



Rapid implementation of telegenetic services during the COVID-19 pandemic allowed continuing patient access, but not equally for all

Ryan Noss¹ · Katherine Carlotti¹ · Deanna Leingang¹ · David Flannery¹

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Abstract

Telegenetics is the use of telemedicine to deliver clinical genetic services to patients. During the COVID-19 public health emergency (PHE), telegenetics was essential for the Center of Personalized Genetic Healthcare (CPGH). This study reviews and analyzes in the context of the RE-AIM framework CPGH's rapid implementation of telegenetics and its impact. We conducted a chart review of all out-patient telegenetics encounters scheduled in CPGH during the first five weeks of the COVID-19 PHE. Data analyzed included demographics; number of encounters scheduled; subspecialties and providers; outcome of encounter (completed, cancelled, no-show); and telehealth platform used. Data were compared to data for out-patient encounters in 2019. In the first five weeks of the COVID-19 PHE, 465 virtual visits were scheduled and 428 were completed, involving all six subspecialties and 86% of CPGH providers. The no-show plus cancellation rate was significantly lower than in 2019. By week four, CPGH's virtual visit volume was 82% of its out-patient volume during the same time period in 2019. Patients over 60 and Black patients were significantly more likely to use phone-audio only appointments. CPGH rapidly implemented telegenetic services to continue providing care to patients. We identified success factors that enabled this. However, our analysis also identified a possible "digital divide" for Black and older patients.

Keywords Telegenetics · Telehealth · Digital Divide · Genetic services · Healthcare policy

1 Introduction

Improving access to and efficiency for clinical services has long been a goal for healthcare. One strategy to achieve this has been to leverage technology via telemedicine. Telemedicine services in Medical Genetics are frequently described as telegenetics [2, 6]. Prior research has demonstrated the ability of telegenetics to increase access while providing quality of care comparable to in-person services [1, 7, 10, 11]

The United States has been dealing with the COVID-19 pandemic since March of 2020. Ohio Governor Michael Dewine declared a State of Emergency for Ohio on March 9th, 2020. This order and subsequent executive and Ohio

Department of Health orders included closing non-essential businesses, closing schools, limiting gathering of people to groups of fewer than 50 individuals, postponing elective surgeries/procedures, and requiring social distancing [3]. These changes led healthcare providers to implement new models of providing care, chiefly virtual visits via telehealth technology. To facilitate this implementation, national, state, and institutional policies were changed to broaden access to telehealth [8, 9].

The Center for Personalized Genetic Healthcare (CPGH) is the clinical services unit of the Genomic Medicine Institute of the Cleveland Clinic. This clinical team is composed of 20 genetic counselors (GC), eight M.D. geneticists, one PharmD, three genetic counselor assistants and three schedulers dedicated to the CPGH. The providers are divided into sub-specialty teams: cancer, cardiovascular, general, ocular, prenatal, and pharmacogenetics. CPGH has several types of outpatient visits, including GC-only, MD only, GC + MD, and PharmD + MD. Prior to the public health emergency (PHE), the majority of outpatient genetic services were provided in-person. CPGH has offered telegenetic services since 2016; however, there had typically been low uptake,

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✉ David Flannery
flanned@ccf.org

¹ Center for Personalized Genetic Health Care, Genomic Medicine Institute and Cleveland Clinic Community Care, Cleveland Clinic, Cleveland, OH, USA

with 129 telegenetics encounters out of the 8,186 total outpatient encounters in the 12 months prior to the PHE.

On March 13, 2020, CPGH decided to offer all patients a choice between an in-person genetics visit and a virtual visit. By the following week, patients were offered a virtual visit or an in-person visit at a later date, after the PHE was projected to have ended.

This study reports and examines in the context of the RE-AIM implementation framework [5], our Center's experience during the COVID-19 PHE, in which in-person outpatient genetic encounters were converted rapidly to telegenetic encounters. The intervention was changing from in-person visits to live interactive audiovisual virtual visits. Our hypothesis was that we could switch over rapidly and provide genetic services to patients and these would be equivalent to past in-person experience.

