

# Cystic Fibrosis Research News

**Title:**

DEVELOPMENT AND ELECTRONIC VALIDATION OF THE REVISED CYSTIC FIBROSIS QUESTIONNAIRE (CFQ-R Teen/Adult): New tool for monitoring Psychosocial Health in CF

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**What was your research question?**

Can the Cystic Fibrosis Questionnaire-Revised (CFQ-R), a paper copy health-related quality of life Instrument, be replaced reliably by an electronic version?

**Why is this important?**

There is a misbalance between the effort in analysing the results of the CFQ-R paper copy and the lack of immediate results. The e-CFQ-R, is an electronic version which simplifies the assessment of quality of life by reducing the time associated with data entry and scoring. The e-CFQ-R produces more accurate data as it reduces data entry errors to zero and decreases the possibility of missing data (e.g., not being able to accidentally skip a question or typing mistakes).and implements the use of patient-reported outcomes in real-time care. Integral evaluations (physical and psychological) usually occur at the same appointment and by instituting an electronic version of the CFQ-R, delays in the management of our patients can be avoided, providing better quality care.



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## What did you do?

We used new technology to develop an electronic version of the CFQ-R+14 allowing us to collect patient-reported outcomes in clinic. Fifty adult CF patients completed the CFQ-R paper and electronic versions on the first day and repeated just the electronic version 15 days later. We analysed if the answers provided on the paper copy and electronic version were similar on the first day. We also verified if there was an agreement between patients electronic answers on the first day and 15 days later, to validate the electronic tool for use in CF care.

## What did you find?

We demonstrated that the e-CFQ-R is a valid tool and can substitute the paper copy accurately. This is a great step forward in implementing “the voice of the patient” in real time care. The e-CFQ-R can be used for standard care, clinical trials and other study designs.

## What does this mean and reasons for caution?

Currently, the use of the CFQ-R, paper copy, is used only scarcely in clinical practice within most EU centers. As a result, we are losing critical input from the patient that can orientate care givers to mood changes or poorer physical functioning better than a clinical interview or through lung tests. The electronic version can provide a standardized, valid, and reliable way of gaining the patients’ perspective in real time as to “how they are or feel” and the benefits and limitations of interventions. The electronic version will allow us to make accurate appointments with different consultants as required (e.g. psychologist, psychiatrist, social worker...).

## What’s next?

The next step is to use the e-CFRQ in daily practice. Having immediate scoring will allow us to better understand its relationship to the patient’s clinical status. In addition, during the follow-up period we can correlate these results with the evolution of the disease and the social and psychosocial aspects.

## Original manuscript citation in PubMed

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