



August 12, 2022

Effective Health Care Program
Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, Maryland

Re: Agency for Healthcare Research and Quality (AHRQ) Effective Health Care (EHC) Program's Public Review of "Use of Telehealth During the COVID-19 Era"

Dear Members of the AHRQ Effective Health Care (EHC) Program:

On behalf of the Cystic Fibrosis Foundation, we write to provide public comment on the AHRQ EHC Program's draft publication "Use of Telehealth During the COVID-19 Era" (Draft).

About Cystic Fibrosis & the Cystic Fibrosis Foundation

Cystic fibrosis (CF) is a severe, progressive genetic disease that affects nearly 40,000 individuals in the United States. CF causes the body to produce thick mucus that clogs the lungs and other organ systems, which results in lung damage, life-threatening infections, and other complications. As a complex, multi-organ system condition, CF requires targeted, specialized treatment regimens. Despite significant advances in CF care, CF remains a life-shortening disease.

As the world leader in the search for a cure for CF, the Cystic Fibrosis Foundation's mission is to give all people with CF the opportunity to lead long, fulfilling lives. We do so by funding research and drug development, advancing high-quality, specialized care, and partnering with the CF community to ensure that people with cystic fibrosis and their families have the tools, resources, and support they need to thrive.

We are pleased to have the opportunity to review and share our thoughts on the publication "Use of Telehealth During the COVID-19 Era" and are encouraged to see that much of it aligns with the observations and data on telehealth use from the CF community throughout the pandemic. These include increased convenience and flexibility for many patients, less missed work and school, decreased travel expenses, potential improvements to health equity, technology and technical challenges for some, and financial concerns for providers. With that in mind, we would like to offer additional recommendations on areas of further research and considerations for those in the CF community.

Considerations for complex chronic care community

In this review, it is emphasized that telehealth may be an inadequate mode of care delivery for people requiring specialized care for complex conditions. While it may be true that telehealth alone is not advisable as an exclusive platform for healthcare delivery in complex conditions that require frequent testing and multimodal assessments, it has proven to be complimentary to traditional clinic-based care in cystic fibrosis. We recommend reevaluating and rephrasing the suggestion that telehealth may not be well suited for complex conditions as the reality is more nuanced than the draft implies.

Telehealth is an important tool in the toolbox for CF care, when coupled with in person visits. Utilization of telehealth for CF care delivery peaked in April 2020 immediately after COVID-19 pandemic declaration and

has fluctuated based on community COVID-19 transmission since then. The Experience of Care survey taken by people and their families after CF visits revealed that 25 percent of respondents had a fully remote or hybrid visit (with a virtual and in-person component) between October 2021 and February 2022.¹ About two thirds of surveyed CF patients and families feel that the quality of telehealth visits is as good or better than in person care.² This data suggests that cystic fibrosis care will continue to encompass some degree of telehealth going forward.

CF care teams report 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 Indeed, telehealth visits facilitate same day urgent assessments by the specialized CF care team to triage patients with new or changing symptoms so that treatment is not delayed or deferred to an emergency room setting. Likewise, telehealth provides a platform for interim assessments between clinic visits when frequent contact is required for dynamic clinical situations such as active mental health or pulmonary issues, or titration of new medications. The incorporation of telehealth into clinical practice has been an unanticipated consequence of the pandemic and should remain a viable method to enhance traditional care delivery. A means by which to access timely and specialized care, such as telehealth, is particularly important in chronic, rare diseases where expertise is geographically disparate, and the burden of treatments and medical visits are already quite high for patients and their families.

Clinicians and patients are working to understand how to best integrate telehealth into management of this chronic, multi-system disease.⁴ CF care teams are multi-disciplinary and include physicians, nurses, respiratory therapists, dietitians, social workers, and program coordinators, at a minimum. Telehealth offers an alternate venue for synchronous, comprehensive visits with all team members without additional infection risk. Conversely, telehealth also facilitates additional visits with specific team members if specific areas of concern and focus are identified such as weekly visits with the CF dietitian if malnutrition is recognized.

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 best collect and integrate remote monitoring data to enrich the value of telehealth is a significant undertaking. The CF Foundation is leading a body of research to investigate how high-quality telehealth may supplant or supplement certain elements of the intensive CF care model and for which CF patients.

Additional barriers to telehealth

¹ <https://www.cff.org/community-posts/2021-10/feedback-my-sons-cf-care-team-together-we-make-it-better>

² Solomon GM, Bailey J, Lawlor J, Scalia P, Sawicki GS, Dowd C, Sabadosa KA, Van Citters A. Patient and family experience of telehealth care delivery as part of the CF chronic care model early in the COVID-19 pandemic. *J Cyst Fibros*. 2021 Dec;20 Suppl 3:41-46. doi: 10.1016/j.jcf.2021.09.005. PMID: 34930542; PMCID: PMC8683126.

³ Van Citters, 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](https://www.cysticfibrosisjournal.com/article/S1569-1993(21)01404-1/fulltext)

⁴ Albon D, Thomas L, Hoberg L, Stamper S, Somerville L, Varghese P, Balasa E, Roman M, Britto MT, Miner M, Gehring E, Gammon C, Amin RS, Seid M, Powers M; CF Learning Network telehealth iLab working group. Cystic fibrosis learning network telehealth innovation lab during the COVID-19 pandemic: a success QI story for interdisciplinary care and agenda setting. *BMJ Open Qual*. 2022 May;11(2):e001844. doi: 10.1136/bmjopen-2022-001844. PMID: 35589277; PMCID: PMC9121114.

While there has been widespread adoption of telehealth across CF patients and providers since 2020, there are several barriers related to the provision and use of telehealth that were not mentioned within this systematic review and may warrant consideration and inclusion.

A key barrier not identified in this draft is provider licensing. Providers continue to report that licensing creates a significant barrier to telehealth care for patients with a rare disease like CF who often receive care across state lines. Because CF care is highly specialized, 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.⁵ People living with cystic fibrosis may seek care in another state for a variety of reasons, including geographic proximity to the state line, access to specialists with expertise in their specific CF-related complications, or enrollment in clinical trials. 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 patients' state of residence, remote care may be entirely inaccessible. Further, differences in licensing between provider types (i.e., physicians and advanced practice providers) can potentially create disjointed care and reduce the opportunities telehealth provides.

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 and paucity of best practices for collection of high quality remote 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 common recommendation among people with CF, including the ability to accurately measure lung function, weight, and other vital signs.⁶ Expanded insurance coverage of home monitoring devices could help overcome this barrier and improve the quality of telehealth visits by ensuring the availability of adjunct data to inform clinical decision making.

The Cystic Fibrosis Foundation appreciates the opportunity to provide feedback on this important research and draft publication. We stand by to answer any questions you may have. Please contact Olivia Dieni, MPH, at odieni@cff.org or 240-200-3715 to discuss further.

Sincerely,



Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President of Policy and Advocacy



A. Whitney Brown, MD
Senior Director, Clinical Affairs

⁵ Cystic Fibrosis Foundation Patient Registry 2020 Annual Data, Bethesda, Maryland

⁶ 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](https://www.cysticfibrosisjournal.com/article/S1569-1993(21)01376-X/fulltext)