National Report 2023

EXPERIENCE OF CARE

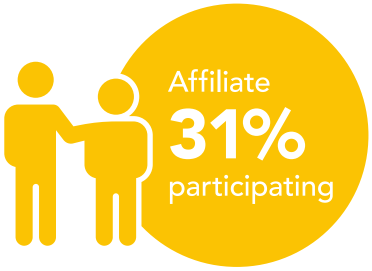
CYSTIC FIBROSIS FOUNDATION®

This report includes data collected between October 2021 and October 2023 to highlight important trends over time. These data are made possible by people with CF and family caregivers who respond to the Experience of Care survey and clinicians at participating programs.

Understanding care as experienced by people with CF and family caregivers is essential to providing quality, patient-centered care. The CF Foundation Experience of Care (XoC) survey invites adults with CF and family caregivers to provide feedback after an in-person or virtual clinic visit. As of April 2023, patients and families had more opportunities to comment on infection prevention and control practices, access to care, and partnership with their care team by way of a revised version of the survey.

205

programs invite people with CF and family caregivers to complete surveys.



Affiliate
31%
participating

Pediatric
76%
participating

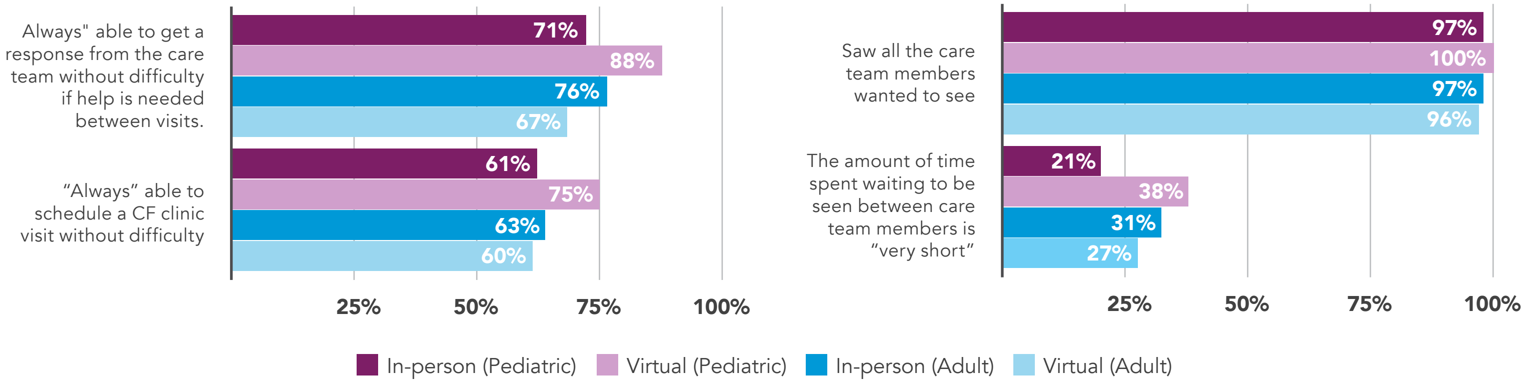
Adult
79%
participating

Opportunities exist to improve ease of communication and scheduling visits.

There is room to improve processes for accessing care both when help is needed outside of a clinic visit and in scheduling visits.

Opportunities exist to improve efficiencies during clinic visits.

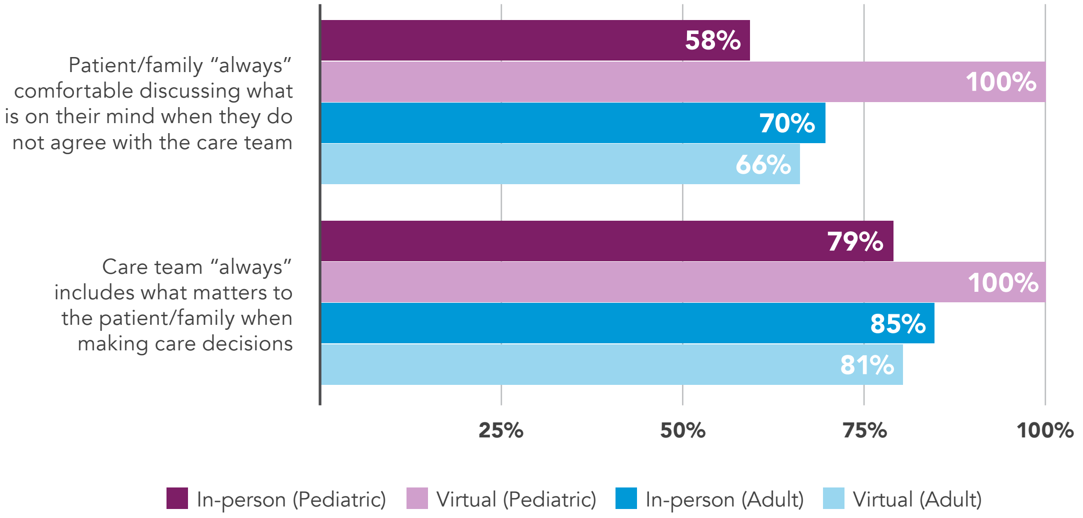
While people with CF and family caregivers report seeing all the care team members they want to see during visits, there is room to improve how long they spend waiting to see care team members.



