



## CF Foundation Patient Registry Variable List

The CF Foundation Patient Registry variable list is organized into the following sections:

- [Demographics](#)
- [Diagnosis](#)
- [Clinic Visits](#)
- [Clinical Measurements](#)
- [Microbiology](#)
- [Treatments](#)
- [Complications](#)
- [Care Episodes \(Hospitalizations/ Home IV\)](#)

Notes:

- Any variable that includes a date or other identifying information is considered protected health information (PHI, **highlighted in yellow**) and will require an Information Use Agreement in order to be included for approved projects.
- CFF provides encounter-level OR annualized data.
- Variables added after 2018 are in **purple**.

**Please submit all data requests through the online portal:** [Patient Registry Data Requests | CF Foundation](#)

Questions? Please contact [datarequests@cff.org](mailto:datarequests@cff.org).

## I. Variable type: DEMOGRAPHICS

- Birth characteristics
  - Date of birth (mm/dd/yyyy) [PHI]
  - Year of birth
  - Patient's sex
  - State of birth
  - Height of baby in cm
  - Weight of baby in kg
  - Baby delivered (full term, premature, unknown)
  - Specify gestational age if under 37 weeks
  - Patient attended day care during this reporting year
- Race / Ethnicity
  - Race includes 'White'
  - Race includes 'Black or African American'
  - Race includes 'American Indian or Alaska Native'
  - Race includes 'Asian'
  - Race includes 'Native Hawaiian or Other Pacific Islander'
  - Race includes 'Some other race'
  - Patient is Hispanic
- Mortality and Transplant
  - Date of Death (if died) [PHI]
  - Year of death (if died)
  - Reason for death (if died)
  - Age at death [PHI]
  - Date of first lung transplant [PHI]
- Health insurance
  - Health insurance policy (i.e. private insurance)
  - Medicare
  - Medicaid
  - State special needs program (BCMh, CCS, CRS, GHPP...)
  - TriCare or other military health plan
  - Indian Health Service
  - Other health insurance
  - Patient has no health insurance for the entire year
  - Patient covered on their parents' insurance plan
  - Receives free medicine/assistance from patient assistance program
- Residence
  - Patient resides in the US permanently
  - Patient state of residence [PHI]
  - Program state used for resident state [PHI]
  - Current zip code [PHI]
- Socioeconomic characteristics
  - Patient's education
  - Spouse's education
  - Total combined household income before taxes
  - Number of people currently living in household
  - Marital Status
  - Employed part time
  - Full time homemaker

- Employed full time
  - Unemployed Student
  - Disabled
  - Retired
  - Employment unknown
- Smoking
  - Patient smokes cigarettes during the reporting year
  - How often was this patient exposed to secondhand smoke
  - Patient lives in household where someone smokes
- Parent characteristics
  - Patient's mother's height in cm
  - Patient's father's height in cm
  - Father's education
  - Mother's education
- Research involvement
  - Patient participated in interventional (drug) studies
  - Patient participated in observational studies
- Patient pregnancy
  - Patient was pregnant during the reporting year
  - Outcome of patient's pregnancy

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## II. Variable type: DIAGNOSIS

- Diagnosis date
  - Diagnosis date [PHI]
  - Patient diagnosis
  - Age at diagnosis
  - Year of CF diagnosis
  - First year in the CFF Patient Registry
- Sweat test
  - Date of last sweat test [PHI]
  - Year of last sweat test
  - First reported sweat test date [PHI]
  - Latest sweat value reported
  - Highest sweat value reported
- Genotyping
  - Has this patient been genotyped
  - Date of genotyping [PHI]
  - Year of last genotyped
  - Mutation classification
  - Name of the first mutation
  - Mutation 1 Class
  - Poly T tract associated with mutation 1
  - Poly TG repeats mutation 1
  - Name of the second mutation
  - Mutation 2 Class
  - Poly T tract associated with mutation 2
  - Poly TG repeats mutation 2
  - Does patient have additional mutations?
  - Delta F508
- Diagnosis characteristics
  - Meconium ileus with or without perforation
  - Patient diagnosed after false-negative newborn screen
  - CF dx sugg by Acute or persistent respiratory abnormalities
  - CF dx sugg by CBAVD or related abnormalities
  - CF dx sugg by Digital clubbing
  - CF dx sugg by DNA Analysis
  - CF dx sugg by Edema
  - CF dx sugg by Electrolyte imbalance
  - CF dx sugg by Failure to thrive/malnutrition
  - CF dx sugg by Family history
  - CF dx sugg by Infertility/GU abnormalities
  - CF dx sugg by Liver problems
  - CF dx sugg by Meconium ileus/intestinal obstruction
  - CF dx sugg by Nasal polyps/sinus disease
  - CF dx sugg by Newborn (neonatal) screening
  - CF dx sugg by Prenatal screening (CVS, amnio)
  - CF dx sugg by Rectal prolapse
  - CF dx sugg by Steatorrhea/abnormal stool/malabsorption
  - CF dx sugg by Other
  - CF dx sugg by unknown
  - Sweat<60, dx sugg DNA Analysis/genotyping

