Cystic Fibrosis Trust

UK CF Registry

Annual review proforma

June 2023

This document displays all of the questions that are available on the Registry. Not all questions will be applicable to all patients.

Please direct any queries to registry@cysticfibrosis.org.uk.

Contents

Patient details			
Name			
Date of birth	___ / ___ / _____	Registry ID	

1. Core information

1.1 Type of encounter
- ☐ Annual review
- ☐ Encounter

1.2 Date of encounter ___ / ___ / _____

1.3 Patient age ___ years ___ months

1.4 Did the patient have an annual review?
- ☐ Yes
- ☐ No – transferred to another centre or clinic
- ☐ No – did not attend appointment
- ☐ No – patient died
- ☐ No – other
- ☐ Not known

1.5 Encounter setting
- ☐ Outpatient
- ☐ Inpatient
- ☐ Day case
- ☐ Virtual/phone
- ☐ Home visit

1.6 Is this patient shared care?
- ☐ Yes
- ☐ No

1.7 If yes:

Encounter location	
Where does this patient receive care?	
What is the patient's regional centre?	

Height and weight

1.8 Height ____ cm ☐ Not known

1.9 Weight ____ kg ☐ Not known

1.10 BMI ____ kg/m^2

1.11 If height/weight not supplied, please give a reason:

- ☐ Behavioural issues
- ☐ Physical disability
- ☐ Remote encounter

Oral antibiotics

1.13 Number of courses of oral antibiotics taken since the last annual review: ____

1.13a Is this an estimate?

- ☐ Estimate
- ☐ Accurate

Oxygen and ventilation

1.14 Oxygen therapy since last annual review

- ☐ Yes
- ☐ No
- ☐ Not known

1.14a If yes, when was oxygen therapy used?

- ☐ Continuously
- ☐ Nocturnal and/or with exertion
- ☐ During exacerbation
- ☐ PRN

Vaccinations

1.15 Has the patient received an influenza vaccine since last annual review?

- ☐ Yes
- ☐ No
- ☐ Not known

1.16 Has the patient received a pneumococcal vaccine since last annual review?

- ☐ Yes
- ☐ No
- ☐ Not known

Clinical trials

1.17 Has the patient participated in any clinical drug trial since last annual review?

- ☐ Yes
- ☐ No
- ☐ Not known

1.18 Has the patient participated in any clinical study other than a drug study since last annual review?

- ☐ Yes
- ☐ No
- ☐ Not known

2. Admissions and IVs

2.1 IV hospital admissions since last visit: ____ Total days: ____

	Start date	End date	Total days	Admission reason	
1	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Eradication of pseudomonas ☐ Induction NTM Haemoptysis	☐ Planned IVs ☐ Induction NTM ☐ Bronchoscopy ☐ Not known Other
2	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Eradication of pseudomonas ☐ Induction NTM ☐ Haemoptysis	☐ Planned IVs ☐ Induction NTM ☐ Bronchoscopy ☐ Not known ☐ Other
3	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Eradication of pseudomonas ☐ Induction NTM ☐ Haemoptysis	☐ Planned IVs ☐ Induction NTM ☐ Bronchoscopy ☐ Not known ☐ Other
4	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Eradication of pseudomonas ☐ Induction NTM ☐ Haemoptysis	☐ Planned IVs ☐ Induction NTM ☐ Bronchoscopy ☐ Not known ☐ Other
5	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Eradication of pseudomonas ☐ Induction NTM ☐ Haemoptysis	☐ Planned IVs ☐ Induction NTM ☐ Bronchoscopy ☐ Not known ☐ Other

2.2 Home IVs since last visit: ____ Total days: ____

	Start date	End date	Total days	Reason for IVs	
1	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Sinus infection ☐ Not known	☐ Planned IVs ☐ Haemoptysis ☐ Other
2	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Sinus infection ☐ Not known	☐ Planned IVs ☐ Haemoptysis ☐ Other
3	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Sinus infection ☐ Not known	☐ Planned IVs ☐ Haemoptysis ☐ Other
4	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Sinus infection ☐ Not known	☐ Planned IVs ☐ Haemoptysis ☐ Other
5	__/__/____	__/__/____		☐ Pulmonary exacerbation ☐ Sinus infection ☐ Not known	☐ Planned IVs ☐ Haemoptysis ☐ Other

