



# Cystic Fibrosis Research News

#### Citation:

Sawicki GS, Ostrenga J, Petren K, D'Agostino E, Strassle C, Schechter MS, Rosenfeld M. Risk Factors for Gaps in Care during Transfer from Pediatric to Adult Cystic Fibrosis Programs in the United States. Annals of the American Thoracic Society. 2018 Feb;15(2):234-240. PMID:29220199

#### What was your research question? (50 words maximum)

We investigated whether there are differences in the length of time when patients move from pediatric to adult cystic fibrosis (CF) care centers. We also wanted to determine what factors relate to prolonged gaps in care when patients move from pediatric to adult care.

### Why is this important? (100 words maximum)

As people living with CF survive further into adulthood, there are increasing numbers of patients moving from pediatric to adult care each year. The transition from pediatric to adult care is a period when many patients may have gaps in their suggested health care. Understanding the factors involved in the transfer of care could help health care providers reduce these gaps in health care and improve the projected health of their patients.

### What did you do? (100 words maximum)

We identified people in the CF Foundation Patient Registry (CFFPR) who moved from pediatric to adult care centers between 2008 and 2012 and had at least two clinic visits in their last year of pediatric care and two clinic visits in their first year of adult care. We looked at differences between people who transferred to adult care less than 365 days or more than 365 days after their last pediatric visit. We then examined the lengths of gaps in care and assessed patient and care program predictors of gaps in care.





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## What did you find? (100 words maximum)

Most patient care transfers occur between ages 18 to 21 and result in small gaps in care. There is a smaller group of patients who have longer gaps in their care. Risk factors for prolonged gap include not having health insurance, leaving pediatric care at a younger age, lack of standard approach to transfer, and starting adult care at a location far away from the pediatric care center.

#### What does this mean and reasons for caution? (100 words maximum)

Transfer from pediatric to adult CF care occurs in later teens in the US, with most patients having small gaps in care. Managing care between pediatric and adult programs during transfer likely reduces gap, and transition programs should focus on patients identified as high risk for prolonged gaps. Some reasons for caution when reviewing these findings are: a gap in care shown in the CFFPR doesn't guarantee care was not received from primary care doctors or unrecognized CF providers, and the CFFPR focuses on the healthcare process in the US, which may not be applicable to other countries.

### What's next? (50 words maximum)

More research is needed to understand how prolonged gaps in care might affect health results and to evaluate best approaches to transition and transfer care for people living with CF.