- Sweat<60, dx sugg Transepithelial potential differences
- Sweat<60, dx sugg Clinical presentation
- Sweat<60, dx sugg unknown

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### III. Variable type: CLINIC VISITS

- Visit details
  - Site ID
  - Date of Encounter [PHI]
  - Location where patient was seen
  - Encounter age [PHI]
  - Patient was seen by a Social Worker
  - Patient was seen by a Dietitian/Nutritionist
  - Patient seen by a Pharmacist
  - Patient seen by a Respiratory Therapist
  - Patient seen by a Physical Therapist
  - Patient seen by a Mental Health Coordinator
  - Was there assessment of oral intake
- Clinic visits - summarized by calendar year
  - # of clinic visits in the review year
  - Primary Program ID
  - Non-primary Program reported in the year
  - Patient was seen by a Social Worker
  - Patient was seen by a Dietitian/Nutritionist
  - Patient was seen by a Pharmacist
  - Patient was seen by a Respiratory Therapist
  - Patient was seen by a Physical Therapist
  - Did the family receive genetic counseling this year
  - Was there assessment of oral intake
  - Patient seen by a Mental Health Coordinator
  - Eye Exam on Annual Form
  - Age on 12/31 of review year [PHI]
  - Any encounter data
  - Any annual data
- Pulmonary exacerbation - encounter level
  - Assessment of potential pulmonary exacerbation
  - Incr. airway clearance, exercise, and/or bronchodilators
  - Oral NON-quinolone antibiotic
  - Oral quinolone antibiotic (e.g. Cipro, levofloxacin)
  - Inhaled antibiotic Inhaled antibiotic PLUS Oral NON-quinolone antibiotic
  - Inhaled antibiotic PLUS Oral quinolone antibiotic
  - Crackles on physical exam
  - None of the above
- Pulmonary exacerbation - summarized by calendar year
  - Any pulmonary exacerbation assessment in the year
  - Any pulmonary exacerbation assessment positive in the year
  - # encounters with pulmonary exacerbation assessments: absent
  - # encounters with pulmonary exacerbation assessments: mild exacerbations
  - # encounters with pulmonary exacerbation assessments: moderate exacerbations
  - # encounters with pulmonary exacerbation assessments: severe exacerbations
  - Encounter exacerbation treatment: Incr. airway clearance
  - Encounter exacerbation treatment: Oral NON-quinolone antibiotic
  - Encounter exacerbation treatment: Oral quinolone antibiotic
  - Encounter exacerbation treatment: Inhaled Antibiotic
  - Encounter exacerbation treatment: Inhaled + Oral NON-quinolone antibiotic

- Encounter exacerbation treatment: Inhaled + oral quinolone antibiotic
- Encounter exacerbation treatment: None of the above
- # of encounters with crackles (rales) on physical exam
  
- Infant feeding - encounter level
  - Type of feeding
  - Infant formula type
  - Caloric density (20, 22, 24, 27 or 30 cal/oz)
  
- Infant feeding - summarized by calendar year
  - Type of infant feeding: breast milk
  - Type of infant feeding: breast milk plus formula
  - Type of infant feeding: formula exclusively
  - Type of infant feeding: other food
  - Type of infant feeding: unknown
  - Infant formula type: Cow's milk
  - Infant formula type: Soy milk
  - Infant formula type: Predigested
  - Infant formula type: Other
  - Infant formula caloric density: 20 cal/oz
  - Infant formula caloric density: 22 cal/oz
  - Infant formula caloric density: 24 cal/oz
  - Infant formula caloric density: 27 cal/oz
  - Infant formula caloric density: 30 cal/oz
  - Infant formula caloric density: other

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#### IV. Variable type: CLINICAL MEASUREMENTS

