**Title:**

Validation of the CFAbd-Score.kid©, a Novel Gastrointestinal Patient Reported Outcome Measure, specific for Children with Cystic Fibrosis

**Lay Title:**

CFAbd-Score.kid: a new, child-friendly version of the CFAbd-Score for tracking abdominal symptoms in children with cystic fibrosis.

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**What was your research question?**

People with cystic fibrosis (CF) often experience gastrointestinal symptoms such as stomach pain, constipation, bloating and a poor appetite. These symptoms can have a serious impact on their daily lives and overall well-being. The CFAbd-Score© is the first questionnaire specifically designed to captures abdominal symptoms in people with CF. We have now developed and validated a new version, the CFAbd-Score.kid©, which specifically aims at young children to report these issues in a way that they can easily understand and respond to the questions. The CFAbd-Score.kid© is a reliable, child-friendly, CF-specific questionnaire that empowers children with CF below the age of 12years to express their experience of abdominal symptoms and their impact on quality of life. It is already being used in clinics and studies in CF centers in Germany, England and Ireland to improve care and support for children with CF.

**Why is this important?**

The CFAbd-Score.kid© was scientifically developed and tested with the active involvement and support of children with CF and their proxies. It was designed to be easy and engaging for children of all ages, using simple language, colorful pictograms and smiley scales. Younger children can complete it with help from their parents or carers, while older children can do so independently.

**What did you do?**

In the study, over 100 children with CF from different CF-centers and 72 healthy children completed the CFAbd-Score.kid©.

**What did you find?**

The results showed that children with CF reported significantly more abdominal symptoms, particularly relating to bowel movements, appetite, and general well-being. The questionnaire also showed to be reliable and consistent, even when completed at different time points. Importantly, children, parents, healthcare professionals and pedagogues found the questionnaire easy to use, relevant, and helpful. Feedback from these groups led to meaningful improvements, such as pertinent pictures and concise wording, to ensure that children could fully understand and respond to the questions.

**What does this mean and reasons for caution?**

New CF treatments, such as CFTR-modulators, do not only have an effect on the lungs, but also improve abdominal symptoms. However, until now, there has not been an effective way to measure these changes in younger children. The CFAbd-Score.kid© closes this gap. It enables doctors and researchers to track abdominal symptoms over time and gain a better understanding of how children respond to new treatments.

**What’s next?**

In future, the CFAbd-Score.kid©, originally developed in German and then in English, can be made available to other countries by translating the questionnaire to allow widespread use in clinical routine and international studies. This becomes even more important since new therapies, such as CFTR-modulators, are gradually admitted for even younger age groups.

**Original manuscript citation in PubMed**

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