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1. Core Information

OVERVIEW

- 1.1. What type of encounter are you recording? Annual
- 1.2. Date encounter booked for
- 1.3. Age of Patient at Encounter (years) (months)
- 1.4. Was the patient seen for this Annual Review?
- Yes
 - No - Transferred to another centre or clinic
 - No - Did not attend
 - No - Patient died
 - No - Other
 - Not known
- 1.5. Encounter setting
- Out patient
 - Inpatient
 - Daycase
 - Virtual/Phone
 - Home visit
- 1.6. Is this patient shared care? Yes No
- 1.7. Locations
- a. Encounter Location
 - b. Where does this patient receive care?
 - c. Which is the patients' regional centre?

Height / Weight

- 1.8. Height (cm)
- a. Height Percentile (%)
- 1.9. Weight (kg)
- a. Weight Percentile (%)
- 1.10. BMI (kg/m²)

Oxygen and ventilation

- 1.12. Oxygen therapy since last annual review? Yes No Not known
- a. When was oxygen therapy used?
 - Continuously
 - Nocturnal and/or with exertion

During exacerbation PRN

b. Used non invasive ventillation?

 Yes No Not known

Vaccinations

1.13. Has patient received an influenza vaccination since last annual review? Yes No Not known1.14. Has patient received a pneumococcal vaccination since last annual review? Yes No Not known

Clinical trials

1.15. Has patient participated in any clinical drug trial since last annual review? Yes No Not known

a. Please select from study list

- ATCF - Azole Therapy in Cystic Fibrosis (ATCF)
- An open-level, crossover, interventional Phase IV study to compare the ease of use of tobramycin inhalation powder with tobramycin inhalation solution and inhaled colistimethate for the treatment of pulmonary Pseudomonas aeruginosa in patient with cystic fibrosis
- TORPEDO-CF
- Safety and Efficacy Study of 2 Pancreatic Enzymes for Treatment of Exocrine Pancreatic Insufficiency in Cystic Fibrosis
- Rollover Study of Ivacaftor in Subjects With Cystic Fibrosis and a Non G551D CFTR Mutation
- Phase 1 Study Assessing the Safety and Tolerability of CTX-4430 in Cystic Fibrosis Patients
- Study of VX-661 Alone and in Combination With Ivacaftor in Subjects Homozygous or Heterozygous to the F508del-Cystic Fibrosis Transmembrane Conductance Regulator(CFTR) Mutation
- Ease of Use and Microbial Contamination of TIP vs Nebulised TIS and Nebulised Colistimethate
- Circadian Rhythm In Tobramycin Elimination In Cystic Fibrosis (CRITIC)
- Ghrelin in Cystic Fibrosis (ghrelin)
- A Short-term Study of Aerosure for Airway Clearance in Patients With Cystic Fibrosis
- Extension Study of Arikace™ in CF Patients With Chronic Pseudomonas Aeruginosa Infection
- Timing of Hypertonic Saline Inhalation Relative to Airways Clearance in Cystic Fibrosis
- A Cross-over Study of OligoG in Subjects With Cystic Fibrosis
- Single Dose of pGM169/GL67A in CF Patients
- Crossover Trial Determining the Efficacy of Dry Powder Mannitol to Improve Lung Function in Subjects Aged 6-17 Years
- A Phase 3 rollover study of Lumacaftor in combination with Ivacaftor in subjects 12 years and older with CF
- Repeated application of gene therapy in CF patients
- Study of Ivacaftor in CF subjects 2 through 5 years of age with a gating mutation
- Other (Please specify)

i. If 'Other', please specify

1.16. Has patient participated in any clinical study other than a drug study since last annual review? Yes No Not known

a. Please select from study list

- Adherence in Cystic Fibrosis - Multi-method Assessment of Adherence in an Adult Population with Cystic Fibrosis
- Cognition in Cystic Fibrosis Patients and Matched Controls - Cognition (Memory, Attention and Executive Function) in Cystic Fibrosis Patients (with/without CF related Diabetes) and Matched Controls
- Physical activity promotion in cystic fibrosis patients - Technology-based Strategies to Reduce Sedentary Behaviour and Promote Physical Activity among Young People with Cystic Fibrosis
- Prospective Study Investigating Hypersensitivity Reactions - Prospective Study Investigating Hypersensitivity Reactions to Beta-lactam Antibiotics
- Quality improvement in CF - Quality improvement in CF: what can we learn from each other?
- Cognition in Cystic Fibrosis Patients and Matched Controls