- Anthropometric measures - encounter level
  - Patient's height
  - Original height as report (includes suspect values)
  - Height Percentile
  - Height Percentile Z score (age < 20)
  - Height Percentile based on WHO (age < 2 only)
  - Height-for-age Z score based on WHO (age < 2)
  - BMI Value
  - BMI Percentile
  - Weight-for-Length Percentile
  - Weight for length percentile based on WHO (age < 2 only)
  - Weight-for-height Z score based on WHO (age < 2)
  - Weight of Patient
  - Original weight as report (includes suspect values)
  - Weight Percentile
  - Weight Percentile Z score (age < 20)
  - Weight percentile based on WHO (age < 2 only)
  - Weight-for-age Z score based on WHO (age < 2)
  
- Anthropometric measures - summarized by calendar year
  - # height measurements in the review year
  - Patient's height
  - Height Percentile in the review year
  - Height Percentile Z score (age < 20)
  - Height percentile based on WHO (age < 2 only)
  - Height for Age z-score
  - BMI Value
  - BMI Percentile
  - Weight-for-Length Percentile
  - Weight for length percentile based on WHO (age < 2 only)
  - Weight-for-height Z score based on WHO (age < 2)
  - # weight measurements in the review year
  - Weight of Patient
  - Weight Percentile
  - Weight Percentile Z score (age < 20)
  - Weight percentile based on WHO (age < 2 only)
  - Weight for Age z-score
  
- Pulmonary function tests - encounter level
  - Was impossible to take PFTs
  - Measure of FVC
  - Predicted Value for FVC using GLI reference equations
  - Measure of FEV1
  - CF specific FEV1 percentile for kids
  - Predicted Value for FEV1 using GLI reference equations
  - Measure of FEF25-75
  - Predicted Value for FEF25-75 using GLI reference equations
  - Measure of FEV1/FVC
  - Predicted Value for FEV1/FEV1 using GLI reference equations



- Pulmonary function tests - summarized by calendar year
  - Any pulmonary data completed
  - # unable to perform pulmonary function test
  - # FVC measurements in the review year
  - Predicted Value for FVC using GLI reference equations
  - Predicted Value for FEF25-75 using GLI reference equations
  - Measure of FEV1/FVC
  - Predicted Value for FEV1/FVC using GLI reference equations
  - # FEV1 measurements in the review year
  - Predicted Value for FEV1 using GLI reference equations
  - # FEV25-75 measurements in the review year
  - Measure of FEF25-75
  - Post-Transplant Predicted Value for FEF25-75 using GLI reference equations
  - Post-Transplant Predicted Value for FEV1 using GLI reference equations
  - Post-Transplant Predicted Value for FEV1/FVC using GLI reference equations
  - Post-Transplant Predicted Value for FVC using GLI reference equations
  
- Lab values - encounter level
  - WBC count x1,000/microL
  - Platelet Count x1,000/microL
  - Hemoglobin (grams per deciliter)
  - Serum Creatinine Level (mg/dL)
  - Alanine Aminotransferase (ALT or SGPT), IU/L
  - Alkaline phosphatase 2 hour blood glucose (mg/dL)
  - Hgb A1C value, %
  - Fecal elastase value (microg/g of stool)
  - Liver enzymes drawn (pre-2010) Aspartate aminotransferase
  - Liver Function Tests Albumin
  - Total bilirubin, mg/dL
  - GGTP (gamma glutamyl transpeptidase), IU/L
  - Random blood glucose (mg/dL)
  - Fasting glucose level (mg/dL)
  - OGTT Fasting glucose level (mg/dL)
  - 1 hour blood glucose (mg/dL)
  
- Lab values - summarized by calendar year
  - Any lab data completed
  - WBC count x1,000/microL
  - Platelet Count x1,000/microL
  - Hemoglobin (grams per deciliter)
  - Serum creatinine level (mg/dL)
  - Alanine Aminotransferase (ALT or SGPT), IU/L
  - Aspartate aminotransferase
  - Total bilirubin, mg/dL
  - GGTP (gamma glutamyl transpeptidase), IU/L
  - Liver enzymes drawn (pre-2010)
  - Random blood glucose (mg/dL)
  - 1 hour blood glucose (mg/dL)
  - Fasting glucose level (mg/dL)
  - OGTT fasting glucose level (mg/dL)
  - 2 hour blood glucose (mg/dL)