2 Materials and methods

IRB approval for a retrospective chart review in the Cleveland Clinic electronic health record (EHR) was obtained through the Cleveland Clinic (IRB 20–703). The chart review included all out-patient telegenetics encounters scheduled in CPGH during the first five weeks of the COVID-19 PHE. CPGH used an approved data collection form in RedCap. Where appropriate, data were compared to in-person outpatient encounters from 2019.

We used a modified version of the RE-AIM Framework to assess the implementation of virtual visits during the beginning of the COVID-19 pandemic. We were able to assess the Reach, Effectiveness, Adoption, and Implementation of the telegenetic visits. We plan to analyze data on Maintenance later.

Reach refers to the characteristics of the participants. To assess this, we obtained data on the number of scheduled and completed virtual visits during the study period; and also collected patients' demographic data found in the registration information in their EHR record (age, gender, race/ethnicity, geographic location).

Effectiveness refers to the impact of an intervention. For this, we assessed data and determined the proportion of scheduled visits that were completed, cancelled and no-showed.

Adoption refers to the proportion and representativeness of providers who adopt a program. To assess this, we collected data on the number and types of providers conducting virtual visits over the studied time, as well as the number of virtual visits they completed. Implementation refers to the extent to which a program is delivered as intended. To assess this we reviewed clinical documentation and whether the patient needed an in-person encounter to complete the service. We also collected data regarding the virtual platform

used in order to determine whether the encounter was the intended intervention – live, interactive audiovisual.

Descriptive statistics were used to assess significance, using Student's unpaired t-test, with $p < 0.05$ as the cutoff for statistical significance. All statistical analyses were performed on de-identified data using JMP 9.0.0.

3 Results

Between March 16, 2020 and July 31, 2020, a total of 1539 virtual Genetics visits were scheduled and 1450 were completed. For this paper we chose to analyze the first five weeks of experience in detail for three reasons: 1) we experienced a large number of encounters, 2) the number of weekly encounters reached a steady state, and 3) data had to be extracted from the EHR and entered manually into our structured datasheet.

