

# **Regional Challenges and Advances in Telegenetics During the COVID-19 Pandemic**

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## **Abstract**

During the COVID-19 pandemic, telehealth services were rapidly implemented to continue providing care to patients. The New York-Mid Atlantic Caribbean (NYMAC) Regional Genetics Network (RGN) has worked to facilitate the use of telehealth to improve access to genetics services in the region.

This study surveyed and interviewed NYMAC genetics providers to assess barriers and facilitators to the provision of telegenetics during the COVID-19 pandemic, the perceived value and demand for telegenetics services during this time, and any resources necessary to continue using telegenetics after the pandemic.

A 29-question survey was developed and distributed in July 2020 through multiple email listservs, receiving 169 responses. Among respondents, the most commonly reported barriers to telegenetics prior to COVID-19 were inadequate funding/billing/reimbursement (14% of selections; n=54) and lack of institutional support (12%; n=45). During the pandemic, workflow/logistical issues (22%; n=45) ranked most highly. Facilitators were similar before and during the pandemic, and included provider interest, patient interest and institutional support. Approximately 60% of respondents (n=48) said they planned to continue providing telehealth services after the pandemic while 7% (n=6) did not, showing uncertainty about the future of telegenetics in the region.

For the interviews, NYMAC TCOP leadership invited members to participate. Five genetics providers were interviewed, with each interview recorded and transcribed. Thematic analysis was performed and six themes and two sub-themes were identified: the Benefits of Telehealth; the Limitations of Telehealth (sub-themes: Social Factors and Patient Technology); External Factors; Evolving Models; Provider Adaptation; and Institutional Engagement.

Results show that NYMAC genetics providers had diverse experiences adapting to the COVID-19 pandemic, informed by prior experiences with telehealth, practice settings, patient populations, and chosen service delivery models. Even so, each participant described a role for telegenetics in the future, to retain the flexibility to meet patient needs and ensure broader access services. Participants described policies and resources that would facilitate the future use of telegenetics, including changes to licensure and reimbursement policies, CMS recognition of genetic counselors, and funding. This study is significant to public health because it indicates areas in which NYMAC and other organizations may provide support to telegenetics programs moving forward.