- HgbA1C value, %
- Fecal elastase value (microg/g of stool)
- Alkaline phosphatase
- Albumin
- Screening tests
  - Was chest x-ray performed in the reporting year
  - Was IgE screening performed in the reporting year
  - Liver function tests performed
  - Fat soluble vitamin levels measured?
  - Most recent fecal elastase value
  - Patient screened for anxiety disorder
  - Patient screened for symptoms of classic depression
  - DEXA scan for bone density performed in the reporting year
  - DEXA scan result is normal
  - DEXA scan result is osteopenia
  - DEXA scan result is osteoporosis
  - DEXA scan result is other
  - DEXA scan result is unknown
  - Colonoscopy performed
  - Colonoscopy\_results

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## V. Variable type: MICROBIOLOGY

- Bacteria - encounter level
  - Was bacterial culture done?
  - Date of bacterial culture [PHI]
  - Type of specimen (for bacterial culture)
  - Culture results
  - Staphylococcus aureus
  - MRSA
  - Any Burkholderia Complex species
  - Resistant to all aminoglycosides tested
  - Resistant to all quinolones tested
  - Resistant to all beta lactams tested
  - Multidrug-Resistant P. aeruginosa (MDR-PA) Infection
  - Alcaligenes
  - Stenotrophomonas
  - MSSA
  - Haemophilus influenzae (any species)
  - Pseudomonas aeruginosa found in the culture
  - Mucoid Pseudomonas aeruginosa
  - Non-mucoid Pseudomonas aeruginosa
  - Mucoid Pseudomonas aeruginosa status unknown
- Bacteria - summarized by calendar year
  - Any respiratory microbiology data completed
  - Was bacterial culture done?
  - Number of cultures in the year
  - Number of Micro cultures in the year
  - Number of Myco cultures in the year
  - # respiratory culture type: sputum
  - # respiratory culture type: induced sputum
  - # respiratory culture type: throat/nasal
  - Any Burkholderia Complex species
  - Resistant to all aminoglycosides tested
  - Resistant to all quinolones tested
  - Resistant to all beta lactams tested
  - Resistant to at least 2 (beta lactams, aminoglycosides, quinolones)
  - Alcaligenes
  - Stenotrophomonas
  - MSSA
  - Haemophilus influenzae (any species)
  - Pseudomonas aeruginosa found in the culture
  - Mucoid Pseudomonas aeruginosa
  - Non-mucoid Pseudomonas aeruginosa
  - Mucoid Pseudomonas aeruginosa status unknown
  - # respiratory culture type: bronchoscopy
  - Any culture result: no growth/sterile
  - Any culture result: normal flora
  - Any culture result: microorganisms
  - Staphylococcus aureus
  - MRSA

- Bacteria - other frequency
  - First year Burkholderia species was reported
  - First year b. cepacia was confirmed at ref. lab
  
- Mycobacteria - encounter level
  - Was mycobacterial culture done?
  - **Date of myco culture [PHI]**
  - Type of specimen (for mycobacterial culture)
  - Acid-Fast Bacilli Smear
  - Myco culture results
  - Mycobacterial tuberculosis
  - Mycobacterium terrae
  - Mycobacterium other
  - Mycobacterium abscessus/chelonae
  - Mycobacterium avium complex
  - Mycobacterium fortuitum group
  - Mycobacterium gordonae
  - Mycobacterium kansasii
  - Mycobacterium marinum
  
- Mycobacteria - summarized by calendar year
  - Was mycobacterial culture done?
  - # mycobacterial culture type: sputum
  - # mycobacterial culture type: induced sputum
  - # mycobacterial culture type: bronchoscopy
  - Any Acid-Fast Bacilli smear: Positive
  - Any Acid-Fast Bacilli smear: Negative
  - Mycobacterium terrae
  - Mycobacterium other
  - Mycobacterium abscessus/chelonae
  - Mycobacterium avium complex
  - Mycobacterium fortuitum group
  - Mycobacterium gordonae
  - Mycobacterium kansasii
  - Mycobacterium marinum
  - Any Acid-Fast Bacilli smear: Not done
  - Any mycobacterial result: no growth/sterile
  - Any mycobacterial result: normal flora
  - Any mycobacterial result: microorganisms
  - Nontuberculous mycobacteria - pre 2010
  - Mycobacterial tuberculosis
  
- Fungus - encounter level
  - Aspergillus Candida Scedosporium species
  - Other bacterial or fungal microorganism species, specify
  
- Fungus - summarized by calendar year
  - Aspergillus Candida Scedosporium species
  - Other bacterial or fungal microorganism species, specify

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## VI. Variable type: TREATMENTS

