

Adult Survey – for individuals with CF that are 18 years or older

Please answer the following questions about visits to your CF center in the last 12 months.

Experiences with Timely Care							
In the last 12 months	Never	Almost Never	Sometimes	Usually	Almost always	Always	Don't know or not applicable
How often did you get a response from the health care team (doctor, nurse or other CF care team member) the same day when you called during office hours?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
How often were appointments scheduled at a time that worked well for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
When you called the CF center to get an appointment for care you needed right away, how often did you get care as soon as you thought you needed it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When you asked the healthcare team for medicine refills, how often did you get the medicine as soon as you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health Care Resources							
In the last 12 months, how many times did you visit the CF center?	1	2	3	4	5 to 9	10 or more	<input type="checkbox"/>
	Yes	No					
In the last 12 months, which of the following types of health care team members were involved in providing your care at the CF center. Was a dietitian involved in providing your care at the CF center?	<input type="checkbox"/>	<input type="checkbox"/>					
Was a physical therapist involved in providing your care at the CF center?	<input type="checkbox"/>	<input type="checkbox"/>					
Was a respiratory therapist involved in providing your care at the CF center?	<input type="checkbox"/>	<input type="checkbox"/>					
Was a social worker involved in providing your care at the CF center?	<input type="checkbox"/>	<input type="checkbox"/>					
Experiences with Timely Care							
These next questions are about your experiences <u>during your most recent visit?</u>							

Your most recent visit	Yes, definitely	Yes, somewhat	No	Does not apply			
Were you brought to the exam room as soon as you arrived for your appointment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Experiences with the Health Care Team							
During your most recent visit, did the health care team treat you with courtesy and respect?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
During your most recent visit, did the health care team explain things in a way that was easy to understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
During your most recent visit, did the health care team spend enough time with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
During your most recent visit, did the health care team ask about your mental or emotional health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
During your most recent visit, did the health care team seem informed and up-to-date about the care you received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
During your most recent visit, were your questions answered or concerns addressed by the health care team? (This can include visits to the center and other forms of communication, such as emails and phone conversations.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
During your most recent visit, were you involved in decisions about your care as much as you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Experiences with Infection Control These next questions are about your experiences with infection control <u>during your most recent visit</u> .							
During your most recent visit	Yes	No					
Was a mask available for your use when you went to the health care center?	<input type="checkbox"/>	<input type="checkbox"/>					
During your most recent visit, did all care team members that spent time with you in the exam room wear a gown and gloves?	<input type="checkbox"/>	<input type="checkbox"/>					
During your most recent visit, did the health care technicians in other services (pulmonary function testing area, blood draw, or x-ray) wear a gown and gloves?	<input type="checkbox"/>	<input type="checkbox"/>	Did not visit these areas				

[illegible]

How often were you able to handle CF care on your own at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often were you able to maintain your body weight at the level you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tell me in your own words what have you learned or found to be helpful in managing your CF?							
Please tell me in your own words what do you find to be the hardest thing in managing your CF?							
Health Care Resources							
In the last 12 months, how many times did you go to the Emergency Department (ED) for a CF related concern (such as, coughing more, fever, or any other concerns)?	None	1	2	3 or more			
Did you have a lung infection (pulmonary exacerbation) or have any of these symptoms: shortness of breath, being really tired, coughing more?	Yes	No	Don't Know				
In the last 12 months, how many times have you spent one night (or more) in the hospital for a CF related concern?	None	1	2	3	4	5 or more	
<i>If one or more hospital stay then answer the next 2 questions.</i> These next questions are about your experiences with hospital care. Please think about your last hospital stay when answering these questions.							
	Never	Almost Never	Sometimes	Usually	Almost always	Always	
How often was hospital staff (doctors, nurses, and other staff) knowledgeable about CF care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Please tell me in your own words any suggestions you have for the hospital to improve the care and services?							
About You							

In general, how would you rate your overall health?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

In general, how would you rate your overall mental or emotional health?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

How long have you been receiving care at the CF Center?

- ☐ Less than 2 years
- ☐ 2 to 5 years
- ☐ 6 to 10 years
- ☐ Greater than 10 years

Do you have CF-related diabetes (CFRD)?

- ☐ Yes
- ☐ No
- ☐ Prefer not to answer

What is your weight in pounds without shoes or clothes on?
_____ pounds

What is your height in feet and inches without shoes on?
| _____ feet _____ inches

What was your pulmonary function (FEV1) on your last visit?
_____ or leave blank if not applicable or don't know

Are you male or female?

- ☐ Male
- ☐ Female
- ☐ Prefer not to answer

What is your age?

- ☐ 18 to 24 years
- ☐ 25 to 34 years
- ☐ 35 to 44 years
- ☐ 45 to 54 years
- ☐ 55 to 64 years
- ☐ 65 years or older
- ☐ Prefer not to answer

What is the highest grade or level of school you have completed?

- ☐ 8th grade or less
- ☐ Some high school, but did not graduate
- ☐ High school graduate or GED
- ☐ Some college or 2-year degree
- ☐ 4-year college graduate
- ☐ More than 4-year college degree



☐ Prefer not to answer

Are you of Hispanic or Latino origin or descent?

- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino
- ☐ Prefer not to answer

What is your race? Please choose all that apply.

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ Asian or Pacific Islander
- ☐ Aleut, Eskimo, or American Indian
- ☐ Unknown
- ☐ Other
- ☐ Prefer not to answer

What is your health care coverage?

- ☐ Private Insurance
- ☐ Medicaid or Medicare
- ☐ Other
- ☐ Self-pay
- ☐ Prefer not to answer

☐ Prefer not to answer

In the last 12 months, what were the estimated costs of CF care that you paid for “out of pocket” (that is care that was not paid for by insurance or other sources)?

- ☐ Less than \$100
- ☐ Between \$101 and \$500
- ☐ Between \$501 and \$1,000
- ☐ Between \$1,001 and \$2,500
- ☐ Between \$2,501 and \$5,000
- ☐ Greater than \$5,000
- ☐ Prefer not to answer

Pediatric Survey – for a family member or caregiver with a child with CF (less than 18 years old)

Most of the questions in the adult survey are asked on the pediatric survey with the addition of “your child” included in the question.

The following are additional questions asked:

What is your child’s Body Mass Index (BMI) percentile? (Not asked height and weight)

The caregiver or parent asked the following questions: age, education, ethnicity, race, health care coverage and cost.