> **"I timed it. They were 30 minutes late for the breathing test appointment, then we waited another 25 minutes for pharmacy to come in for 5 minutes, waited 13 minutes for nurse to be in there for 3 minutes, then a whopping 31 minutes for the 4 minutes doctor spent in the room. If we were that late, you would've canceled our appointments and still billed the insurance." — Parent of a child with CF.**
>
> **"Just a long delay while waiting for a vaccine. Also, was late to my 2-hour post blood draw where I had been fasting for 14 hours." — Adult with CF**

People with CF and family caregivers are not always comfortable speaking up and may not feel included in care decisions.

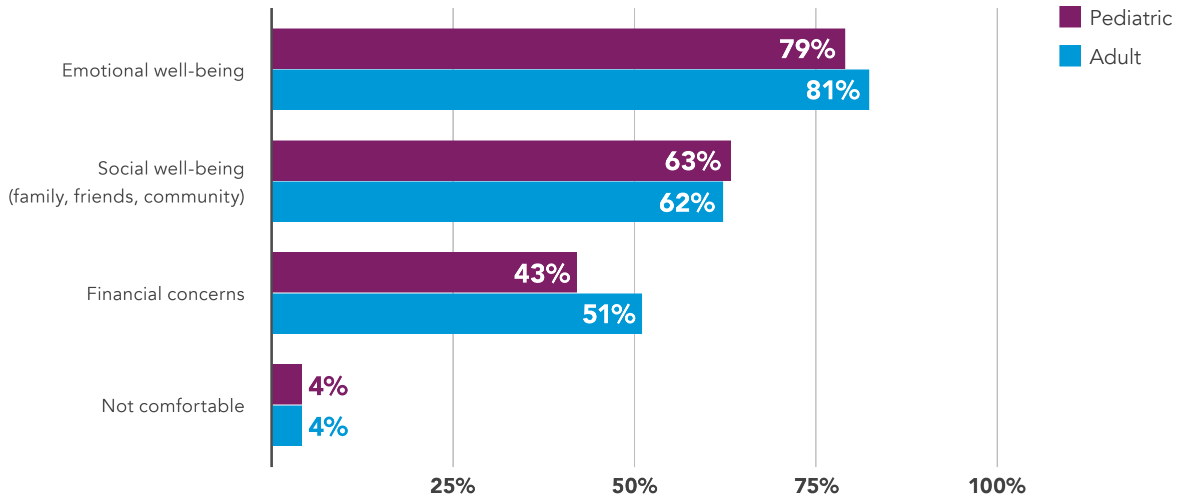
Adults with CF and family caregivers report that they do not "always" feel they can speak-up when they disagree with the care team. More can be done to invite adults with CF and family caregivers to share what is on their mind during clinic visits.



> **"Pues si que el que el equipo tenga la cortesía de tender por igual al latino que los de mas."**
>
> ***"Well, yes, the fact that the team has the courtesy to treat Latino the same as they treat everyone else."***
>
> **— Parent of a child with CF**
>
> **"My lung function has dropped significantly- but nothing was proposed to help. Trikafta was pushed on me—I had terrible side effects when I last tried it—that was ignored, overlooked, or seemed to be taken as a lie." — Adult with CF**

If needed, how comfortable are people with CF and family caregivers with discussing aspects of their well-being with the care team.

Emotional, social, and financial well-being are important to maintaining physical health. People with CF and family caregivers most often shared discussing emotional well-being during clinic visits, with fewer discussing social (family, friends, community) and financial well-being.