- Antibiotics - encounter level
  - Tobramycin solution for inhalation (i.e. TOBI)
  - TOBI frequency
  - TOBI Podhaler
  - TOBI Podhaler Frequency
  - Other inhaled aminoglycoside (e.g. gentamicin, amikacin)
  - Other aminoglycoside - frequency
  - Colistin
  - Colistin Frequency
  - Aztreonam - Inhaled
  - Aztreonam frequency
  - Chronic oral macrolide antibiotic
  - Azithromycin
  - Clarithromycin
  - Sulfa
  - Amoxicillin
  - Tetracycline
  - Other oral antibiotic
  - Other chronic oral antibiotic
  - Quinolone
  - Cephalosporin
  - Bethkis
  - Bethkis frequency
- Antibiotics - summarized by calendar year
  - Tobramycin solution for inhalation (i.e. TOBI)
  - TOBI 300 mg BID alternate month schedule
  - TOBI 300 mg BID continuous
  - TOBI Other regimen (different dose or freq)
  - TOBI for Eradication
  - TOBI as needed
  - TOBI Podhaler
  - TOBI Podhaler Four 28mg capsules BID alternate month schedule
  - TOBI Podhaler Other regimen (different dose or frequency)
  - TOBI Podhaler for Eradication
  - TOBI Podhaler as needed
  - Other inhaled aminoglycoside (e.g. gentamicin, amikacin)
  - Aminoglycoside alternate month schedule
  - Aminoglycoside Continuous
  - Aminoglycoside Other regimen (different dose or frequency)
  - Aminoglycoside for Eradication
  - Aminoglycoside as needed
  - Colistin
  - Colistin alternate month schedule
  - Colistin Continuous
  - Colistin Other regimen (different dose or frequency)
  - Colistin for Eradication
  - Colistin as needed
  - Aztreonam 75 mg TID Alternate Month Schedule
  - Aztreonam 75 mg TID Continuous

- Aztreonam - other regimen
- Aztreonam for eradication
- Aztreonam as needed
- Aztreonam – Inhaled
- Chronic oral macrolide antibiotic
- Azithromycin
- Tetracycline
- Other oral antibiotic
- Clarithromycin
- Other chronic oral antibiotic
- Quinolone
- Cephalosporin
- Sulfa
- Amoxicillin
- Bethkis for Eradication
- Bethkis as needed
- Bethkis
- Bethkis 300 mg BID alternate month schedule
- Bethkis: other regimen (different dose of freq)
- Pulmonary meds - encounter level
  - Not on any chronic pulmonary medications
  - Dornase alfa (i.e. Pulmozyme)
  - Dornase frequency
  - Acetylcysteine or Mucomist
  - High-dose ibuprofen (e.g. 25-30 mg/kg)
  - Hypertonic saline
  - Leukotriene modifiers
  - Mast cell stabilizers
  - Antifungals
  - Oral (e.g. prednisone)
  - Inhaled (e.g. fluticasone, Flovent, budesonide)
  - Inhaled in combination wth bronchodilator (e.g. Advair)
  - Other Corticosteroids type
  - Other Corticosteroids Total (mg/dose)
  - Other Corticosteroids frequency
  - Hypertonic saline concentration (%)
  - Hypertonic Saline Frequency
  - Short acting anticholinergic
  - Long acting anticholinergic
  - Combination beta agonist and anticholinergic
  - Beta agonist
  - Theophylline product
  - Short acting beta agonist
  - Long acting beta agonist
  - Allergic/intolerant to Macrolide antibiotics
  - Allergic/intolerant to High-dose ibuprofen
  - Allergic/intolerant to Hypertonic saline
  - Allergic/intolerant to Aztreonam
  - Drug intolerance/allergies for Ivacaftor
  - Drug intolerance/allergies for Ivacaftor Lumacaftor
  - Drug intolerance/ allergies for Tezacaftor/Ivacaftor (i.e. Symdeko)
  - Drug intolerance/allergies for Elexa/Tez/Iva

