Title: Average Rate of Lung Function Decline in Adults with Cystic Fibrosis in the United Kingdom: Data from the UK CF Registry

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What was your research question?
We wanted to find out the average rate of lung function decline each year in pancreatic insufficient (where the pancreas does not work normally, leading to difficulty in digesting food) and sufficient adults with CF in the United Kingdom (UK). We also wanted to calculate the rate of decline between different age groups and between males and females.

Why is this important?
For people with CF, lung function often declines over time. It is important to look at both the lung function values and how fast they are changing. It appears that the rate of decline varies at different ages, if female or male, or pancreatic insufficient or sufficient. However, we did not have any recent UK figures for this in adults with CF. We thought it would be helpful to calculate these values to allow us to see if someone’s rate of lung function decline is more rapid than expected for their age, sex and pancreatic status (insufficient or sufficient).

What did you do?
Over 99% of the UK CF population have consented to non-identifiable data being collected for research use by the UK CF registry. We analysed data from this registry on individuals’ lung function results, age, sex and if taking pancreatic supplements or not (as a marker of pancreatic status) for 2015-2017. We calculated the overall average rate of decline in a year for those taking pancreatic supplements and those not and how this varied by different sex and age groups.
What did you find?
Adults with CF in the UK who were pancreatic insufficient had three times the annual rate of decline in lung function compared to those who were pancreatic sufficient. Females often had a higher rate of lung function decline than males. For both females and males with pancreatic insufficiency, the biggest rate of lung function decline was seen in the 18-28 years old age category. Whereas, for adults with pancreatic sufficiency, the largest rate of decline was seen in the 18-28 years old age category for females and the 29-39 years old category for males.

What does this mean and reasons for caution?
It may be useful for the multi-disciplinary team and the individual with CF to look at both the lung function value and its rate of change. This may help us to identify adults who are changing more rapidly than the UK average, to best monitor, support and pro-actively manage lung health. We can also see that it is useful to factor in an individual’s age, sex and if they are pancreatic sufficient or insufficient when looking at rate of lung function decline. Younger adults, particularly females, taking pancreatic supplements appear to have a steeper rate of decline.

What’s next?
There were factors not included in this model which may be important, such as certain bacterial infections. We only used one lung function result per year so big changes throughout the year were not included. This means we need to test these figures more before knowing how useful they are.

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