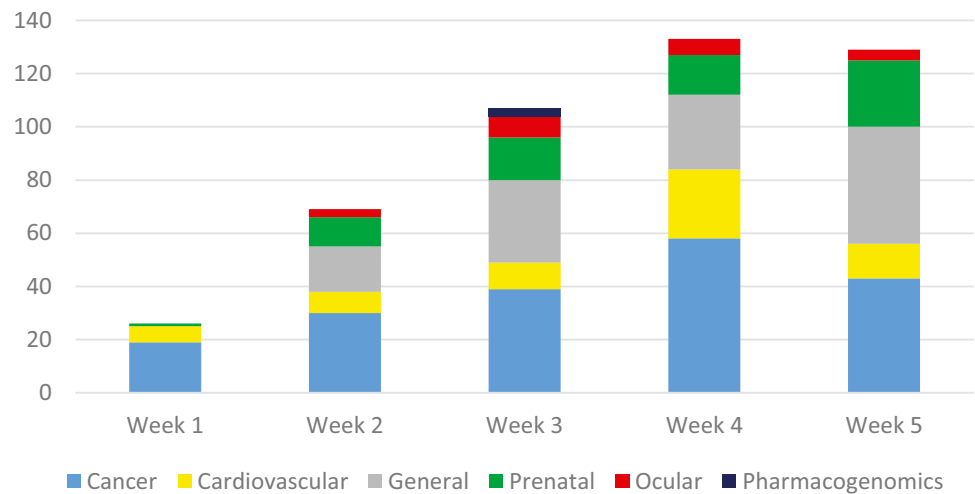
3.1 Reach

There were 465 virtual visits scheduled and 428 completed during the study period. The youngest outpatient seen virtually was 12-days-old, while the oldest was 92-years-old. The mean age was 41.5 and the median age was 41. 61 patients were 18 years and younger (14% of all patients visits), while there were 99 patients aged 60–92 (23%). For comparison, the age distribution for the 8,359 out-patients seen by CPGH providers in 2019 was 18 and younger 1874 (22.4%); 60 and older, 1951 (23%); and the mean was 20.3 years. There was no statistically significant difference between encounters for patients over 60 in the analyzed period versus 2019 (p value = 0.97, 95% CI [-0.1, 0.1]). However, patients 18 and younger were significantly less likely to access a virtual visit in 2020 versus all types of outpatient encounters in 2019 (p value ≤ 0.01 , 95% CI [0.1, 0.2]).

The race and ethnicity of patients seen virtually was White 78.3%, Black 11.3%, Asian 2.2%, Hispanic 2.4%, Middle Eastern 2.7%, Other 2.2%, not specified 0.9%. Due to differences in classification categories for race and ethnicity between the studied period and 2019, a full comparison of race and ethnicity was not possible. However, we compared the percentage of patients identifying as Black to the racial distribution in our historical outpatient data for 2019 to those seen in the first five weeks of the PHE. There was a statistically significant greater percentage of Black patients accessing Genetic service virtually in 2020 compared to Black patients seen in-person in 2019 (11.3% versus 8.8%, p value ≤ 0.01 , 95% CI [-0.1, 0.0]).

Cleveland Clinic is a healthcare system with national reach, and it is not surprising to see patients from out of state. The geographic location of the 428 patients during the studied period was unknown in 5 instances. Of the 423

Fig. 1 Weekly Encounters by Specialty



visits for which we have data, 413 were in Ohio, with three in New York state, two in California, one in Arizona, one in Utah, one in Tennessee, one in Colorado, and one in Michigan. All of these were new patient encounters.

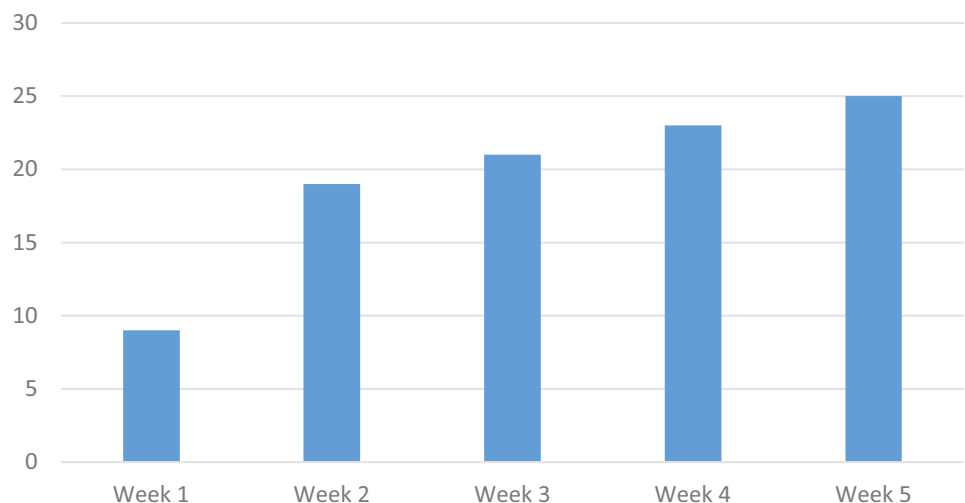
3.2 Effectiveness

During the study period there were 465 virtual visits scheduled and 428 were completed. The no-show plus cancellation rate for scheduled virtual visits for the studied period was 8%. The no-show plus cancellation rate for outpatient genetics visits for the previous year (2019) was 34%. This difference is significant (p value < 0.01, 95% CI [0.19, 0.33]). Since this study is a chart review, we do not know what fraction of patients who were offered virtual visits declined.