- White Blood Cell Function in Cystic Fibrosis utilising Blood and Sputum Samples
- Comparing Laboratory Blood Glucose Results With HemoCue Glucose 201 RT (CFRD)
- Home Monitoring of Adults with Cystic Fibrosis (HOME-CF) - A Prospective Pilot Study of Home Monitoring in Adults with Cystic Fibrosis (HOME-CF)
- The Addition of Non-Invasive Ventilation To Airway Clearance Techniques In Adults With Cystic Fibrosis (NIV)
- Pilot Study of Behavioural Intervention for Nutrition in Cystic Fibrosis (PIN-CF)
- Duration of Antibiotics in Infective Exacerbations of Cystic Fibrosis
- INSPIRE-CF: an alternative model for children with CF
- Investigating the Incretin Effect in Cystic Fibrosis
- Urinary biomarkers of Aminoglycoside- induced nephrotoxicity in children with CF
- Other (Please specify)

i. If 'Other' please specify

2. Admissions & IVs

ADMISSIONS & IVs

Hospital IV Admissions

2.1. IV hospital admissions since last visit

	Start	End	Total days	Admission reason
Hospital IV admission 1	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 2	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 3	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 4	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 5	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 6	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 7	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 8	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 9	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 10	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV admission 11	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>	<input style="width: 100%; height: 15px;" type="text"/>
Hospital IV				

admission 12	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 13	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 14	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 15	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 16	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 17	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 18	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 19	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Hospital IV admission 20	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Total	<input type="text"/>			(days)

Home IV Courses

2.2. Home IVs since last visit

	Start	End	Total days	Reason for IVs
Home IV course 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 6	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 7	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 8	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 9	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 10	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 11	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 12	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 13	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>

Home IV course 14	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 15	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 16	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 17	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 18	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 19	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Home IV course 20	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Total	<input type="text"/>			(days)

Non IV Hospital Admissions

2.3. Non IV hospital admissions since last visit

	Start	End	Total days	Admission reason
Non IV hospital admission 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 6	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 7	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 8	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 9	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV hospital admission 10	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>
Non IV	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text" value="▼"/>

%**FEF25-75**

e. FEF25 - 75 raw value

 (l/s) Not measured

f. FEF25 % predicted

 %**Best FEV₁ since last annual review**3.2 Best FEV₁a. Height at best FEV₁ value (cm)b. Weight at best FEV₁ value (kg)c. Date of best FEV₁ valued. Best FEV₁ (l)e. Best FEV₁ % predicted %**Faecal elastase**

3.4. Faecal elastase

 (mcg/ml) Not known or Not done**CF-related diabetes (CFRD)**

3.5. Patient has been screened for CFRD?

 Yes No No (Prior CFRD diagnosis) Not known

a. Blood taken?

 Yes No

i. HBA1C value

 (mmol/ml) Not done

ii. Random blood glucose

 (mmol/l) Not done

iii. Fasting blood glucose taken

 (mmol/l) Not done

iv. Oral glucose tolerance test fasting

 (mmol/l) Not done

v. Oral glucose tolerance 1 hour post

 (mmol/l) Not done

vi. Oral glucose tolerance 2 hour post

 (mmol/l) Not done

vii. Continuous Glucose Monitoring result

 Normal Abnormal CFRD Not done**DEXA scan**

3.6. DEXA scan performed

 Normal Abnormal Not done Not known

a. DEXA scan date

- b. DEXA scan total body under 20 years of age (z-score)
- c. DEXA scan lumbar spine under 20 years of age (z-score)
- d. DEXA scan lumbar spine over 20 years of age (z-score)
- e. DEXA scan total hip over 20 years of age (z-score)
- f. DEXA scan femoral neck under 20 years of age (z-score)
- g. DEXA scan femoral neck over 20 years of age (z-score)
- h. DEXA scan lumbar spine over post menopausal women and men >50 years of age (T-score)
- i. DEXA scan total hip over post menopausal women and men >50 years of age (T-score)
- j. DEXA scan femoral neck over post menopausal women and men >50 years of age (T-score)

X-ray / Scan

- 3.7. Chest x-ray result? No change
 New changes
 Done but result Not known
 Not done

Liver ultrasound

- 3.8. Liver ultra sound scan performed? Yes No Not known
 a. Liver ultra sound scan type Normal Abnormal

Serum creatinine

- 3.9. Serum creatinine (mmol/dl) Not done

Liver Tests

- 3.10. Laboratory liver enzymes done? Yes No Not Known

[Add new Liver Lab Enzyme details](#)

No records to display.