- Allergic/intolerant to Dornase alfa
- Allergic/intolerant to Tobramycin solution for inhalation
- Allergic/intolerant to Colistin
- Pulmonary meds - summarized by calendar year
  - Not on any chronic pulmonary medications
  - Dornase alfa (i.e. Pulmozyme)
  - Dornase alfa 2.5 mg qd
  - Dornase alfa 2.5 mg BID
  - Dornase alfa: Other regimen (different dose or frequency)
  - Dornase alfa as needed
  - Acetylcysteine or Mucomist
  - High-dose ibuprofen (e.g. 25-30 mg/kg)
  - Oral (e.g. prednisone)
  - Inhaled (e.g. fluticasone, Flovent, budesonide)
  - Inhaled combination wth bronchodilator (e.g. Advair)
  - Oral Corticosteroids Types – Prednisone
  - Oral Corticosteroids Types - Methylprednisolone (Medrol)
  - Oral Corticosteroids Types – Dexamethasone
  - Oral Corticosteroids Types – Other
  - Average Oral Corticosteroids Total (mg/dose)
  - Oral Corticosteroids Frequency - Short Term (Less Than Two Weeks)
  - Oral Corticosteroids Frequency - Chronic, Low Dose
  - Oral Corticosteroids Frequency - Chronic, High Dose
  - Oral Corticosteroids Frequency - Other
  - Leukotriene modifiers
  - Mast cell stabilizers
  - Antifungals
  - Hypertonic saline
  - Hypertonic saline concentration: 1
  - Hypertonic saline concentration: 2
  - Hypertonic saline concentration: 3
  - Hypertonic saline concentration: 4
  - Hypertonic saline concentration: 5
  - Hypertonic saline concentration: 6
  - Hypertonic saline concentration: 7
  - Hypertonic saline concentration: 8
  - Hypertonic saline frequency: QD
  - Hypertonic saline frequency: BID
  - Hypertonic saline frequency: Other
  - Hypertonic saline frequency as needed
  - Beta agonist
  - Theophylline product
  - Short acting beta agonist
  - Long acting beta agonist
  - Short acting anticholinergic
  - Long acting anticholinergic
  - Combination beta agonist and anticholinergic
  - Drug intolerance/allergies for Dornase alfa
  - Drug intolerance/allergies for tobramycin
  - Drug intolerance/allergies for Colistin

- Drug intolerance/allergies for Macrolide antibiotics
  - Drug intolerance/allergies for High-dose ibuprofen
  - Drug intolerance/allergies for Hypertonic saline
  - Drug intolerance/allergies for Aztreonam
  - Drug intolerance/allergies for Ivacaftor
  - Drug intolerance/allergies for Ivacaftor Lumacaftor
  - Drug intolerance/allergies for Elexa/Tez/Iva
- CFTR modulators - encounter level
    - On Ivacaftor medication (VX-770)
    - VX770 (Ivacaftor) dosage
    - Ivacaftor/Lumacaftor (i.e., Orkambi)
    - Ivacaftor/Lumacaftor (i.e., Orkambi) dosage
    - Triple Combo Combination Therapy, Elexacaftor / Tezacaftor / Ivacaftor (i.e., Trikafta)
    - Triple Combo Dose
    - First date prescribed a modulator
    - First date prescribed Ivacaftor (i.e., Kalydeco)
    - First date prescribed Lumacaftor / Ivacaftor (i.e., Orkambi)
    - First date prescribed Tezacaftor / Ivacaftor (i.e., Symdeko)
    - First date prescribed Elexacaftor / Tezacaftor / Ivacaftor (i.e., Trikafta)
    - First date taking Elexacaftor / Tezacaftor / Ivacaftor (i.e., Trikafta)
- CFTR modulators - summarized by calendar year
    - On Ivacaftor medication (VX-770)
    - Ivacaftor - 150 mg BID
    - Ivacaftor - Other regimen
    - Ivacaftor/Lumacaftor (i.e., Orkambi)
    - Ivacaftor/Lumacaftor - Full dose BID
    - Ivacaftor/Lumacaftor - Half dose BID
    - Ivacaftor/Lumacaftor - Other regimen
    - Triple Combo Combination Therapy (i.e. Trikafta)
    - Triple Combo - Full Dose BID
    - Triple Combo Dose - Half Dose BID
    - Triple Combo Dose - Other
- Other treatments - encounter level
    - Patient is taking enzymes
    - Lipase Units per Largest Meal
    - Lipase Units per Day
    - H2 Blocker
    - Proton Pump Inhibitor
    - Acid blocker unknown
    - GI Other: Ursodeoxycholic acid
    - Salt supplementation
    - CF-specific vitamins (i.e. vitamins A, D, E and K)
    - Is patient currently receiving supplemental feeding
    - Supplemental feeding: total parenteral nutrition
    - Supplemental feeding: oral supplementation