3.3 Adoption

Completed encounters were documented in the EHR in the same documentation templates we use for in-person encounters. During this period there was a marked increase of completed encounters, subspecialties involved, and provider participation. During the first week 26 virtual encounters were accomplished by nine different providers in two subspecialties. By the second week, use increased to 69 completed encounters by 19 providers in five subspecialties. Completed encounters continued to increase over the next two weeks. The third week saw participation by all six subspecialties. By the fifth week, 25 of 29 providers (86%) were providing virtual visits (Figs. 1 and 2). The 4 providers who had not done virtual visits were providers who have part-time clinical responsibilities. Eventually all providers were doing virtual visits, after the study period. By weeks 4 and 5, the

Fig. 2 Number of Different Providers Performing Virtual Visits



mean number of encounters per day reached 26.2, compared to the mean daily encounters for 2019 which was 32. During this study period 53 encounters were provided by MD geneticists, 3 by the PharmD, and 372 by genetic counselors. The ratio of MD vs. GC encounters in this time period was not significantly different from the ratio for 2019 encounters.

3.4 Implementation

A wide variety of institutionally approved virtual visit platforms/modalities were utilized (Fig. 3). 80% of virtual visits during the studied period were conducted through an audiovisual platform. Express Care Online (ECO), our institution-provided audiovisual telemedicine platform, was utilized most often (50% of all completed encounters). Telephone-audio only, was the second most utilized platform and typically was used because a patient did not have access to a computer or smartphone. Due to a variety of technical issues, 13% of completed encounters required the use of more than one platform (labeled “hybrid” in Fig. 3).

Of the 99 patients 60 years and older who completed a virtual outpatient visit, 58 were conducted using a telemedicine platform or videoconferencing platform alone, 4 began with a telemedicine or video platform but shifted to phone-audio only, and 37 were phone-audio only to begin with. Those over 60 were significantly more likely to use phone-audio only for their appointments compared to the group as a whole, 58 of 99 vs. 84 of 428 (p value ≤ 0.01 , 95% CI [-0.5, -0.3]). Of the 58 patients 60 and older who had phone-audio only encounters, 3 were with MDs, and

55 with GCs. This ratio of MD vs GC is not different than the ratio for in-person visits in 2019 (p value = 0.11, CI -0.16 –0.02).

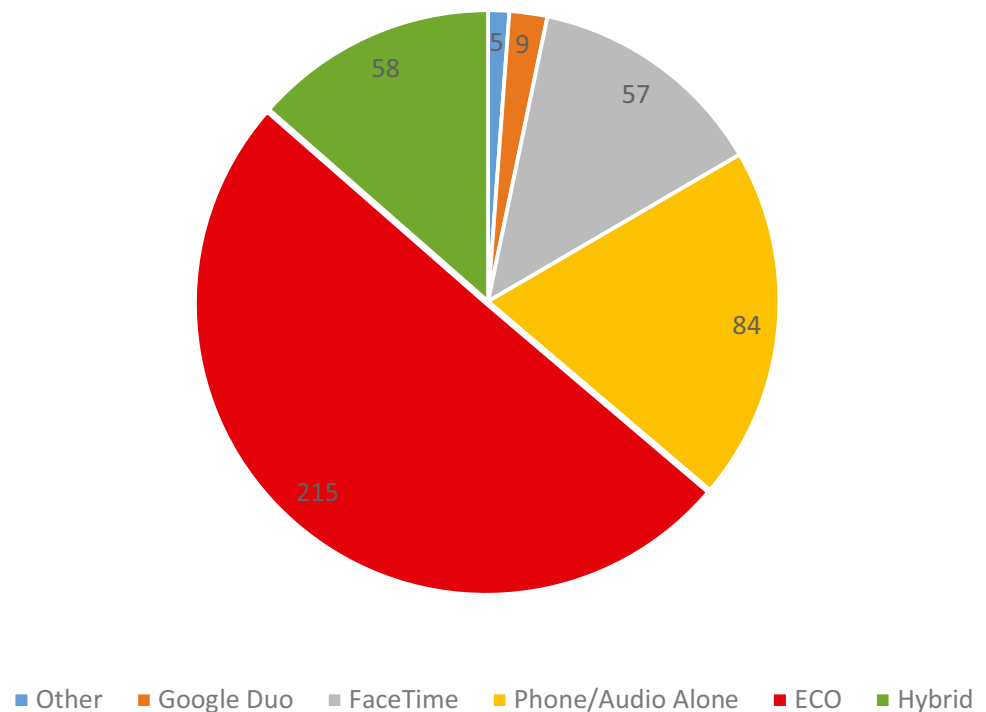
Among patients identified as Black in 2020, virtual visits used ECO 49%, phone audio only 37%, Facetime 22%, GoogleDuo 8%, Other 6%. As with the larger data set, the percentages add up to more than 100 because some visits required more than one platform. Patients who identified as Black were more likely to pursue their virtual visit via phone-audio alone compared to the group as a whole (p value ≤ 0.01 , 95% CI [-0.3, -0.1]). Of the 19 Black Phone audio only encounters, 2 were with MDs and 17 were with GC. This ratio of MD vs GC visits is not different from the ratio for in-person visits in 2019 (p value = 0.81, CI -0.17 –0.13).