4. Chronic Medications

CHRONIC MEDICATIONS

- 4.1. Has this patient had any chronic medications? Yes No

4.2. [Add new Other Medications/Drugs details](#)

No records to display.

- 4.3. Drug Intolerance (Please tick all that apply) DNase

- Tobramycin solution for inhalation
- Colistin
- Macrolide antibiotics
- High-dose ibuprofen
- Hypertonic saline
- IV antibiotics

i. If 'IV antibiotics' please specify

- None known

5. Culture & Microbiology

CULTURE & MICROBIOLOGY

Respiratory microbiology

5.1.1 Number of samples

1. Number of sputum samples since last annual review

2. Number of cough/throat/nasal samples since last annual review

3. Number of Bronchoscopy samples since last annual review

5.1.2 Culture result

- Positive culture sample
- No growth
- Normal flora
- Awaited

5.1.3 Culture growth

1. Pseudomonas Aeruginosa

- Pseudomonas aeruginosa

a. Number of Pseudomonas aeruginosa samples since last annual review

b. *Pseudomonas* mucoid status

- Mucoid
- Non mucoid
- Not known

c. *Pseudomonas* drug resistance

- Pseudomonas multi drug resistant
- Pseudomonas other resistance pattern
- Pseudomonas fully sensitive
- Pseudomonas ciprofloxacin resistant

d. Is Pseudomonas Chronic or Intermittent?

- Chronic Intermittent

2. Bukholderia Cepacia complex

- Bukholderia cepacia
- Bukholderia cenocepacia
- Bukholderia multivorans

3. Fungal

Other Bukholderia cepacia species

Aspergillus fumigatus

Scedosporium species

Aspergillus species

Candida

4. Staphylococcus aureus

Staphylococcus aureus

i. Is Staphylococcus aureus Chronic or Intermittent?

Chronic Intermittent

5. Other Cultures

Alcaligenes (Achromobacter) xylosoxidans

Other Pseudomonas Species

e coli

Haemophilus influenza

Klebsiella

MRSA

Pandoria

Strenotrophomans (Xanthomas) maltophilia

Other

i. If 'Other', please specify

[Add culture taken?](#)

No records to display.

NTM

5.2.1. Has the patient been on treatment for NTM pulmonary disease at any time since last annual review?

Yes No

a. Please select NTM species being treated

M. abscessus complex [MABSC] including M. abscessus, M. bolletii, M. massiliense

i. Start date

M. avium complex (MAC) including M. avium, M. intracellulare

i. Start date

M. chelonae

i. Start date

M. fortuitum

i. Start date

M. genavense

i. Start date

M. gordonae

i. Start date

M. haemophilum

i. Start date

M. immunogenum

i. Start date

M. kansasii

i. Start date

M. malmoense

i. Start date

M. marinum

i. Start date

M. mucogenicum

i. Start date

M. nonchromogenicum

i. Start date

M. scrofulaceum

i. Start date

M. simiae

i. Start date

M. smegmatis

i. Start date

M. szulgai

i. Start date

M. terrae complex

i. Start date

M. ulcerans

i. Start date

M. xenopi

i. Start date

Mycobacterium species (unidentified)

i. Start date

a. Provide details of unidentified Microbacterium species?

b. Has the patient stopped all NTM antibiotic treatment? Yes No

i. Date of stopping treatment

ii. Reason for stopping

Completed treatment

Declined further treatment

Intolerant of treatment

Stopped treatment then later restarted it

Other

a. If 'Other' specify the reason

5.2.2. Has the patient had NTM positive samples since last annual review? Yes No

a. Negative Culture Result

- Negative culture sample
- Contaminated culture sample
- No samples taken
- Not known

5.2.3. [Add Culture](#)

No records to display.