2.3 Non-IV hospital admissions since last visit: ____ Total days: ____

	Start date	End date	Total days	Admission reason	
1	__/__/____	__/__/____		☐ Non-exacerbation pulmonary complication ☐ Transplant related ☐ Bowel ☐ Haemoptysis ☐ Not known	☐ GI complication ☐ Non-transplant surgery ☐ Liver ☐ Diabetes ☐ Other
2	__/__/____	__/__/____		☐ Non-exacerbation pulmonary complication ☐ Transplant related ☐ Bowel ☐ Haemoptysis ☐ Not known	☐ GI complication ☐ Non-transplant surgery ☐ Liver ☐ Diabetes ☐ Other
3	__/__/____	__/__/____		☐ Non-exacerbation pulmonary complication ☐ Transplant related ☐ Bowel ☐ Haemoptysis ☐ Not known	☐ GI complication ☐ Non-transplant surgery ☐ Liver ☐ Diabetes ☐ Other
4	__/__/____	__/__/____		☐ Non-exacerbation pulmonary complication ☐ Transplant related ☐ Bowel ☐ Haemoptysis ☐ Not known	☐ GI complication ☐ Non-transplant surgery ☐ Liver ☐ Diabetes ☐ Other
5	__/__/____	__/__/____		☐ Non-exacerbation pulmonary complication ☐ Transplant related ☐ Bowel ☐ Haemoptysis ☐ Not known	☐ GI complication ☐ Non-transplant surgery ☐ Liver ☐ Diabetes ☐ Other

3. Investigations

Pulmonary function tests

3.1a FEV_1 raw value ____ l ☐ Not measured

3.1b FEV_1 % predicted ____ %

3.1c FVC raw value ____ l ☐ Not measured

3.1d FVC % predicted ____ %

3.1e FEF 25-75 raw value ____ l/s ☐ Not measured

3.1f FEF 25-75 % predicted ____ %

3.1g Were these spirometer readings taken at home or in hospital?

- ☐ Patient's own/home spirometer
- ☐ Hospital spirometer
- ☐ Not known

Best FEV_1 since last annual review

☐ Best FEV_1 not measured

3.2a Height at best FEV_1 value ____ cm

3.2b Weight at best FEV_1 value ____ kg

3.2c Date of best FEV_1 value __ / __ / ____

3.2d Best FEV_1 ____ l

3.2e Best FEV_1 % predicted ____ %

3.2f Were these spirometer readings taken at home or in hospital?

- ☐ Patient's own/home spirometer
- ☐ Hospital spirometer
- ☐ Not known

Faecal elastase

3.4 Faecal elastase ____ mcg/ml ☐ Not known/not done

CF-related diabetes (CFRD)

3.5 Patient screened for CFRD?

- ☐ Yes
- ☐ No
- ☐ No – prior diagnosis of CFRD
- ☐ Not known

3.5a Bloods taken?

- ☐ Yes
- ☐ No

HbA1c value	____ mmol/ml	☐ Not measured
Random blood glucose	____ mmol/l	☐ Not measured
Fasting blood glucose	____ mmol/l	☐ Not measured
Oral glucose tolerance test fasting	____ mmol/l	☐ Not measured
Oral glucose tolerance 1 hour post	____ mmol/l	☐ Not measured
Oral glucose tolerance 2 hours post	____ mmol/l	☐ Not measured

Continuous glucose monitoring result

- ☐ Normal
- ☐ Abnormal
- ☐ CFRD
- ☐ Not done

DEXA scan

3.6 DEXA scan performed?

- ☐ Normal
- ☐ Abnormal
- ☐ Not done
- ☐ Not known

If DEXA scan performed:

3.6a DEXA scan date __ / __ / ____

3.6d DEXA scan lumbar spine over 20 years of age ____ (z-score)

3.6e DEXA scan total hip over 20 years of age ____ (z-score)

3.6g DEXA scan femoral neck over 20 years of age ____ (z-score)

X-ray

3.7 Chest x-ray result

- ☐ No change
- ☐ New changes
- ☐ Done but result not known
- ☐ Not done

Liver ultrasound

3.8 Liver ultrasound performed?

- ☐ Yes
- ☐ No
- ☐ Not known

3.8a If liver ultrasound scan done, result:

- ☐ Normal
- ☐ Abnormal

Serum creatinine

3.9 Serum creatinine ____ µmol/l ☐ Not measured

Liver tests

3.10 Have laboratory liver enzymes been done since last encounter?

- ☐ Yes
- ☐ No
- ☐ Not known

If yes:

Date of liver test __ / __ / ____

3.10a ALT liver enzyme result ☐ Not done

- ☐ Normal
- ☐ >1 to ≤3 x ULN
- ☐ >3 to ≤5 x ULN
- ☐ >5 to ≤8 x ULN
- ☐ >8 x ULN

3.10b AST liver enzyme result ☐ Not done
- ☐ Normal
- ☐ >1 to ≤3 x ULN
- ☐ >3 to ≤5 x ULN
- ☐ >5 to ≤8 x ULN
- ☐ >8 x ULN

3.10c GGT liver enzyme result ☐ Not done
- ☐ Normal
- ☐ >1 to ≤3 x ULN
- ☐ >3 to ≤5 x ULN
- ☐ >5 to ≤8 x ULN
- ☐ >8 x ULN

3.10d ALP liver enzyme result ☐ Not done
- ☐ Normal
- ☐ >1 to ≤2 x ULN
- ☐ >2 x ULN