A subsequent in-person encounter was needed for 8 out of the 428 completed virtual visits. In 2 instances the provider determined that the patient needed a more thorough physical examination, while the rest were patient or parent’s request.

4 Discussion

These data demonstrate that CPGH was able to scale up virtual visits quickly and continue to provide genetic services to a wide range of patients in all genetic subspecialties. The rapid expansion is evidence that patients and providers were comfortable with virtual visits. The number of MD encounters is consistent with the typical distribution

Fig. 3 Platforms Utilized



of types of encounters prior to the pivot to virtual care. It should be noted that the majority of published studies of telegenetics deal with genetic counseling visits only, which makes this study and subsequent further data analysis a valuable addition to the literature.

The age distribution reflects the breadth of specialties in our Genetics service, with cardiovascular and cancer genetics patients tending to be middle age or older. The observed lower percentage of children and adolescents may reflect decreased referrals from primary care providers (PCPs) during the PHE, whereas adult patients are frequently referred by a specialist provider who may be following them for an on-going and/or time sensitive health concern, such as a cancer diagnosis/treatment, cardiovascular disease, or prenatal care. The referring provider specialty was not specifically assessed in this study. The significant number of older patients completing virtual visits would indicate, also, that this population is accepting of technology.

We looked for evidence of a potential “digital divide” by analyzing data from those patients 60 and older and from those identifying as Black during the study period and then comparing that data to historic data for the same groups from 2019. At first, the comparisons seem to disprove such a “divide”. However, when we looked at the platforms used by older patients and Black patients, each group used phone- audio only more frequently than other groups and the group as a whole. This implies that these patient groups were not able to access audiovisual telemedicine platforms or chose not to use them. These differences could be due to any of several factors, such as lack of access to computers or smartphones, lack of access to broadband connectivity, unfamiliarity with apps, or uncomfortableness with technology. This possible digital divide may be underestimated because we do not have data on patients who were offered a virtual visit and declined. Having recognized this potential divide, we will be looking for ways to offer at the time of initial appointment scheduling, patients’ access to data plans, such as the Emergency Broadband Benefit program [4].

We are able to assess our results through the RE-AIM Framework in all areas except one. The large number of patients seen, reaching 82% of our historical daily volume, and the demographic range demonstrates the Reach of our implementation, although the issue of a possible “digital divide” for older patients and Black patients needs to be addressed for the future. Effectiveness is demonstrated by the high percentage of completed visits with significantly lower cancellation and no-show rates compared to our historical data. Adoption is demonstrated by the rapid increase of number of providers, to the point where 100% of our specialties and 86% of our providers conducted virtual visits. Implementation is demonstrated by the high

rate of encounters completed and documented in the EHR and the low number of follow-up in-person visits. Data collection and analysis throughout the duration of the PHE and afterwards will be necessary to assess Maintenance of this intervention.