- 5.2.4. Did the patient fulfil ATS criteria for NTM pulomary disease before starting treatment? Yes No
- a. Select reason why NTM treatment did not start
- The patient is about to start NTM treatment
 - The patient declined NTM treatment
 - The clinical team did not think that NTM treatment was appropriate
 - Other
- 5.2.5. Was an intrevenous induction regimen used at the beginning of the NTM treatment? Yes No
- 5.2.6. Which of the following antibiotics were prescribed as NTM treatment during the last period? Please tick all that apply:
- | | | |
|---|---|--|
| <input type="checkbox"/> Amikacin | <input type="checkbox"/> Azithromycin | <input type="checkbox"/> Capreomycin |
| <input type="checkbox"/> Cefoxitine | <input type="checkbox"/> Clarithromycin | <input type="checkbox"/> Ciprofloxacin |
| <input type="checkbox"/> Clofazimine | <input type="checkbox"/> Coamoxiclav | <input type="checkbox"/> Cotrimoxazole |
| <input type="checkbox"/> Cycloserine | <input type="checkbox"/> Doxycycline | <input type="checkbox"/> Ertepenem |
| <input type="checkbox"/> Ethambutol | <input type="checkbox"/> Ethionamide | <input type="checkbox"/> Imipenem |
| <input type="checkbox"/> Interferon gamma | <input type="checkbox"/> Isoniazid | <input type="checkbox"/> Levofloxacin |
| <input type="checkbox"/> Linezolid | <input type="checkbox"/> Meropenem | <input type="checkbox"/> Minocycline |
| <input type="checkbox"/> Moxifloxacin | <input type="checkbox"/> Ofloxacin | <input type="checkbox"/> Prothionamide |
| <input type="checkbox"/> Pyrazinamide | <input type="checkbox"/> Rifabutin | <input type="checkbox"/> Rifampicin |
| <input type="checkbox"/> Rifinah | <input type="checkbox"/> Rifater | <input type="checkbox"/> Streptomycin |
| <input type="checkbox"/> Tetracycline | <input type="checkbox"/> Tigecycline | <input type="checkbox"/> None |
- 5.2.7. Has the patient cultured Aspergillus in Sputum/BAL since the last data set? Yes No Not known
- 5.2.8. Has the patient been on a Proton Inhibitor since the last data set? Yes No Not known
- 5.2.9. Has the patient been on oral corticosteroid since the last data set? Yes No Not known
- 5.2.10. Has the patient been on immunosuppressive drugs since the last data set? Yes No Not known

6. Complications

Impaired glucose tolerance

- 6.1. Does patient have CFRD or impaired glucose tolerance? Yes No

CF-related diabetes (CFRD)

Diagnosis

- 6.2 Does patient have CF-related diabetes

(CFRD) Diagnosis

- CFRD with fasting hyperglycaemia
 CFRD without fasting hyperglycaemia
 CFRD
 No CFRD

Complications

a. CF-related diabetes (CFRD) Complications

- None
 Diabetic Retinopathy
 Diabetic Microalbuminuria
 Other
 Not known

i. If 'Other', please specify

Treatment

b. Was patient prescribed treatment for CFRD?

- Yes No

If 'Yes',

- Dietary change
 Oral hypoglycaemic agents
 Intermittent insulin
 Chronic insulin

