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Cystic Fibrosis Research News

Title:

Identifying People Living with Cystic Fibrosis in the Danish National Patient Registry: A Validation Study

Lay Title:

Accurate identification of people living with cystic fibrosis (CF) in the Danish National Patient Registry

Authors:

Hans Kristian Råket[1,2], Joanna Nan Wang[1,2], Janne Petersen[2,7], Tacjana Pressler[3,4], Hanne Vebert Olesen[5], Søren Jensen-Fangel[6], Thomas Bryrup[3], Espen Jimenez-Solem[1,2,8], Camilla Bjørn Jensen[2]

Affiliations:

[1] Department of Clinical Pharmacology, Copenhagen University Hospital – Bispebjerg and Frederiksberg, DK; [2]Copenhagen Phase IV Unit, Department of Clinical Pharmacology and Center for Clinical Research and Prevention, University Hospital of Copenhagen – Bispebjerg and Frederiksberg, DK; [3]Department of Infectious Diseases, University Hospital of Copenhagen – Rigshospitalet, Cystic Fibrosis Centre, DK; [4]Department of Pediatrics, University Hospital of Copenhagen – Rigshospitalet, Cystic Fibrosis Centre, DK [5]Department of Pediatrics and Adolescent Medicine, Aarhus University Hospital, DK; [6]Department of Infectious Diseases, Aarhus University Hospital, DK; [7]Section of Biostatistics, Department of Public Health, University of Copenhagen, DK; [8]Faculty of Health and Medical Sciences, University of Copenhagen, DK.

What was your research question?

How can we accurately identify people living with CF in the Danish National Patient Registry?

Why is this important?

Large healthcare databases, such as the Danish National Patient Registry, can be used for research in CF. This could enable research into several new aspects of CF. However, we need to be certain that the individuals we identify in these databases do in fact have CF.

What did you do?

We developed and tested several algorithms to identify people with CF within the Danish National Patient Registry. These algorithms consisted of two criteria: the number of hospital visits where CF was registered as the diagnosis, and the time between these visits. We then measured the overlap between people identified by the algorithms and people in the Danish Cystic Fibrosis Registry, who were known to have CF.

What did you find?

The most effective algorithm required a minimum of two hospital visits and 182 days between the first and last visit. This algorithm was highly accurate in identifying those living with CF and identified 95.9% of people who were known to have CF. If we were to use the Danish National Patient Registry for CF research, this algorithm enables us to follow people with CF from shortly after they are diagnosed, as only two hospital visits are required for them to be identified.

What does this mean and reasons for caution?

Our findings allow researchers who do not have access to the Danish Cystic Fibrosis Registry to undertake CF research. Our findings suggest that the diverse data in Danish Health Registries can be used to gain new insights into CF.

Researchers need to consider the aims of their studies when choosing an algorithm. For example, choosing a less restrictive algorithm would yield a larger study population, but some of them might not have CF. Conversely, a highly restrictive algorithm requiring a high number of hospital visits would yield a smaller population where all individuals are highly likely to have CF.

What's next?

Our study shows how to identify individuals with CF in an administrative health care database such as the Danish National Patient Registry. This enables studies using a wide range of variables, such as hospital admissions, prescription medicines, use of other health care services as well as socioeconomic factors such as education and income. These methods might also extend to identification of individuals with other chronic diseases.

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