CYSTIC FIBROSIS
FOUNDATION®

February 25, 2022

Jacqueline Ward
Assistant Director
Office of Science and Technology Policy
Executive Office of the President
Eisenhower Executive Office Building
1650 Pennsylvania Avenue
Washington, D.C. 20504

Re: Request for Information on Strengthening Community Health Through Technology

Dear Ms. Ward:

We were pleased to see the Office of Science and Technology Policy's (OSTP) interest in improving access to digital health technologies and high-quality telehealth services. Like many communities, the COVID-19 pandemic rapidly accelerated the use of telehealth among people with cystic fibrosis and our experience from the last two years is instructive for understanding promoters of digital health care and telehealth, and remaining barriers.

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 chronic infection is irreversible and can have a lasting impact on length and quality of life. Nearly all people with CF in the United States receive care at an accredited CF care center, which provides multidisciplinary, specialized care in accordance with evidence-based guidelines. While great strides have been made in the treatment of the disease, CF requires uninterrupted access to high-quality care and therapies for patients to maintain their health and well-being.

Trends from the COVID-19 pandemic
While there was almost no use of telehealth in CF in the United States prior to the COVID-19 pandemic, all CF care centers were providing telehealth care within a few months after the pandemic began. By the fall of 2020, about 80 percent of patients and families who responded to a CF Foundation survey indicated that they used telehealth for their CF care.[1] Use of telehealth has ebbed and flowed since then, with increased use during COVID-19 surges. Most recently, 25 percent of respondents from a survey of patients and families had a fully remote or hybrid visit (with a virtual and in-person component) between October 2021 and February 2022—indicating that some level of telehealth will remain in cystic fibrosis care going forward.

---

[1] Solomon, G.M. et al. (2021) Patient and family experience of telehealth care delivery as part of the CF chronic care model early in the COVID-19 pandemic. *Journal of Cystic Fibrosis,* 20S3, S41-S46. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8683126/pdf/main.pdf

1

In our surveys of patients and families, the majority report that telehealth services were of equal or higher quality than in-person services and nearly half said they want telehealth to remain part of their care in the future.[2] Adults indicated a stronger desire to continue using telehealth than parents of children, which is not surprising given some of the challenges with getting younger children to interact meaningfully during remote visits. CF care teams reported several advantages of telehealth for patients, including less time spent traveling and away from work, ability to stay connected with care teams during the pandemic, and earlier identification of health issues.[3]

Clinicians and patients are working to understand how to best integrate telehealth into management of this chronic, multi-system disease. CF care teams are multi-disciplinary and include physicians, nurses, respiratory therapists, dieticians, social workers, and program coordinators, at a minimum. Care guidelines recommend routine appointments every 3 months for most patients, including assessment of vital signs, lung function, and nutritional status. Collection of respiratory specimens for cultures and blood laboratory values are also standard components of care. Understanding how to incorporate remote care into this model is a significant undertaking and the Foundation is leading a body of research to investigate how telehealth may supplant or supplement elements of the CF care model and for which CF patients.

Barriers to using digital health technologies
While there was widespread adoption of telehealth across CF patients and providers beginning in 2020, there are several barriers related to the provision and use of telehealth.

First, providers continue to report that licensing is a significant barrier to telehealth care for patients with a rare disease like CF who often seek care across state lines. Because CF care is highly specialized, many patients travel out-of-state for care and over 10 percent of people with CF receive care in a different state than their state of residence, according to the CF Foundation patient registry. People living with cystic fibrosis may seek care in another state for a variety of reasons, including geographic proximity or access to specialists with expertise in their specific CF-related complications. For example, those who harbor certain bacteria or have had a lung transplant may need to travel out-of-state to get appropriate care. In these cases, if physicians are not licensed in the patient's state of residence, remote care may be entirely inaccessible.

Access to remote monitoring technology can be another obstacle to telehealth care. In response to the immediate concerns around COVID-19 infection at the beginning of the pandemic, the CF Foundation distributed handheld spirometers for patients to use at home, as these devices are typically not covered by insurance. Patients also relied on home scales and pulse oximeters and some CF care centers set up methods for collecting sputum or throat specimens by mail. These ad hoc solutions provided short-term access during the pandemic but gaps in evidence about how to remotely collect high-quality data to guide clinical decision-making and corresponding insurance coverage remain. When asked about ways to improve telehealth care, improved access to reliable remote monitoring devices was the most

---

[2] Solomon, G.M. et al.
[3] Van Critters, A.D., et al. (2021). Barriers and facilitators to implementing telehealth services during the COVID-19 pandemic: A qualitative analysis of interviews with cystic fibrosis care team members. Journal of Cystic Fibrosis, 20S23, S23-S28. https://www.cysticfibrosisjournal.com/article/S1569-1993(21)01404-1/fulltext

common recommendation among people with CF, including the ability to accurately measure lung function, weight, and other vital signs.[4]

Financial considerations for health care institutions are another barrier to the provision of remote care. Telehealth visits often have lower reimbursement rates than in-person visits. Institutions also lose revenue associated with facility fees and other in-person services, such as pulmonary function tests, blood draws, and x-rays. CF clinicians report that these financial pressures influence their ability to offer remote options to their patients.

Finally, broadband access continues to be a challenge for some populations. While the vast majority of CF telehealth visits were conducted over video—the preferred modality for providers and patients—some populations do not have sufficient broadband to support video conferencing or do not have any internet access at all. Lack of internet access among patients was the most frequently reported barrier to telehealth by CF care centers and the challenges accessing telehealth in rural and low-income populations are well documented.[5] For these patients, telephone visits with their care team are their primary option for accessing remote care until access to reliable broadband improves.