Cancer

6.3. Has patient been newly diagnosed with a cancer since last annual review?

- Yes No

a. If 'Yes', Cancer type

i. If 'Other' please specify

Septicaemia

6.4. Septicaemia positive blood cultures since last encounter

- Yes No Not known

a. Septicaemia related to indwelling port catheter

- Yes No Not known

6.5. Septicaemia cultures identified

If 'Other' please specify

a. Septicaemia episode number

1st date

 Not known

2nd date

 Not known

3rd date

 Not known

4th date

 Not known

5th date

 Not known

6st date

 Not known

7nd date

 Not known

8 rd date	<input type="text"/>	<input type="checkbox"/> Not known
9 th date	<input type="text"/>	<input type="checkbox"/> Not known
10 th date	<input type="text"/>	<input type="checkbox"/> Not known
11 th date	<input type="text"/>	<input type="checkbox"/> Not known
12 th date	<input type="text"/>	<input type="checkbox"/> Not known
13 th date	<input type="text"/>	<input type="checkbox"/> Not known
14 th date	<input type="text"/>	<input type="checkbox"/> Not known
15 th date	<input type="text"/>	<input type="checkbox"/> Not known
16 th date	<input type="text"/>	<input type="checkbox"/> Not known
17 th date	<input type="text"/>	<input type="checkbox"/> Not known
18 th date	<input type="text"/>	<input type="checkbox"/> Not known
19 th date	<input type="text"/>	<input type="checkbox"/> Not known
20 th date	<input type="text"/>	<input type="checkbox"/> Not known
21 th date	<input type="text"/>	<input type="checkbox"/> Not known
22 th date	<input type="text"/>	<input type="checkbox"/> Not known
23 th date	<input type="text"/>	<input type="checkbox"/> Not known
24 th date	<input type="text"/>	<input type="checkbox"/> Not known
25 th date	<input type="text"/>	<input type="checkbox"/> Not known

Haemoptysis

6.6. Has the patient had any Haemoptysis occurrences? Yes No

a. How many massive, severe and/or moderate haemoptysis episodes has the patient had? Not known

Massive/Severe/Moderate Haemoptysis episodes

	Type	Date
1 st episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not known
2 nd episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not known
3 rd episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not known
4 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not known
5 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not known
6 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known
7 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known
8 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known
9 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known
10 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known
11 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known
12 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known
13 th episode	<input type="text"/>	<input type="text"/> <input type="checkbox"/> Not Known

14 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
15 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
16 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
17 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
18 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
19 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
20 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
21 st episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
22 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
23 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
24 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
25 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not Known
26 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
27 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
28 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
29 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
30 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
31 st episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
32 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
33 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
34 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
35 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
36 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
37 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
38 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
39 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
40 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
41 st episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
42 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
43 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
44 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
45 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
46 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
47 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
48 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
49 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known
50 th episode	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Not known

6.7. Haemoptysis scanty (<=5 mls in 24

hours)

Yes No Not known

a. Haemoptysis scanty (<=5 mls in 24 hours) number

Chest tightness/wheezing

6.8. Acute chest tightness and/or wheezing related to medication

Yes No Not known

a. Acute chest tightness and/or wheezing related to medications number of episodes

	Date	Medication details
1 st episode	<input type="text"/>	<input type="text"/>
2 nd episode	<input type="text"/>	<input type="text"/>
3 rd episode	<input type="text"/>	<input type="text"/>
4 th episode	<input type="text"/>	<input type="text"/>
5 th episode	<input type="text"/>	<input type="text"/>
6 th episode	<input type="text"/>	<input type="text"/>
7 th episode	<input type="text"/>	<input type="text"/>
8 th episode	<input type="text"/>	<input type="text"/>
9 th episode	<input type="text"/>	<input type="text"/>
10 th episode	<input type="text"/>	<input type="text"/>
11 th episode	<input type="text"/>	<input type="text"/>
12 th episode	<input type="text"/>	<input type="text"/>
13 th episode	<input type="text"/>	<input type="text"/>
14 th episode	<input type="text"/>	<input type="text"/>
15 th episode	<input type="text"/>	<input type="text"/>
16 th episode	<input type="text"/>	<input type="text"/>
17 th episode	<input type="text"/>	<input type="text"/>
18 th episode	<input type="text"/>	<input type="text"/>
19 th episode	<input type="text"/>	<input type="text"/>
20 th episode	<input type="text"/>	<input type="text"/>

Cough Fracture

6.9. Cough fracture

Yes No

a. Cough fracture number of episodes

1 st date	<input type="text"/>	<input type="checkbox"/> Not known
2 nd date	<input type="text"/>	<input type="checkbox"/> Not known
3 rd date	<input type="text"/>	<input type="checkbox"/> Not known
4 th date	<input type="text"/>	<input type="checkbox"/> Not known
5 th date	<input type="text"/>	<input type="checkbox"/> Not known

6 th date	<input type="text"/>	<input type="checkbox"/> Not known
7 th date	<input type="text"/>	<input type="checkbox"/> Not known
8 th date	<input type="text"/>	<input type="checkbox"/> Not known
9 th date	<input type="text"/>	<input type="checkbox"/> Not known
10 th date	<input type="text"/>	<input type="checkbox"/> Not known
11 th date	<input type="text"/>	<input type="checkbox"/> Not known
12 th date	<input type="text"/>	<input type="checkbox"/> Not known
13 th date	<input type="text"/>	<input type="checkbox"/> Not known
14 th date	<input type="text"/>	<input type="checkbox"/> Not known
15 th date	<input type="text"/>	<input type="checkbox"/> Not known
16 th date	<input type="text"/>	<input type="checkbox"/> Not known
17 th date	<input type="text"/>	<input type="checkbox"/> Not known
18 th date	<input type="text"/>	<input type="checkbox"/> Not known
19 th date	<input type="text"/>	<input type="checkbox"/> Not known
20 th date	<input type="text"/>	<input type="checkbox"/> Not known