We have identified several success factors that enabled our Center to pivot rapidly to virtual care and scale up quickly.

4.1 Public policy makers

HHS and CMS waived restrictions on telemedicine services, including geographical restrictions, and implemented payment parity between synchronous audiovisual virtual visits and telephone services. Also, HHS announced that it would exercise enforcement discretion which would allow health-care providers to use HIPAA non-compliant telemedicine platforms to provide care during the PHE.

4.2 Societal

The general public was concerned about the pandemic and wanted ways to reduce risk associated with in-person visits while receiving necessary healthcare services. This is even more important to patients and families of patients with genetic or suspected genetic disorders, as we have learned that they are concerned that they may be more vulnerable to COVID-19 infection and more likely to experience severe disease.

4.3 Institutional

Prior to the pandemic, in 2019, the Cleveland Clinic CEO set a goal of expanding telemedicine services to achieve 50% of all outpatient visits conducted virtually by 2023.

At the beginning of the PHE, institutional leaders provided clear messaging to all Cleveland Clinic providers that converting to virtual care was an institutional priority. Providers had clear guidelines regarding flexibility in use of virtual visit platforms to begin and complete virtual visits.

Further, the institution committed to waiving co-pays for all virtual visits during the studied period, which eliminated a likely significant barrier to patient uptake.

The Cleveland Clinic Legal Office provided clear advice regarding providers seeing patients residing in other states and provided frequent updates as national policies evolved.

4.4 Departmental

CPGH had already been committed to growing telegenetics (TG). In mid-2018 the CPGH hired an MD geneticist to be Director of Telegenetics and Digital Genetics. We already

had three GCs with experience in TG and four MDs with TG experience or training. The experienced providers rapidly taught the inexperienced providers how to conduct virtual visits and were involved in ongoing troubleshooting and problem solving.

CPGH has three dedicated schedulers. They rapidly contacted existing scheduled patients and converted the appointment to a virtual visit in the scheduling and registration system, as well as explained virtual visits to newly referred patients, leading to a high uptake of virtual visits for Genetics patients.

Prior to the PHE, most of CPGH's telegenetics encounters were to outreach clinics which required that patients travel to a local hospital outpatient facility for their virtual visit. It is clear that being able to be seen from home was an important factor leading to increased patient uptake of virtual visits.

5 Conclusions

The COVID-19 Pandemic presented many challenges to healthcare systems and providers. Also, it presented opportunities for transforming healthcare delivery. As with our experience in delivering genetic services, changes in institutional and national policy facilitated a successful shift to virtual care across the entire US healthcare system. However, as with our study, the response to the pandemic uncovered systemic weaknesses in the US healthcare system. Whether the shift towards virtual care becomes a permanent inflection point in healthcare delivery will depend on continuation of these policy changes and increasing availability of digital data to all.

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Data availability In a manner consistent with Cleveland Clinic Foundation (CCF) policies and applicable data privacy laws, CCF will make de-identified data set of study data available under terms of a standard data transfer agreement, such as CCF's standard data transfer template and/or the Federal Demonstration Partnership template for the transfer of a de-identified data set. All transfers shall be done in such a way as to ensure patient privacy is preserved and that the data set is used in accordance with all applicable laws and industry standards.

Compliance with ethical standards

Consent for publication This study and its data collection form were approved by the Cleveland Clinic Institutional Review Board as an exempt protocol #20-703, not requiring informed consent.

Conflict of interest Ryan Noss, Katherine Carlotti, Deanna Leingang and David Flannery declare that they have no conflicts of interest related to this research.

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