- Supplemental feeding: nasogastric tube
  - Supplemental feeding: gastrostomy tube/button
  - Supplemental feeding: jejunal tube
  - Enzyme use with supplemental feeding
  - Primary Airway Clearance technique
  - Forced expiratory techniques
  - Oscillating PEP
  - High frequency chest wall oscillation
  - Exercise
  - Positive Expiratory Pressure
  - Postural drainage with clapping
- Other treatments – annual
    - Did patient use oxygen therapy during this year
    - Use non-invasive ventilation
    - Did the patient receive an influenza vaccination
    - Was the patient started on treatment for NTM
    - Patient given palivizumab (Synagis) this season
    - Patient on growth hormone in the reporting year
- Other treatments - summarized by calendar year
    - Not on any chronic pulmonary medications
    - Any medicine data completed
    - Patient is on enzymes
    - Patient received supplemental feeding during year
    - Primary airway clearance technique - most frequently used
    - Salt supplementation (encounter age < 2)
    - CF-specific vitamins (i.e. vitamins A, D, E and K)
    - Any airway clearance technique data completed
    - Heart/lung transplant in review year
    - Kidney Transplant in review year
    - Liver Transplant in review year
    - Bilateral lung transplant in review year
    - Lung Transplant: Lobar/living donor transplant in review year
    - Lung Transplant: Lobar/cadaveric transplant in review year
    - Other Transplant in review year
    - Supplemental feeding: oral supplementation
    - Supplemental feeding: nasogastric tube
    - Supplemental feeding: gastrostomy tube/button
    - Supplemental feeding: jejunal tube
    - Supplemental feeding: total parenteral nutrition
    - No enzymes recommended with tube feeding
    - Yes, enzymes mixed into the formula
    - Yes, enzymes administered directly through the tube (i.e., not into the formula)
    - Yes, enzymes taken by mouth prior to, during and/or after the feeding
    - Yes, formula infused through Relizorb (enzyme cartridge)
    - Enzymes, other
    - Exercise
    - No primary airway clearance technique
    - Other primary airway clearance technique: Positive Expiratory Pressure (PEP)

- Postural drainage with clapping (CPT)
  - Forced expiratory techniques (e.g. autogenic drainage)
  - Oscillating PEP (e.g. Flutter, acapella, IPV)
  - High frequency chest wall oscillation (e.g. Vest)
  - Oscillating PEP (e.g. Flutter, acapella, IPV)
  - High frequency chest wall oscillation (e.g. Vest)
  - Airway clearance technique: Exercise Positive Expiratory Pressure (PEP)
  - Postural drainage with clapping (CPT)
  - Forced expiratory techniques (e.g. autogenic drainage)
- Transplant
    - Current transplant status (includes prior years)
    - First year had a lung transplant Ever
    - Bilateral lung transplant Ever
    - Heart/lung transplant Ever
    - Lung Transplant: Lobar/cadaveric transplant
    - Ever Lung Transplant: Lobar/living donor transplant
    - Ever Any lung transplant
    - Ever Liver transplant
    - Ever Kidney transplant
    - Ever Other transplant
    - Were there post transplant complications
    - Bronchiolitis obliterans syndrome
    - Lympho-proliferative disorder
    - Other transplant complications

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## VII. Variable type: COMPLICATIONS

- CF related diabetes - encounter level
  - CFRD Status
  - Retinopathy
  - Microalbuminuria
  - Chronic renal insufficiency
  - Chronic renal failure requiring dialysis
  - Peripheral neuropathy
  
- CF related diabetes - annual
  - CFRD status on annual form
  - Retinal eye exam performed by an ophthalmologist
  - Spot urine sent for albumin/creatinine ratio
  - Was the patient prescribed treatment for CFRD
  - Spot urine sent for albumin/creatinine ratio
  - Was the patient prescribed treatment for CFRD
  - Dietary change
  - Oral hypoglycemic agents
  - Intermittent insulin (with illness, steroids, etc.)
  - Chronic insulin
  - Any episodes of severe hypoglycemia
  - Retinopathy
  - Microalbuminuria
  - Chronic renal insufficiency
  - Chronic renal failure requiring dialysis
  - Peripheral neuropathy
  
- Liver disease - encounter level
  - Gall stones
  - Gall stones, requiring surgery/procedure
  - Liver disease, cirrhosis
  - Esophageal varices
  - Gastric varices
  - GI bleed related to varices
  - Splenomegaly
  - Hypersplenism
  - Ascites
  - Encephalopathy
  - Acute hepatitis
  - Acute hepatitis - infectious
  - Acute hepatitis - non-infectious
  - Acute hepatitis - unknown
  - Liver disease, non-cirrhosis
  - Hepatic Steatosis
  - Liver disease, other Acute liver failure

