Cystic fibrosis: adherence to therapy

NICE indicator
Published: 30 September 2023

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.

ISBN: 978-1-4731-6867-1