. Hussman Institute for Human Genomics, University of Miami Miller School of Medicine, Miami, FL, USA

⁷ University of Miami, Miller School of Medicine, John P. Hussman Institute for Human Genomics, Miami, FL, USA

⁸ Dr. John T. Macdonald Foundation Department of Human Genetics, University of Miami Miller School of Medicine, Miami, FL, USA

⁹ Columbia University, Depts. of Neurology and Epidemiology, New York, NY, USA

Correspondence

Francelethia S Johnson, John P. Hussman Institute for Human Genomics, University of Miami Miller School of Medicine, Miami, FL, USA

Email: fxs121@miami.edu

Abstract

Background: The COVID-19 pandemic has placed a demand on researchers to limit in-person contact with participants, greatly impacting Alzheimer Disease (AD) research. To address this problem, we describe here an approach to using digital technology to continue nationwide clinical recruitment and ascertainment of biological samples while adhering to COVID-19 guidelines and travel restrictions.

Method: To accomplish this, we considered a videoconferencing approach for remote delivery of cognitive assessments. A multi-site panel of neurologists and clinical psychologists and a detailed literature review ensured a protocol that captures the best-practices for administering assessments through videoconferencing while ensuring consistency between remote and in-person administration. Clinical coordinators underwent training to ensure good agreement with in-person administration. Most aspects of the cognitive assessments easily transferred to videoconferencing, though Trail Making A and B, and Digit Symbol-Coding were removed to protect the integrity of the evaluation. Additionally, we coordinated the collection of biological samples with a national company, Quest Diagnostics, to provide phlebotomy services at the participant's residence. All protocols were developed under the guidance of the Human Subjects Research Office at the University of Miami and with approval of local IRB.

Result: Our clinical coordinators completed over two dozen remote assessments using these protocols. Both cases and controls were enrolled, across various ethnic populations within our study. The distributions of age and 3MS were similar between in-person and remote assessments. The uptake of videoconferencing enrollment varied among the age groups, level of impairment, at-home support system and telemedicine readiness. For example, earlier-onset groups had the best uptake, while older-onset groups showed the least uptake due to a higher prevalence of telemedicine unreadiness (Lam et al., 2020; Bossen et al., 2015).

Conclusion: This study demonstrates that remote enrollment and ascertainment of biological samples through videoconferencing and partnering with national mobile phlebotomy services is feasible. This approach allows researchers to continue ascertainment efforts while maintaining their participants' autonomy through informed consent and privacy throughout the process and minimizing their exposure to COVID-19.