



# Cystic Fibrosis Research News

## **Title:**

**DOES CURRENT REPORTING OF LUNG FUNCTION BY THE UK CYSTIC FIBROSIS REGISTRY ALLOW A FAIR COMPARISON OF ADULT CENTRES?**

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## **What was your research question?**

In the United Kingdom, all CF centres send patient data to a central registry database each year. These data are used to write a report that compares centres by ranking them for lung function and body weight. We wanted to see if the ranking tells us anything about the quality of care provided by adult CF centres.

## **Why is this important?**

Because the report is available to both health professionals and the public we felt it was important to understand whether a centres' ranking is a way of telling whether it provides better care than a lower ranked centre. The ranking of a centre may depend on things other than quality of care, for example, the ages of patients attending the centre or how many patients there are with severe disease at a centre or just by chance if all the centres are really quite similar to each other.

## **What did you do?**

We used UK registry data from several years (2007-2013) to check whether it was possible to find a big enough difference in average lung function between adult centres to be reasonably sure that there was a real difference and not just differences due to chance. We then used a further statistical modeling method that took other important factors about the patients attending each centre into account (age, sex, gene type and whether they used pancreatic enzymes which tells us about how severe their CF is) and checked again for a

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difference between centres. We also checked whether a different measure (how fast patient's lung function was changing over time) changed the rankings.

## What did you find?

For four of the seven years we were able to show a small difference in lung function between centres. However, there were also big differences in the mix of patients attending different centres, with some having a much higher number of patients with more severe CF. When we took other factors into account the difference in lung function between centres disappeared. If we ranked centres by average change in lung function then the rankings were very different. This makes it very likely that there is no real difference in quality of care between adult CF centres in the UK.

## What does this mean and reasons for caution?

Our study suggests that the rankings in the UK registry report do not reflect any differences in care between adult CF centres. Despite the fact that we had data from over 4000 patients it is possible that the reason that we did not find a difference is because the number of people in our study was not enough to reliably pick up small differences. It is also possible that the results were influenced by an unknown factor that we did not take into account in our statistical model.

## What's next?

It would be interesting to do a similar study to compare the outcomes between paediatric CF centres in the UK.

## Original manuscript citation in PubMed

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