

Identifying exceptional cystic fibrosis care services: combining statistical process control with focus groups

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Plain English summary

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Cystic fibrosis (CF) affects approximately 9000 people in the UK. People with CF are treated at specialist centres; the national CF Registry contains data on patients attending these centres. Until 2015, annual reports based on these data included comparisons between centres using rankings. These comparisons, however, do not tell us whether or not the differences between the 'best'- and 'worst'-performing centres are clinically or statistically meaningful. We explored whether or not adopting a different approach, based on statistical modelling that accounted for important patient characteristics (such as sex, CF disease severity and socioeconomic deprivation), and displaying the results in easy-to-interpret graphs, may identify exceptional CF centres. Outcomes will never be the same everywhere and, owing to the size of centre, variability is expected. Our approach helps to identify differences that are within the scope of what would be expected and differences that are exceptional.

We used data from patients who were attending adult and paediatric CF centres. We focused on predicted lung function, studying it in different age groups, using different reference equations and considering single-year measures as well as changes over time. It was found that in some centres, both adult and paediatric, lung function results were repeatedly statistically meaningfully different from the overall average – either better or worse. Some differences were explained by patient characteristics. In other cases, the results indicate an association of lung function with the use of intravenous antibiotics, although the evidence is mixed and needs further exploration.

We spoke to clinicians and patients to understand what they perceived to be important for good CF care. Clinicians highlighted, among other things, the importance of leadership, education, monitoring and treatment policies. From these factors, we developed questionnaires for all patients and clinicians. Response rates to the clinician questionnaire were poor and we did not have sufficient time to disseminate the patient questionnaire, although we still plan to do so. Future work is needed to link how care is delivered with our centre comparisons, to understand how differences in outcomes arise.

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