3.10e Total bilirubin liver enzyme result ☐ Not done
- ☐ Normal
- ☐ >1 to ≤2 x ULN
- ☐ >2 x ULN

Immunoglobulin E

3.11 Total IgE at annual review ____ iu/ml ☐ Not measured

3.12 Aspergillus specific IgE at annual review ____ iu/ml ☐ Not measured

Immunoglobulin G

3.13 Aspergillus specific IgG at annual review ____ iu/ml ☐ Not measured

Eosinophils

3.14 Eosinophil count at annual review ____ $x10^9/l$ ☐ Not measured

Serology tests including covid-19 antibody blood tests

3.15 Serology type
- ☐ SAR-COV-2 ☐ Serology not done
- ☐ Other

Serology date __ / __ / ____

Serology result
- ☐ Positive
- ☐ Negative
- ☐ Inconclusive

Chloride sweat tests

3.16 Sweat chloride value ____ mmol/l ☐ Not measured

Sweat chloride date __ / __ / ____

Sweat test origin
- ☐ Diagnosis
- ☐ Investigations

4. Chronic medications

4.1 Does this patient take any chronic medications?

- ☐ Yes
- ☐ No

4.2 Chronic medication details

Drug name	Start date	End date	Reason for stopping
	__ / __ / ____	__ / __ / ____	
	__ / __ / ____	__ / __ / ____	
	__ / __ / ____	__ / __ / ____	
	__ / __ / ____	__ / __ / ____	
	__ / __ / ____	__ / __ / ____	

4.3 Drug intolerance (tick all that apply)

Inhaled
- ☐ DNAse
- ☐ Tobramycin
- ☐ Colistin
- ☐ Hypertonic saline

IVs
- ☐ Meropenem
- ☐ Ceftadazime

Oral
- ☐ CFTR modulator
- ☐ Voriconazole
- ☐ Macrolides

- ☐ Other:
- ☐ None known

CFQ-R

4.4 Are CFQ-R scores available for this patient since their last annual review?

- ☐ Yes
- ☐ No

4.4i Who completed the CFQ-R questionnaire?

- ☐ Patient
- ☐ Parent or carer

4.4ii Date of CFQ-R questionnaire: __ / __ / ____

4.4iii How should the CFQ-R score be entered? (Please attach the scores/questionnaire if using this form to collect clinical data)

- ☐ Domain scores only
- ☐ Full questionnaire

Please see Appendix A to view the CFQ-R domain scores and questionnaires.

Covid vaccinations

4.5 Covid vaccinations

	Vaccine name		**Date received**	
1	☐ Oxford-AstraZeneca (AZD1222) ☐ Novavax (NVX-CoV2373) ☐ Pfizer-BioNTech (BNT162b2) ☐ Moderna (mRNA-1273) ☐ Other:	☐ Valneva (VLA2001) ☐ GlaxoSmithKline (SCB-2019) ☐ Janssen and Johnson & Johnson (JNJ-78436735)	__ / __ / ____	☐ Accurate ☐ Estimate
2	☐ Oxford-AstraZeneca (AZD1222) ☐ Novavax (NVX-CoV2373) ☐ Pfizer-BioNTech (BNT162b2) ☐ Moderna (mRNA-1273) ☐ Other:	☐ Valneva (VLA2001) ☐ GlaxoSmithKline (SCB-2019) ☐ Janssen and Johnson & Johnson (JNJ-78436735)	__ / __ / ____	☐ Accurate ☐ Estimate
3	☐ Oxford-AstraZeneca (AZD1222) ☐ Novavax (NVX-CoV2373) ☐ Pfizer-BioNTech (BNT162b2) ☐ Moderna (mRNA-1273) ☐ Other:	☐ Valneva (VLA2001) ☐ GlaxoSmithKline (SCB-2019) ☐ Janssen and Johnson & Johnson (JNJ-78436735)	__ / __ / ____	☐ Accurate ☐ Estimate

5. Culture and microbiology

5.1.1 Number of sputum samples since last annual review ____

Number of cough/throat/nasal samples since last annual review ____

Number of bronchoscopy samples since last annual review ____

5.1.2 Results

- ☐ Positive sample
- ☐ No growth

5.1.3 Bacterial growth (if applicable)

- ☐ Pseudomonas aeruginosa
- ☐ Other Pseudomonas species
- ☐ Burkholderia cepacia complex
- ☐ Staphylococcus aureus
- ☐ MRSA
- ☐ Stenotrophomonas (Xanthomonas) maltophilia
- ☐ Alcaligenes (Achromobacter) xylosoxidans
- ☐ Escherichia coli (E coli)
- ☐ Haemophilus influenzae
- ☐ Klebsiella species
- ☐ Pandoraea species
- ☐ Other:

5.1.4 Fungal result (if applicable)

- ☐ Aspergillus fumigatus
- ☐ Aspergillus species
- ☐ Scedosporium species
- ☐ Candida
- ☐ Other:

5.1.5 Viral result (if applicable)

- ☐ SARS-COV-2
- ☐ Influenza
- ☐ RSV
- ☐ Other:

NTM: non-tuberculosis mycobacterium

5.2.1 Has the patient had NTM positive samples since their last annual review?

- ☐ Yes
- ☐ No – negative culture sample
- ☐ No – contaminated culture sample
- ☐ No – no samples taken
- ☐ No – unknown reason

5.2.2 NTM positive sample details, if applicable:

Date of sample __ / __ / ____

Sample type

- ☐ Sputum
- ☐ Induced sputum
- ☐ Lung biopsy
- ☐ Broncho-alveolar lavage
- ☐ Not known

Species

- ☐ M. abscessus complex (MABSC) including M. abscessus, M. bolletii, M. massiliense
- ☐ M. chelonae
- ☐ M. fortuitum
- ☐ M. genavense
- ☐ M. gordonae
- ☐ M. haemophilum
- ☐ M. immunogenum
- ☐ M. kansasii
- ☐ M. malmoense
- ☐ M. marinum
- ☐ M. mucogenicum
- ☐ M. avium complex (MAC) including M. avium, M. intracellulare
- ☐ M. nonchromogenicum
- ☐ M. scrofulaceum
- ☐ M. simiae
- ☐ M. smegmatis
- ☐ M. szulgai
- ☐ M. terrae complex
- ☐ M. ulcerans
- ☐ M. xenopi
- ☐ Mycobacterium species (unidentified)

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

- ☐ Yes
- ☐ No

5.2.3a Please select NTM species being treated.

- ☐ M. abscessus complex (MABSC) including M. abscessus, M. bolletii, M. massiliense
- ☐ M. chelonae
- ☐ M. fortuitum
- ☐ M. genavense
- ☐ M. gordonae
- ☐ M. haemophilum
- ☐ M. immunogenum
- ☐ M. kansasii
- ☐ M. malmoense
- ☐ M. marinum
- ☐ M. mucogenicum
- ☐ M. avium complex (MAC) including M. avium, M. intracellulare
- ☐ M. nonchromogenicum
- ☐ M. scrofulaceum
- ☐ M. simiae
- ☐ M. smegmatis
- ☐ M. szulgai
- ☐ M. terrae complex
- ☐ M. ulcerans
- ☐ M. xenopi
- ☐ Mycobacterium species (unidentified)

5.2.3b Has the patient stopped all NTM treatment?

- ☐ Yes
- ☐ No

If patient has stopped treatment:

Date of stopping treatment __ / __ / ____

Reason for stopping

- ☐ Completed treatment
- ☐ Declined further treatment
- ☐ Intolerant of treatment
- ☐ Stopped treatment then later restarted it
- ☐ Other (please specify):

5.2.4 Did the patient fulfil ATS criteria for NTM pulmonary disease before starting treatment?

- ☐ Yes
- ☐ No

5.2.5 Was an intravenous intensive 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.

☐ Amikacin	☐ Azithromycin	☐ Capreomycin
☐ Cefoxitine	☐ Clarithromycin	☐ Ciprofloxacin
☐ Clofazimine	☐ Co-amoxiclav	☐ Cotrimoxazole
☐ Cycloserine	☐ Doxycycline	☐ Ertepenem
☐ Ethambutol	☐ Ethionamide	☐ Imipenem
☐ Interferon gamma	☐ Isoniazid	☐ Levofloxacin
☐ Linezolid	☐ Meropenem	☐ Minocycline
☐ Moxifloxacin	☐ Ofloxacin	☐ Prothionamide
☐ Pyrazinamide	☐ Rifabutin	☐ Rifampicin
☐ Rifinah	☐ Rifater	☐ Streptomycin
☐ Tetracycline	☐ Tigecycline	☐ None

5.2.7 Has the patient been on oral corticosteroids since the last data set?

- ☐ Yes
- ☐ No
- ☐ Not known

Covid tests

If covid test done:

5.3i Primary covid test reason

- ☐ Symptoms
- ☐ Contact tracing
- ☐ Routine
- ☐ Monitoring previous positive result
- ☐ Other:

5.3ii When was the covid test carried out? __ / __ / ____

5.3iii Type of test

- ☐ PCR
- ☐ Antigen (e.g. lateral flow)

5.3iv Was the covid test positive?

- ☐ Yes
- ☐ No

If the test was positive:

5.3v Was the patient symptomatic?

- ☐ Yes
- ☐ No

If yes, how did they present? Please tick all that apply.

- ☐ Fever
- ☐ Altered cough
- ☐ Loss of smell
- ☐ Loss of taste
- ☐ Fatigue (tiredness)
- ☐ Myalgia (muscle pain)
- ☐ Dyspnoea (shortness of breath)
- ☐ Other:

5.3vi Was the patient pregnant at time of diagnosis?