Pulmonary

6.10. Complication pulmonary abscess Yes No

a. Complication pulmonary abscess number

Not known

1 st date	<input type="text"/>	<input type="checkbox"/> Not known
2 nd date	<input type="text"/>	<input type="checkbox"/> Not known
3 rd date	<input type="text"/>	<input type="checkbox"/> Not known
4 th date	<input type="text"/>	<input type="checkbox"/> Not known
5 th date	<input type="text"/>	<input type="checkbox"/> Not known
6 th date	<input type="text"/>	<input type="checkbox"/> Not known
7 th date	<input type="text"/>	<input type="checkbox"/> Not known
8 th date	<input type="text"/>	<input type="checkbox"/> Not known
9 th date	<input type="text"/>	<input type="checkbox"/> Not known
10 th date	<input type="text"/>	<input type="checkbox"/> Not known
11 th date	<input type="text"/>	<input type="checkbox"/> Not known
12 th date	<input type="text"/>	<input type="checkbox"/> Not known
13 th date	<input type="text"/>	<input type="checkbox"/> Not known
14 th date	<input type="text"/>	<input type="checkbox"/> Not known
15 th date	<input type="text"/>	<input type="checkbox"/> Not known

Cardiac

6.11. Are there any cardiac complications? Yes No

If 'Yes', please tick all that apply

- i. Arrhythmia type
- Arrhythmia
 Bradycardia Tachyarrhythmia
- ii. Bradycardia options
- a. HeartBlock Yes No
- b. Pauses Yes No
- c. Asymptomatic Bradycardia Yes No
- iii. Tachyarrhythmia options
- Atrial fibrillation Ventricular fibrillation
- Atrial flutter Ventricular flutter
- Paroxysm atrial tachycardia Other
- Ventricular tachycardia
- a. If 'Other' please specify
-
- Cardiac arrest
- Cardiomyopathy
- Congenital heart disease
- Heart failure
- Ischaemic heart disease
- Valvular disease
- Other

Hepatobiliary complications

6.12. Were there any Hepatobiliary complications?

Yes No

If 'Yes',

2. Acute liver failure
(no underlying liver disease, ALT >3x ULN, INR > 2, not responsive to vitamin K)

Acute hepatitis (ALT > 5 x ULN and duration of illness < 6 months)

Yes No

3. Hepatic Encephalopathy

Yes No

If 'Yes', check all complications that apply,

- Cirrhosis with portal hypertension
- Cirrhosis with no portal hypertension
- Gall Bladder Disease
- Gastrointestinal bleeding from varices
- Liver Disease with no Cirrhosis
- Raised Liver Enzymes

Gut Complications

6.13. Were there any Gut complications?

Yes No

If 'Yes', check all complications that apply,

- DIOS (distal intestinal obstruction syndrome)
- Fibrosing colonopathy/colonic stricture
- Intestinal obstruction

- Gastro oesophageal reflux disease
- Gastrointestinal non varices as source
- Pancreatitis
- Peptic ulcer
- Rectal prolapse

Kidney / Renal Disease

- 6.14. Were there any Kidney/Renal complications? Yes No

If 'Yes', check all complications that apply,

- Hypertension
- Kidney stones
- Acute kidney injury requiring dialysis
- Chronic kidney disease (Chronic renal failure)

OTHER COMPLICATIONS

- 6.15. Are there any other complications? Yes No

If 'Yes', check all complications that apply,

- Arthritis
- Arthropathy
- Allergic Bronchial Pulmonary Aspergillosis (ABPA)
- Asthma
- Bone fracture
- Depression
- Hearing loss
- Admission to intensive care unit
- Paediatric intensive care unit
- Nasal polyps
- Osteopenia
- Osteoporosis
- Pneumothorax requiring chest drain
- Port inserted or replaced in current 12 month period
- Sinus disease
- Absence of Vas deferens
- Other (please specify)

i. If 'Other', please specify

7. Growth & Nutrition

NUTRITIONAL ASSESSMENT

- 7.1. Nutritional assessment carried out this encounter? Yes No
- 7.2. Seen by specialist CF Dietitian Yes No

