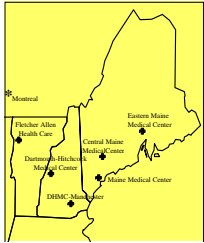


# CF Clinic-Based Assessment of Health-Related Quality of Life Data Over Time

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## The Northern New England Cystic Fibrosis Consortium



The NNECFC is a regional, voluntary consortium of more than 80 clinicians and researchers from the CF care centers in Maine, New Hampshire and Vermont.

The mission of the group is to improve CF care and patient outcomes.

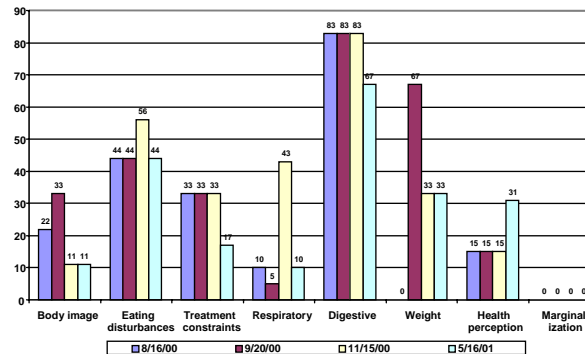
## Goals

- Collect health-related quality of life (HRQOL) data in CF children and adults at repeat outpatient clinic visits.
- Assess change in HRQOL over time and relationship to disease severity.

## Methods

- Data was collected from 56 patients for 22 months (183 patient visits; 73% capture rate).
- Generic HRQOL scores were assessed using PedsQL for children and SF-36 for adults.
- Disease-specific scores were assessed using selected subscales from the CFQ.
- These analyses describe changes in HRQOL measures between first and second visits. The average time between clinic visits was 8.0 months.

CFQ Subscales: Sample Patient Repeat Assessment



## Patient Characteristics (n=56)

	Number	Mean age	% male	1st visit FEV <sub>1</sub>
Children	28	12.1	62.1%	89.3%
Adults	28	28.7	48.2%	62.1%

## Results

- In this study, CF children and adults had a high participation rate in repeat clinic-based HRQOL assessment.
- Generic HRQOL scales for children and adults were less sensitive from first to second clinic assessments than disease-specific subscales.
- CFQ subscales for patients 14 and older demonstrated the most sensitivity and variability from first to second clinic assessment.
- Changes in individual CFQ subscale scores were inconsistently related to disease severity.

## CFQ Subscale Change Scores: Teen/Adult Mean/Range by Disease Severity<sup>1</sup>

	Mild	Moderate	Severe
Body image <sup>2</sup>	2.1 (-22 to 34)	3.7 (-45 to 56)	6.2 (-44 to 56)
Eating disturbances	-3.3 (-56 to 33)	1.9 (-11 to 12)	1.0 (-44 to 34)
Treatment constraints	7.1 (-16 to 33)	6.9 (-33 to 33)	4.5 (-45 to 45)
Respiratory	-9.3 (-45 to 38)	6.3 (-43 to 33)	-2.4 (-33 to 50)
Digestive	2.8 (-33 to 67)	1.3 (-34 to 50)	-0.1 (-33 to 38)
Weight	-11 (-67 to 34)	11.2 (-100 to 67)	9.2 (-33 to 33)
Health perception	-3.8 (-47 to 30)	7.5 (-23 to 54)	0.5 (-33 to 67)
Marginalization	-1.8 (-34 to 56)	-0.2 (-45 to 44)	5.3 (-54 to 43)

<sup>1</sup>FEV<sub>1</sub>% predicted: mild 71 - 100+, moderate 40 - 69, severe <40

<sup>2</sup>CFQ Subscales: 0 = most trouble, 100 = no trouble

## Conclusions

- It is possible to use brief, validated HRQOL assessment tools in CF clinic.
- While generic HRQOL scales allow for general population comparisons, CF disease-specific domains as measured on the CFQ appear to be most sensitive to change in CF patients.
- Tracking HRQOL over time helps clinicians assess changes in physical health status and its relationship to patient perception of disease burden.