



# Cystic fibrosis: adherence to therapy

NICE indicator

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[www.nice.org.uk/indicators/ind293](https://www.nice.org.uk/indicators/ind293)

## Indicator

Adherence to nebulised therapy in cystic fibrosis.

## Indicator type

Network / system level indicator. The indicator would be appropriate to understand and report on the performance of networks or systems of providers.

This document does not represent formal NICE guidance. For a full list of NICE indicators, see our [menu of indicators](#).

To find out how to use indicators and how we develop them, see our [NICE indicator process guide](#).

## Rationale

The indicator supports adherence to treatment. Daily treatment with inhaled mucolytics and antibiotics is associated with preserved lung health (lung function improvement [FEV1]) and reducing respiratory exacerbations. People with cystic fibrosis find it difficult to establish sustained habits of self-care and median adherence to inhaled therapy in adults is less than 40% ([Daniels et al. 2011](#)). The [CFHealthHub \(CFHH\)](#) is a digital information technology platform that automatically collects adherence data and makes time- and date-stamped data describing daily and weekly adherence to inhaled therapy (mucolytics and antibiotics) available to people with cystic fibrosis and their clinical teams. This provides a mechanism to improve adherence and, in turn, improve outcomes. Indicator data made available beyond people with cystic fibrosis and their immediate clinical team enable a cystic fibrosis centre to track their performance over time and performance between centres to be compared.

## Source guidance

[Cystic fibrosis: diagnosis and management. NICE guideline NG78 \(2017\)](#), recommendations 1.6.17 to 1.6.24 and 1.6.35 to 1.6.40.

## Specification

**Numerator:** Number of doses (of inhaled therapy: antibiotics and mucolytics) taken in a day (per person with cystic fibrosis) is found from CFHH inhalation data. This is capped at 100% based on the prescription. Adjusted for nebulised antibiotics that require multiple accentuations for a complete dose.

**Denominator:** Prescription (number of doses) per day as defined within CFHH.

**Exclusions:** People with lung transplants, as identified from the [UK Cystic Fibrosis Registry](#).

**Calculation:** Percentage adherence (of individual patients). A centre median based over an identified time period is calculated from individual patients' percentage daily adherence.

**Data source:** CFHH.

**Expected population size:**

The [UK Cystic Fibrosis Registry annual data report for 2022](#) and [Office for National Statistics 2024 analysis of population estimates tool for UK](#) show that 0.02% of people (9,259 divided by 57,112,542) in England have cystic fibrosis: 1.62 per 10,000 patients served by a network. There is no minimum number of patients required for network level indicators. However, consideration should be given to whether the majority of results would require suppression because of small numbers.

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