

The CFF Registry as a Tool to Track Guideline Compliance for Outpatient Management

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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.

Goal

The Clinical Practice Guidelines for CF are considered the standard of care for CF patients in the US. The goal of this study was to assess the utility of using the US CFF Registry to track compliance with the outpatient management recommendations in the Guidelines.

Methods

We created a list of 218 care variables including: symptoms, complications, screening and treatments from the Caremap for Outpatient Management of CF from the Clinical Practice Guidelines for Cystic Fibrosis, (Chapter 1, pp. 19-26). A multi-disciplinary clinician panel prioritized the variables based on relevance for key care decisions using a 1 to 3 scale. We then assessed whether these variables were collected in the 1999 CFF Registry annual data form.

Priority Scoring Definitions/Examples

Priority 1:

patient care

Collected

Spirometry

Respiratory tract culture

Weight

Use of enzymes

Enteral/parenteral feeding

Diabetes screening

Urgent information with immediate impact on decisions.

Not Collected

ACT, bronchodilators used

Antibiotics used

Liver and spleen size

Oral supplementation

Use of vitamins

Exercise tolerance, clubbing

Priority 2:
urgent for care

Rectal prolapse

Pneumothorax

BUN, creatinine

Nasal polyps

Osteoporosis

Relevant, but not decisions.

3-day dietary intake taken

Environmental exposures

Audiology, urinalysis

Chest radiograph

Vitamin levels checked

Priority 3: Information in the yearly workup with little impact on pressing care decisions.

Gene mutation analysis

Triceps skin-fold

Liver function tests

Onset of puberty

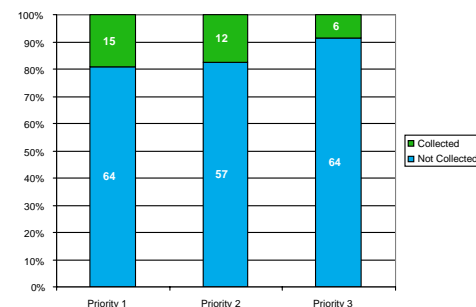
Immunizations done

Patient education done

Results

Two-hundred and eighteen variables were identified in the Outpatient Caremap. Thirty-three (15%) were captured in the CFF Registry. Of the 218 variables, 79 were ranked as Priority 1, 69 as Priority 2, 70 as Priority 3. Collection rate by Priority is displayed below.

Variable Collection Rate by Priority



Conclusions

- The CFF Registry was not designed to be, and is not currently, a comprehensive tool to track compliance with key outpatient management recommendations.
- There is an opportunity to identify key high leverage areas for clinical improvement detailed in the Guidelines and measure them using the patient Registry, as well as track changes in process and outcome over time.