



August 14, 2020

Donna Frescatore
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Dear Ms. Frescatore,

On behalf of the 1,600 people in New York living with cystic fibrosis (CF), we write to thank you for expanding access to telehealth services during the COVID-19 crisis and ask you to extend many of these flexibilities while COVID-19 remains a threat for people with CF. Continuing these flexibilities past the current expiration date of August 15, 2020 will help ensure those at high-risk of complications related to COVID-19—including people with cystic fibrosis—have continued access to care without putting themselves at greater risk of infection.

About cystic fibrosis and COVID-19

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 children and adults in the United States. CF is a complex, multi-system disease that causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. While great strides have been made in the treatment of the disease, CF continues to be a severe condition for which COVID-19 can pose serious health risks.

Access to telehealth services is especially important for those with CF and other underlying health conditions who, according to the Centers for Disease Control and Prevention (CDC), may be at increased risk of developing serious illness if they become infected with the coronavirus.¹ Recognizing the need for strict adherence to social distancing guidelines and taking into account special considerations for their patient population, CF care teams have responded rapidly to changes in care delivery and are embracing telehealth in their clinics. Today, nearly all of the 130 CF care centers in the U.S., including 23 centers in New York, are providing some form of telehealth services to their patients.

COVID-19 continues to present serious risk to New York residents, including those with CF. As of August 13th, more than 165,000 people in the United States have died as a result of COVID-19, including more than 33,000 in New York.² Furthermore, over the last seven days, more than 4,500 cases in New York have been reported. As the number of cases increases in many states and the risks continue, the CDC has recommended Americans continue to reduce the risk of transmission of COVID-19 and protect those who are most vulnerable to infection.³

Extend telehealth flexibilities

The CF Foundation commends New York and the Department of Health for recognizing the critical role of telehealth during the COVID-19 pandemic and providing temporary flexibilities to increase access to remote care. These flexibilities

¹ https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fgroups-at-higher-risk.html

² <https://www.cdc.gov/covid-data-tracker/>

³ <https://www.cdc.gov/media/releases/2020/s0528-coronavirus-death-toll.html>

have helped mitigate the effects of the coronavirus pandemic by removing barriers to telehealth services and reducing unnecessary exposure to the virus for both patients and providers. We appreciate your efforts to ensure patients' access to telehealth services and ask that New York Medicaid extend the following flexibilities for as long as COVID-19 remains a threat to people with CF:

1. Permitting a patient's home to serve as the originating site for care;
2. Expanding the range of providers eligible for telehealth reimbursement; and
3. Ensuring payment parity between telehealth and in-person services

Permitting a patient's home to serve as the originating site for care

Continuing to ease originating site restrictions will help ensure patients can access telehealth from their home. This enables infected patients to receive care without spreading the virus and allows other patients—including those with underlying conditions like CF—to receive care without putting themselves at increased risk of coronavirus infection. This flexibility also reduces unnecessary exposure for CF providers. If originating site restrictions were to go back into effect, it would undermine the real value of telehealth in this pandemic—which has been allowing patients to receive health care while continuing to practice social distancing.

Expanding the range of providers eligible for telehealth reimbursement

Continuing to reimburse additional providers for telehealth services is also critical. Cystic fibrosis is a complex disease that requires multidisciplinary, patient-centered care; each care team has a pulmonologist, nurse, respiratory therapist, dietician, and social worker, and often includes additional staff such as a mental health coordinator or pharmacist. In order for patients with CF to continue to receive the highest quality of care from their homes, they must be able to access their entire care team. Therefore, it is critical that each discipline remain eligible for reimbursement for telehealth services beyond the current public health emergency. Therefore, we encourage New York to continue to allow flexibility as to which providers are eligible for reimbursement for telehealth services, including at least those added during your initial response to COVID-19 in March.

Ensuring payment parity between telehealth and in-person services

Extending reimbursement parity between telehealth and in-person services will ensure that CF care centers are able to continue offering telehealth services for as long as their patients need it and will relieve some of the financial pressure for institutions to bring patients back in-person. The CF Foundation funds and accredits more than 130 care centers—including 23 across New York—that provide expert, coordinated cystic fibrosis care and specialized disease management so people living with the disease can live longer, healthier lives. These care centers are often housed within academic medical centers that serve a disproportionate number of low-income patients and rely on Medicaid reimbursement for a significant amount of their revenue. Therefore, it is critical that providers are adequately reimbursed for services delivered to Medicaid patients, including those provided via telehealth. In the absence of sufficient reimbursement, the financial viability of our care center network and access to care for people with CF could be at risk.

Finally, permitting the continued use of audio-only communication will help ensure that patients without access to the internet, a computer, or smartphone are still able to receive care while it is not safe to be seen in-person. We thank the State of New York for passing SB 8416 to make this offering permanent for Medicaid members, effective immediately. This flexibility is especially critical for providers that serve rural or low-income populations, as many of these patients lack internet access. For instance, a CF clinician from Tucson, Arizona said that most of her patients do not have access to the internet and many are relying on audio-only telehealth visits with their care team during the pandemic.

Cover remote monitoring devices and services

To experience the full benefits of New York's telehealth expansions, people with CF also need access to remote monitoring devices, including home spirometers, pulse oximeters, and scales. As a complex, chronic disease, cystic fibrosis requires regular physiologic monitoring. CF clinicians monitor patient wellbeing through key health indicators, most notably lung function and weight. Studies show that home spirometry use, for example, can help detect pulmonary

exacerbations in adults and may improve medication adherence in adolescents.^{4,5} Additionally, people with cystic fibrosis can experience complications that lead to malnutrition and other digestive issues that hinder their ability to maintain a healthy weight. Infant and adult scales are critical for people with CF to monitor their weight and body mass index (BMI) in consultation with their care team. Coverage of these devices, in addition to provider time spent on remote patient monitoring, is vital for CF patients to maintain their health while remaining at home.

We urge you to extend the flexibilities detailed in this letter beyond August 15th and to provide coverage of remote monitoring devices and related services. The coronavirus is still very much a threat for people with cystic fibrosis and ongoing access to telehealth care is imperative for avoiding unnecessary exposure to the virus.

We stand ready to serve as a resource to New York as you consider coverage and reimbursement changes during and beyond the current public health emergency. Please contact Adam Kellermann at akellermann@cff.org or (240) 200-3713 if you would like to discuss this issue further.

Thank you for your attention to this important issue.

Sincerely,

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⁴ Shakkottai A, Kaciroti N, Kasmikha L, Nasr SZ. Impact of home spirometry on medication adherence among adolescents with cystic fibrosis. *Pediatric Pulmonology*. 2018;53:431–436. <https://doi.org/10.1002/ppul.23950>

⁵ Lechtzin, Noah et al. "Home Monitoring of Patients with Cystic Fibrosis to Identify and Treat Acute Pulmonary Exacerbations. eICE Study Results." *American journal of respiratory and critical care medicine* vol. 196,9 (2017): 1144-1151. doi:10.1164/rccm.201610-2172OC