- 7.3. Assessed for oral intake Yes No
- 7.4. Supplemental Feeding
- None Oral
- Nasogastric Gastrostomy
- Jejunal tube Parenteral
- Yes but method unknown Not known
- 7.5. Dose of Lipase (iu/kg per day)
- Not known
- Not applicable
- 7.6. Does the patient take pancreatic enzyme supplements? Yes No Not known
- 7.7. Has the patient been on Oestrogen? Yes No Not known
- 7.8. Prescribed daily Ursodexycolic acid? Yes No Not known

8. PHYSIOTHERAPY

PHYSIO

Airway clearance

- 8.1. Primary airway clearance
- a. If 'Other', please specify

Secondary airway clearance

- 8.2. Secondary airway clearance (check all that apply)
- PEP Postural drainage Forced expiration
- Oscillating PEP VEST Exercise
- Active Cycle of Breathing Techniques High Pressure PEP Autogenic drainage
- Assisted autogenic drainage None Other
- i. If 'Other', please specify

Exercise

- 8.3. Has an exercise test been performed? Yes No Not known
- a. If 'Yes', check all that apply
- Submaximal
- Shuttle test
- Walk test
- Step test
- Other
- i. If 'Other', please specify

Continence & Posture

- 8.4. Urinary incontinence Yes No Not known

8.5. Faecal incontinence

 Yes No Not known

8.6. Postural abnormality

 Yes No Not known

9. Lifestyle

LIFESTYLE

Smoking

9.1. Does the patient smoke cigarettes or other forms of tobacco?

9.2. Is the patient regularly exposed to second hand smoke?

 Yes No Not known

Education

9.3. Current education level of patient

Marital status

9.4. Patients marital status

Employment

9.5. What is the patients employment status?

Full time Unemployed

Part time Disabled

Home maker Retired

Student Not known

Pregnancy / Birth

9.6. Since the last annual review:

a. Has the patient or their partner been pregnant?

 Yes No Not known

b. Was conception via IVF?

 Yes No Not known

c. What was the outcome of the pregnancy?

d. Gestational age (weeks)

 Not known

e. Congenital abnormality

 Yes No

i. If 'Yes' please specify

Anencephaly

Meningomyelocele/Spina bifida

Cyanotic congenital heart disease

Congenital diaphragmatic hernia

Omphalocele

Gastroschisis

Limb reduction defect
(excluding congenital amputation & dwarfing syndromes)

Cleft Lip with or without Cleft Palate

- a. Down Syndrome
- i. Down Syndrome Karyotype
- b. Suspected chromosomal disorder
- i. Suspected chromosomal disorder Karyotype
- Cleft Palate alone
- Hypospadias
- None of the above
- Yes No
- Karyotype confirmed
- Karyotype pending
- Yes No
- Karyotype confirmed
- Karyotype pending

10. Outcome

OUTCOME

Death

- 10.1. Has the patient died? Yes No
- a. Date of death
- i. Is date of death an estimate? Yes No
- b. Cause of Death
- If 'Cancer', please specify
- Bowel
- Breast
- Brain
- Liver
- Lung
- Lymphoma
- Pancreatic
- Skin
- Testicular
- Other
- Other
- c. ONS Date of Death 01/01/0001 00:00:00
- d. ONS Primary cause of death

Diagnosis reversal

- 10.2. Diagnosis reversed? Yes No
- a. Diagnosis reversal date
- b. Reason for reversal of diagnosis?
- i. If 'Other', please specify
- Not known

Transplants

- 10.3 Since the last annual review:

a. Has this patient been evaluated for transplant during the period since the last annual review?

Yes No

i. What was the outcome of the transplant evaluation?

Accepted
 Declined
 Deferred

a. Date placed onto transplant list

b. Received transplant since last annual review?

Yes No

i. Transplant date

ii. Transplant centre

iii. Transplant type(s)

a. If 'Other', please specify

Transplant Complications

10.4 Within 12 months of surgery, select any complications suffered

None
 LymphoProlifDisorder
 Atypical Infection

Bronchiolitis
 Renal Failure
 Other
 Unknown

i. If 'Other', please specify,