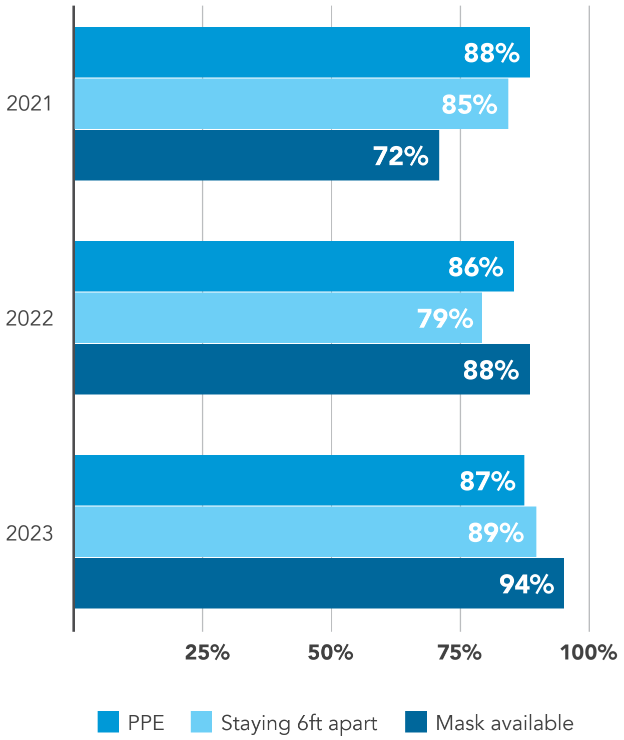


Infection prevention and control practices are trending upward.

Collecting data over time reveals trends in critical aspects of care. Despite changes in COVID-19 precautions, adults with CF and family caregivers report higher adherence to infection prevention and control (IPC) practices, particularly when it comes to the availability of masks. The CF Foundation Infection Prevention and Control guidelines and the short resource "11 Ways to Guard Against Germs in Health Care Settings" are excellent resources to improve IPC practices in clinic.

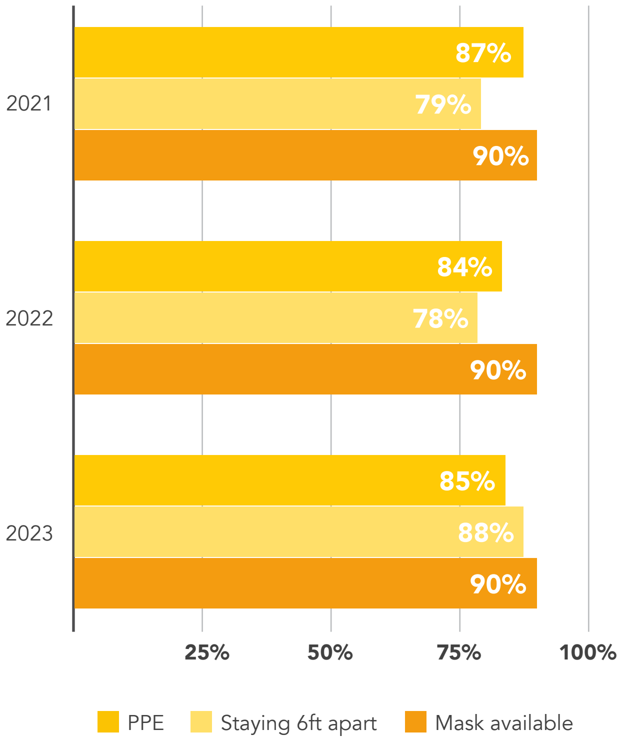
Adults with CF

PPE: Personal Protective Equipment worn by the CF team and other healthcare professionals.



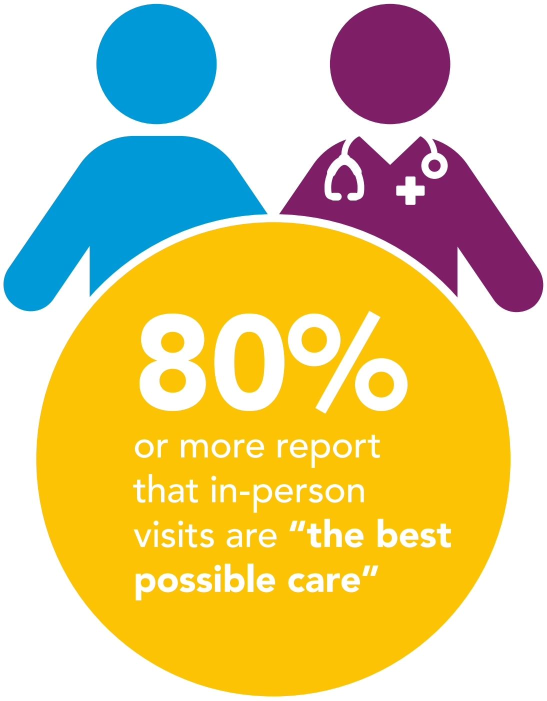
Family Caregivers

PPE: Personal Protective Equipment worn by the CF team and other healthcare professionals.