Tool and training needs
Interviews with CF clinicians revealed that institutional resources to support remote care are critical.[6] Care centers that perceived telehealth care to be of similar quality to in-person care reported benefiting from institutional support such as telehealth software and systems, dual-monitor computer systems, and information technology support. Leadership engagement and support for change was also an important factor for successful delivery of telehealth care. In contrast, programs that perceived telehealth care to be inferior to in-person care reported receiving less institutional support.

Health Equity
Telehealth has the potential to improve access for vulnerable populations by reducing travel costs and time off work, but a survey of CF patients and families found important disparities. Most notably, non-white patients were less likely to have a telehealth visit than their white counterparts and reported barriers related to technology, internet access, and translation services.[7] Specifically, 85 percent of white patients reported a telehealth visit compared to 69 percent of non-white patients. This difference was even starker among Hispanic patients, for whom only 54 percent had a telehealth visit. Consistent with broader trends, Black people with CF were significantly less likely to use video for their telehealth visit: 57 percent compared to 89 percent for all other patients. Importantly, there was no difference in future desire for a telehealth visit by race or ethnicity.

---

[4] Ong, T. et al. (2021) Remote monitoring in telehealth care delivery across the U.S. cystic fibrosis care network. *Journal of Cystic Fibrosis,* 20S3, S57-S63. https://www.cysticfibrosisjournal.com/article/S1569-1993(21)01376-X/fulltext

[5] Gifford, A.H., et al. (2021). Evaluating barriers to and promoters of telehealth during the COVID-19 pandemic at U.S. cystic fibrosis programs. Journal of Cystic Fibrosis, 20S3, S9-S13. https://www.cysticfibrosisjournal.com/article/S1569-1993(21)01375-8/fulltext

[6] Van Critters, A.D., et al.

[7] Albon, D., et al. (2021). Telehealth use in cystic fibrosis during COVID-19: Association with race, ethnicity, and socioeconomic factors. Journal of Cystic Fibrosis, 20S3, S-29-S54. https://www.cysticfibrosisjournal.com/article/S1569-1993(21)01407-7/fulltext

People with CF who reported financial concerns during the pandemic were more likely to say that telehealth was difficult to use and were less likely to feel like their concerns were addressed via telehealth.[8] Insurance type was not associated with differences in access, interest, quality, or barriers to telehealth services.

CF programs reported lack of technology, language barriers (including hearing loss), and home conditions as barriers to telehealth in vulnerable populations and cited the need for additional accommodations such as translators, closed captioning, and American Sign Language interpreters.

Measuring user experience
The CF Foundation regularly collects survey data from patients and families across all care centers to understand their experience of care. In the most recent survey of patients and families, nearly ten percent of respondents reported challenges with remote monitoring—most commonly using their home spirometer. Issues including lack of understanding about how to assemble and use the spirometer, inability to get reliable readings, and challenges for people with cognitive issues. Preliminary results from research into the validity of home spirometry results indicate that patients receive more accurate readings and have an easier time using the device when they receive individual coaching from a respiratory therapist. These reports underscore the wide range of issues patients face when learning how to use remote health technology and the need for education for both patients and care teams.

Proposed government action
Based on the issues outlined above, we recommend the following government actions:

- *Improve broadband access* – COVID-19 highlighted the critical need for all Americans to have access to reliable internet, including to ensure access to remote health care when needed. The administration should continue working with Congress to address the physical infrastructure and financial challenges that result in some populations living without reliable broadband access.

- *Cover audio-only services as clinically appropriate in Medicare* – While audio-only visits are not suitable for all health care services and are not a substitute for in-person care, there are a number of aspects of regular CF care that can be conducted over the phone. For instance, clinicians can easily review medical history, current medications, and symptoms, and make adjustments to care plans. Audio-only visits can be an important option for those with no internet access and those with limited technology literacy and the administration should ensure appropriate coverage in Medicare.

- *Address licensing barriers* – Licensing barriers can completely eliminate access to remote care for people who seek care across states lines. The CF Foundation supports the TREAT Act, which would allow temporary licensing reciprocity for all licensed practitioners in all states during the COVID-19 public health emergency. Beyond that, we encourage the administration to work with Congress to explore additional reciprocity arrangements.

---

[8] Albon, D., et al.

4

- *Research racial, ethnic, and socioeconomic disparities in telehealth* – Given the potential for telehealth to improve access to care for vulnerable populations, it is imperative to continue researching racial, ethnic, and socioeconomic disparities in use of telehealth to understand the underlying causes and identify solutions.

- *Address information technology needs in health care institutions* – Providers need adequate hardware, software, and training to offer remote options to patients. The administration should support efforts to provide these resources as needed to ensure widespread access to telehealth.

- *Support patient use of remote technology* – Improving health and technological literacy will be critical for effective use of remote patient monitoring and telehealth. Early research into use of home spirometers in CF highlights the frequent need for individual instruction to use these devices effectively. The administration should consider ways to provide such resources to patients, including requiring insurance coverage when applicable.

- *Remove geographic restrictions in Medicare* – Before the COVID-19 pandemic, Medicare rules largely restricted use of a patient's home as the originating site to those living in rural areas or with a specific condition. The drastic increase in telehealth usage has shown the futility of such restrictions and it is appropriate and safe for patients to receive care from their homes. We urge the administration to work with Congress to permanently remove originating site and geographic requirements.

Sincerely,

Mary B. Dwight
Senior Vice President
Chief Policy and Advocacy Officer
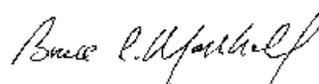
Bruce C. Marshall, MD
Executive Vice President
Chief Medical Officer