- Liver disease - summarized by calendar year
  - Gallstones
  - Gallstones requiring surgery/procedure
  - Liver disease, cirrhosis
  - Esophageal varices
  - Gastric varices
  - GI bleed related to varices
  - Splenomegaly
  - Hypersplenism
  - Ascites
  - Encephalopathy
  - Acute hepatitis
  - Acute hepatitis - infectious
  - Acute hepatitis - non-infectious
  - Acute hepatitis - unknown
  - Liver disease, non-cirrhosis
  - Hepatic steatosis
  - Liver disease, other
  - Acute liver failure
  - Liver enzymes elevated (for years 2003-2009)
  
- Other complications - encounter level
  - Patient does not have any complications
  - Arthritis/Arthropathy
  - Bone fracture
  - Osteopenia
  - Osteoporosis
  - Allergic Bronchial Pulmonary Aspergillosis
  - Asthma
  - Hemoptysis, massive
  - Hemoptysis type
  - Pneumothorax requiring chest tube
  - Distal intestinal obstruction syndrome
  - Fibrosing colonopathy/colonic stricture
  - GERD
  - GI Bleed requiring hospitalization, non-variceal
  - Pancreatitis
  - Peptic ulcer disease
  - Rectal prolapse
  - History of intestinal or colon surgery
  - Anxiety disorder
  - Cancer confirmed by histology
  - Depression
  - Hearing loss
  - Hypertension
  - Kidney Stones
  - Nasal polyps requiring surgery
  - Renal failure requiring dialysis
  - Sinus Disease
  - Absence of vas deferens

- Other complications - summarized by calendar year
  - No complications
  - Arthritis/Arthropathy
  - Bone fracture
  - Osteopenia
  - Osteoporosis
  - Allergic Bronchial Pulmonary Aspergillosis
  - Asthma
  - Any Hemoptysis
  - Hemoptysis - massive
  - Hemoptysis - other
  - Pneumothorax requiring chest tube
  - Distal intestinal obstruction syndrome
  - Fibrosing colonopathy/colonic stricture
  - GERD
  - GI Bleed requiring hospitalization, non variceal
  - Pancreatitis
  - Peptic ulcer disease
  - Rectal prolapse
  - History of intestinal or colon surgery
  - Anxiety disorder
  - Cancer confirmed by histology
  - Depression
  - Hearing loss
  - Hypertension
  - Kidney stones
  - Nasal polyps requiring surgery
  - Renal failure requiring dialysis
  - Sinus Disease
  - Absence of vas deferens

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## VIII. Variable type: CARE EPISODES (HOSPITALIZATIONS/ HOME IV)

- Care episodes
  - Care center ID
  - Start date for care episode [PHI]
  - End date for care episode [PHI]
  - Location of care episode
  - Care Episode Site ID
  - Total Nights for care episode
  - # nights in hospital
  - # nights on home IV
  - # nights with reason pulmonary complication
  - # home IV nights with reason pulmonary exacerbation
  - # hospitalization nights with reason pulmonary exacerbation
  - # home IV nights with reason pulmonary complication
  - # hospitalization nights with reason pulmonary complication
  - # home IV nights with reason GI complications
  - # hospitalization nights with reason GI complications
  - # home IV nights with reason Transplant related
  - # hospitalization nights with reason Transplant related
  - # home IV nights with reason sinus infection
  - # hospitalization nights with reason sinus infection
  - # home IV nights with reason non-Transplant surgery
  - # hospitalization nights with reason non-Transplant surgery
  - # home IV nights with reason other
  - # hospitalization nights with reason other
  - # home IV nights with reason unknown
  - # hospitalization nights with reason unknown
  - # hospitalization nights with reason NTM
  - # home IV nights with reason NTM
  
- Care episodes - summarized by calendar year
  - Any hospitalization in the year
  - # hospitalizations (including partial) in year
  - # nights in hospital
  - Any home IV in the year
  - # nights on home IV
  - Any episode data
  - Total # care episodes in the year
  - Total # pulmonary exacerbations treated by IV antibiotics
  - # nights in hospital for pulmonary exacerbations
  - # nights on home IV for pulmonary exacerbations
  - Total # pulmonary exacerbation treated by IV antibiotics (incl unknown)
  - # nights hospital for pulmonary exacerbation (incl unknown)
  - # nights home IV for pulmonary exacerbation (incl unknown)
  - # nights with reason pulmonary complication
  - # nights with reason GI complications

- # nights with reason transplant related
- # nights with reason sinus infection
- # nights with reason non-transplant surgery
- # nights with reason other
- # nights with reason unknown
- # nights with reason NTM

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