Best possible care is consistently reported for in-person visits.

CF Foundation-accredited CF programs strive to deliver a safe, multidisciplinary care experience for all people with CF. **Eighty percent or more of adults with CF and family caregivers** are reporting in-person visits are "the best possible care". Virtual visits may be limited due to team member availability.



Adults with CF and family caregivers continue to provide rich feedback about what went well and what can be improved.

What went well?

"We always get plenty of time with each part of the team and get all the info we need and all our questions and concerns addressed." — Parent of a child with CF

"Adequate time was given to listen and explain all my questions and concerns. The team seemed genuinely interested in my health and wellbeing." — Adult with CF

"Outstanding doctor and nurse. Effort is always put in to make the clinic visit very efficient, with minimal wait time. A message is sent ahead of time indicating which team members will be seen and what tests are due." — Parent of a child with CF

What could be improved?

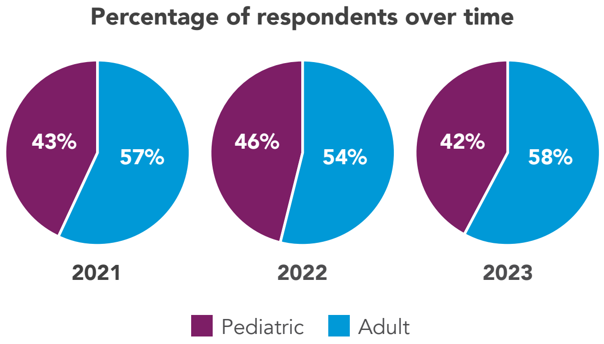
"I met with Dr. S before there were any of the results from the labs or the X-ray. I think CF dr. visits are on Monday, but it would really make much more sense to get all the labs and other tests done on Monday and then meet with the doctor on Tuesday. I got all the results after I got home and have not gotten any feedback yet on them. Thanks." — Adult with CF

"Consistency in greeting staff/nurses who take metrics to wear gowns, gloves, etc. Was very surprised to see no masks by any provider." — Parent of a child with CF

"Shorter visits somehow. I got my port flushed also but we were there for 3 hours. Makes a long day." — Adult with CF

Higher numbers of adults with CF share feedback about care experiences.

Tracking survey respondents over time, more adults with CF are sharing feedback about their care experiences compared to parent/caregivers. The broader the survey participation, the more helpful the data will be to care teams. Various strategies to increase survey uptake and response are underway.


Percentage of respondents over time

Thank you to our Champions and Steering Committee

Clinicians, people with CF, and caregivers serve as XoC Champions for their programs. There are 385 people who play an active role in raising awareness, sharing results, and improving the care experience. We extend our gratitude to all the XoC Champions for their valuable contributions. **Need to get started with the survey or have questions about your data? Contact XoC@cff.org.**

We extend our gratitude to the members of the XoC Steering Committee for their contribution in the development of the surveys, reports, and fostering our community of XoC Champions.

Stacy Allen, Parent of a child with CF, XoC Steering Committee Chair
Primary Children's CF Center, Salt Lake City, UT

Fadi Asfour, MD, XoC Steering Committee Chair
Primary Children's CF Center, Salt Lake City, UT

Julianna Bailey, PhD, RD, LD, XoC Steering Committee Chair
University of Alabama at Birmingham, Birmingham, AL

Gemma Cochrane, Parent of a child with CF
Yale University School of Medicine, New Haven, CT

David Davison, Adult with CF
University of Nebraska Medical Center, Ohama, NE

Cade Hovater, Adult with CF
University of Alabama at Birmingham, Birmingham, AL

Deirdre Jennings, MSW, LCSW
University of Virginia, Charlottesville, VA

Allison Moreau, BS, RRT
The Marie and Raymond Beauregard Adult CF Center at Hartford Hospital, Hartford, CT

Fadel Ruiz, MD, FAAP
Texas Children's Hospital, Houston, TX

Ahmet Uluer, MD
Boston Children's Hospital, Brigham & Women's Hospital, Boston, MA