- ☐ Yes
- ☐ No

5.3vii Was the patient admitted to hospital post diagnosis?

- ☐ Yes
- ☐ No

If no, was the patient already an inpatient at the time of diagnosis?

- ☐ Yes
- ☐ No

If yes, was the covid diagnosis more than 9 days after the initial admission?

- ☐ Yes
- ☐ No

Please list any notable covid complications (e.g. stroke, secondary infection):

☐ Not applicable

Covid treatment

5.3viii Oral antibiotics
- ☐ Yes
- ☐ No

5.3ix IV antibiotics
- ☐ Yes
- ☐ No

5.3x Treated with steroids (e.g. dexamethasone, prednisolone, hydrocortisone)
- ☐ Yes
- ☐ No

5.3xi Did patient receive new/additional oxygen?
- ☐ Yes
- ☐ No

5.3xii Did patient receive new/additional NIV?
- ☐ Yes
- ☐ No

5.3xiii Was patient admitted to intensive care?
- ☐ Yes
- ☐ No

5.3xiv Did patient receive mechanical ventilation?
- ☐ Yes
- ☐ No

5.3xv Was patient put on ECMO?
- ☐ Yes
- ☐ No

6. Complications

CF-related diabetes (CFRD) or impaired glucose tolerance

6.1 CFRD status:

- ☐ CFRD
- ☐ Steroid induced diabetes
- ☐ Impaired glucose tolerance
- ☐ Indeterminate
- ☐ No CFRD

6.1a If CFRD, please specify:

- ☐ CFRD with fasting hyperglycaemia
- ☐ CFRD without fasting hyperglycaemia
- ☐ CFRD (fasting hyperglycaemia status unknown)

If CFRD or steroid induced diabetes:

6.1b Complications:

- ☐ None
- ☐ Diabetic retinopathy
- ☐ Diabetic microalbuminuria
- ☐ Other:
- ☐ Not known

6.1c Was patient prescribed treatment?

- ☐ Yes
- ☐ No

If yes:

- ☐ Dietary change
- ☐ Oral hypoglycaemic agents
- ☐ Intermittent insulin
- ☐ Chronic insulin

Cancer

6.2 Newly diagnosed cancer

- ☐ Yes
- ☐ No

If yes, cancer type:

- ☐ Bowel
- ☐ Brain
- ☐ Breast
- ☐ Liver
- ☐ Lung
- ☐ Lymphoma
- ☐ Pancreatic
- ☐ Skin
- ☐ Testicular
- ☐ Other:

Septicaemia

6.3 Septicaemia with positive blood cultures

- ☐ Yes
- ☐ No
- ☐ Not known

If yes, related to indwelling port catheter?

- ☐ Yes
- ☐ No
- ☐ Not known

Number of episodes ____

	Date	**Culture identified**	
1	__ / __ / ____ ☐ Not known	☐ Burkholderia cepacia ☐ Candida ☐ MRSA (methicillin resistant staphylococcus aureus) ☐ Pseudomonas aeruginosa ☐ Staphylococcus aureus	☐ Stenotrophomonas (Xamthomonas) maltophilia ☐ Staphylococcus aureus ☐ Not known ☐ Other:
2	__ / __ / ____ ☐ Not known	☐ Burkholderia cepacia ☐ Candida ☐ MRSA (methicillin resistant staphylococcus aureus) ☐ Pseudomonas aeruginosa ☐ Staphylococcus aureus	☐ Stenotrophomonas (Xamthomonas) maltophilia ☐ Staphylococcus aureus ☐ Not known ☐ Other:
3	__ / __ / ____ ☐ Not known	☐ Burkholderia cepacia ☐ Candida ☐ MRSA (methicillin resistant staphylococcus aureus) ☐ Pseudomonas aeruginosa ☐ Staphylococcus aureus	☐ Stenotrophomonas (Xamthomonas) maltophilia ☐ Staphylococcus aureus ☐ Not known ☐ Other:
4	__ / __ / ____ ☐ Not known	☐ Burkholderia cepacia ☐ Candida ☐ MRSA (methicillin resistant staphylococcus aureus) ☐ Pseudomonas aeruginosa ☐ Staphylococcus aureus	☐ Stenotrophomonas (Xamthomonas) maltophilia ☐ Staphylococcus aureus ☐ Not known ☐ Other:

5	__ / __ / ____ ☐ Not known	☐ Burkholderia cepacia ☐ Candida ☐ MRSA (methicillin resistant staphylococcus aureus) ☐ Pseudomonas aeruginosa ☐ Staphylococcus aureus	☐ Stenotrophomonas (Xamthomonas) maltophilia ☐ Staphylococcus aureus ☐ Not known ☐ Other:

Haemoptysis

6.4 Haemoptysis massive, severe and/or moderate

☐ Yes
☐ No

If yes, number of episodes ____ ☐ Not known

	Type	Date
1	☐ Massive (>240ml in 24 hours) ☐ Severe (>60ml and <240ml in 24 hours) ☐ Moderate (>5ml and <60ml in 24 hours)	__ / __ / ____ ☐ Not known
2	☐ Massive (>240ml in 24 hours) ☐ Severe (>60ml and <240ml in 24 hours) ☐ Moderate (>5ml and <60ml in 24 hours)	__ / __ / ____ ☐ Not known
3	☐ Massive (>240ml in 24 hours) ☐ Severe (>60ml and <240ml in 24 hours) ☐ Moderate (>5ml and <60ml in 24 hours)	__ / __ / ____ ☐ Not known
4	☐ Massive (>240ml in 24 hours) ☐ Severe (>60ml and <240ml in 24 hours) ☐ Moderate (>5ml and <60ml in 24 hours)	__ / __ / ____ ☐ Not known
5	☐ Massive (>240ml in 24 hours) ☐ Severe (>60ml and <240ml in 24 hours) ☐ Moderate (>5ml and <60ml in 24 hours)	__ / __ / ____ ☐ Not known

6.5 Haemoptysis scanty (≤ 5mls in 24 hours)

☐ Yes
☐ No

If yes, number of episodes ____

Chest tightness / wheezing

6.6 Acute chest tightness and/or wheezing related to medication

☐ Yes
☐ No
☐ Not known

If yes, number of episodes ____

	Date	Medication details
1	__ / __ / ____	
2	__ / __ / ____	
3	__ / __ / ____	
4	__ / __ / ____	
5	__ / __ / ____	

Cough fracture

6.7 Cough fracture

☐ Yes
☐ No

If yes, number of episodes ____

	Date	
1	__ / __ / ____	☐ Not known
2	__ / __ / ____	☐ Not known
3	__ / __ / ____	☐ Not known
4	__ / __ / ____	☐ Not known
5	__ / __ / ____	☐ Not known

Pulmonary

6.8 Pulmonary abscess

☐ Yes
☐ No

If yes, number of episodes ____ ☐ Not known

	Date	
1	__ / __ / ____	☐ Not known
2	__ / __ / ____	☐ Not known
3	__ / __ / ____	☐ Not known
4	__ / __ / ____	☐ Not known
5	__ / __ / ____	☐ Not known

Cardiac

6.9 Any cardiac complications

- ☐ Yes
- ☐ No

If yes, please tick all that apply:

- ☐ Arrhythmia (bradycardia)
- ☐ Arrhythmia (tachyarrhythmia)
- ☐ Cardiac arrest
- ☐ Cardiomyopathy
- ☐ Congenital heart disease
- ☐ Congenital heart disease
- ☐ Heart failure
- ☐ Ischaemic heart disease
- ☐ Valvular disease
- ☐ Other:

Liver / gallbladder (hepatobiliary)

6.10 Any liver/gallbladder complications (including gastrointestinal bleeds with varices as source)

- ☐ Yes
- ☐ No

If yes:

Gallbladder disease (including gallbladder stones)

- ☐ Yes
- ☐ No

Raised liver enzymes

- ☐ Yes
- ☐ No

Liver disease

- ☐ Yes
- ☐ No

6.10i If liver disease, is it cystic fibrosis related liver disease?

- ☐ Yes
- ☐ No

If yes, are there any of the following additional findings?

Hepatic steatosis (fatty liver disease)	☐ Yes	☐ No
Chronic liver disease with no cirrhosis (early fibrosis)	☐ Yes	☐ No
Cirrhosis with portal hypertension	☐ Yes	☐ No
Cirrhosis with no portal hypertension	☐ Yes	☐ No

Please specify complications relating to cirrhosis:

Gastrointestinal bleeding from varices	☐ Yes	☐ No
Oesophageal injection or banding	☐ Yes	☐ No
Hypersplenism (i.e. WBC <3.0 or platelets <100,000)	☐ Yes	☐ No
Ascites	☐ Yes	☐ No
Hepatic encephalopathy	☐ Yes	☐ No

6.10ii Acute liver complications

- ☐ Yes
- ☐ No

If yes, was it:

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

2. Acute hepatitis (ALT >5x ULN and duration of illness <6 months)
   - ☐ Yes
   - ☐ No

If yes to hepatitis:

2a. Infectious hepatitis (Hepatitis A, B, C, EBV, CMV or other known infectious disease)
- ☐ Yes
- ☐ No

2b. Drug induced liver disease
- ☐ Yes
- ☐ No

2c. Other non-infectious (autoimmune, alcohol, or other known cause)
- ☐ Yes – please specify:
- ☐ No

2d. Not known
- ☐ Yes
- ☐ No

If yes to drug induced liver disease:

2bi. Suspected drug
- ☐ Levofloxacin
- ☐ Other
- ☐ Not known

2bii. Was a liver biopsy done?
- ☐ Yes
- ☐ No

2biii. If yes, what were the results?
- ☐ Hepatitis
- ☐ Cholestatic
- ☐ Mixed
- ☐ Other:

Gut

6.11 Any gut complications
- ☐ Yes
- ☐ No

If yes, select all complications that apply:
- ☐ DIOS (distal intestinal obstruction syndrome)
- ☐ Fibrosing colonopathy / colonic stricture
- ☐ Intestinal obstruction
- ☐ Gastro-oesophageal reflux disease
- ☐ Gastrointestinal bleeding (non varices as source)
- ☐ Pancreatitis
- ☐ Peptic ulcer
- ☐ Rectal prolapse

Kidney / renal

6.12 Any kidney or renal complications (including hypertension)
- ☐ Yes
- ☐ No

If yes, select all complications that apply:
- ☐ Hypertension
- ☐ Kidney stones
- ☐ Acute kidney injury (plasma creatinine >50% of ULN for age; requiring dialysis/intensive monitoring)
- ☐ Chronic kidney disease (chronic renal failure)

Tendon

6.13 Any tendon complications

- ☐ Yes
- ☐ No

If yes:

Tendon rupture	☐ Yes	☐ No
Tendinitis	☐ Yes	☐ No
Other tendinopathy	☐ Yes	☐ No

If yes to tendon rupture:

A. Specify location of tendon rupture
- ☐ Shoulder/forearm
- ☐ Wrist/hand
- ☐ Hip/knee
- ☐ Ankle/foot – if yes: ☐ Achilles ☐ Other:
- ☐ Other:

B. Was the tendon rupture unilateral or bilateral?
- ☐ Unilateral – left
- ☐ Unilateral – right
- ☐ Bilateral

C. Treatment for tendon rupture
- ☐ NSAIDs
- ☐ Narcotics
- ☐ Other medication (please give details):
- ☐ Physiotherapy
- ☐ Injection (please specify location):
- ☐ Surgery (please specify type):

D. Date of tendon rupture __ / __ / ____

E. Tendon rupture outcome
- ☐ Resolved – please specify stop date: __ / __ / ____
- ☐ Permanent disability
- ☐ Ongoing
- ☐ Other:

ABPA (Allergic Broncho-Pulmonary Aspergillosis) / other Aspergillus disease

6.14 ABPA

ABPA (Allergic Broncho-Pulmonary Aspergillosis)	☐ Yes	☐ No
Aspergillosis bronchitis	☐ Yes	☐ No
Aspergilloma	☐ Yes	☐ No
Other	☐ Yes	☐ No

If yes to any of the above:

Highest IgE result since last annual review: ____ IU/ml ☐ Not known

Date of highest IgE result __ / __ / ____ ☐ Not known

Has patient received any active treatment for this since last annual review?

- ☐ Yes
- ☐ No

If yes, which treatment was used?

- ☐ Steroid
- ☐ Azole antifungals
- ☐ Other:
- ☐ Nebulised amphotericin
- ☐ Anti-IgE

Other complications

6.15 Any other complications

- ☐ Yes
- ☐ No

If yes, select all that apply:

- ☐ Arthritis
- ☐ Arthropathy
- ☐ Asthma
- ☐ Bone fracture
- ☐ Depression
- ☐ Hearing loss
- ☐ Intensive care unit admission
- ☐ Nasal polyps
- ☐ Osteopenia
- ☐ Osteoporosis
- ☐ Pneumothorax requiring chest drain
- ☐ Port inserted/replaced since last annual review
- ☐ Sinus disease
- ☐ Absence of vas deferens
- ☐ Other:

7. Growth and nutrition

Please ensure you have recorded all relevant prescribed medications in the chronic medication tab e.g. Ursodeoxycholic acid.

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
- ☐ Nasogastric
- ☐ Jejunal tube
- ☐ Yes, but method unknown
- ☐ Oral
- ☐ Gastrostomy
- ☐ Parenteral
- ☐ Not known

7.5 Does the patient take pancreatic enzyme supplements?

- ☐ Yes
- ☐ No
- ☐ Not known

7.6 Dose of lipase ____ iu/kg per day

- ☐ Not applicable
- ☐ Not known

7.7 Has the patient been on oestrogen/testosterone?

- ☐ Yes
- ☐ No
- ☐ Not known

8. Physiotherapy

Airway clearance

8.1 Primary airway clearance

- ☐ Active cycle of breathing techniques
- ☐ Assisted autogenic drainage
- ☐ Autogenic drainage
- ☐ Exercise
- ☐ Forced expiration
- ☐ High pressure PEP
- ☐ Incentive spirometer
- ☐ Manual in/ex-sufflation (aka cough assist)
- ☐ Manual techniques (percussion, over pressures, vibrations)
- ☐ NIV (non-invasive ventilation)
- ☐ Oscillating PEP
- ☐ PEP
- ☐ Postural drainage
- ☐ Vest
- ☐ None
- ☐ Other:

8.2 Secondary airway clearance (please select all that apply)

- ☐ Active cycle of breathing techniques
- ☐ Assisted autogenic drainage
- ☐ Autogenic drainage
- ☐ Exercise
- ☐ Forced expiration
- ☐ High pressure PEP
- ☐ Incentive spirometer
- ☐ Manual in/ex-sufflation (aka cough assist)
- ☐ Manual techniques (percussion, over pressures, vibrations)
- ☐ NIV (non-invasive ventilation)
- ☐ Oscillating PEP
- ☐ PEP
- ☐ Postural drainage
- ☐ Vest
- ☐ None
- ☐ Other:

NIV

8.3 Has non-invasive ventilation (NIV) been used since last annual review? (Not for airway clearance)

- ☐ Yes
- ☐ No
- ☐ Not known

If yes:

For respiratory failure/to relieve work of breathing/breathlessness?

- ☐ Yes, long term
- ☐ Yes, during an exacerbation only
- ☐ No
- ☐ Not known

For any other reason? If yes, please specify the reason:

- ☐ Yes, long term
- ☐ Yes, during an exacerbation only
- ☐ No
- ☐ Not known

Exercise

8.4 Has an exercise test been performed? (Please attach the results if using this form to collect clinical data)

- ☐ Yes
- ☐ No
- ☐ Not known

Please see Appendix B to view the exercise test forms.

Continence and posture

8.5 Urinary incontinence

- ☐ Yes
- ☐ No
- ☐ Not known

8.6 Faecal incontinence

- ☐ Yes
- ☐ No
- ☐ Not known

8.7 Postural anomaly

- ☐ Yes
- ☐ No
- ☐ Not known

9. Lifestyle

Smoking

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

- ☐ Yes, regularly, 1 pack a day or more
- ☐ Yes, regularly, <1 pack a day
- ☐ Yes, occasionally
- ☐ Yes, amount unknown
- ☐ No
- ☐ Not asked
- ☐ Declined to answer

9.2 Is the patient regularly exposed to second hand smoke?

- ☐ Yes
- ☐ No
- ☐ Not known

Education

9.3 Current education level of patient

- ☐ Less than GCSE
- ☐ GCSE or equivalent
- ☐ A level or equivalent
- ☐ College
- ☐ University
- ☐ Not known

Marital status

9.4 Patient's marital status

- ☐ Single, never married
- ☐ Long term partner
- ☐ Married/civil partnership
- ☐ Not known
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

Employment

9.5a What is the patient's primary employment status?

- ☐ Full time
- ☐ Part time
- ☐ Homemaker
- ☐ Student
- ☐ Unemployed
- ☐ Disabled
- ☐ Retired
- ☐ Voluntary work
- ☐ Not known

9.5b Does the patient have a secondary employment status?

- ☐ Full time
- ☐ Part time
- ☐ Homemaker
- ☐ Student
- ☐ Unemployed
- ☐ Disabled
- ☐ Retired
- ☐ Voluntary work
- ☐ No – not applicable

Parenthood

9.6a Since the last annual review, has the patient or their partner been pregnant?

- ☐ Yes
- ☐ No
- ☐ Not known

If yes:

9.6b Was the conception via IVF?

- ☐ Yes
- ☐ No
- ☐ Not known

9.6c What was the outcome of the pregnancy?

- ☐ Live birth — Gestational age: ____ weeks
- ☐ Spontaneous abortion
- ☐ Stillbirth — Gestational age: ____ weeks
- ☐ Therapeutic abortion
- ☐ Undelivered
- ☐ Not known

9.6e Congenital abnormality?

- ☐ Yes
- ☐ No

10. Outcome

Death

10.1 Has the patient died?

- ☐ Yes
- ☐ No

If yes:

Date of death __ / __ / ____

Is date of death an estimate?

- ☐ Yes
- ☐ No

Cause of death

- ☐ Cancer
- ☐ Liver disease or failure
- ☐ Respiratory or cardiorespiratory
- ☐ Suicide
- ☐ Transplantation related
- ☐ Trauma
- ☐ Other:
- ☐ Not known

If cancer, please specify type:

- ☐ Bowel
- ☐ Brain
- ☐ Breast
- ☐ Liver
- ☐ Lung
- ☐ Lymphoma
- ☐ Pancreatic
- ☐ Skin
- ☐ Testicular
- ☐ Other:

Diagnosis reversal

10.2 Diagnosis reversed?

- ☐ Yes
- ☐ No

If yes:

Diagnosis reversal date __ / __ / ____

Reason for reversal of diagnosis:

- ☐ DNA analysis
- ☐ Repeat normal sweat testing
- ☐ Transepithelial potential differences
- ☐ Other:
- ☐ Not known

Transplant journey

10.3i Does the CF MDT consider the patient sick enough to warrant transplant referral?

- ☐ Yes
- ☐ No

If yes, has this patient been offered evaluation for transplant?

- ☐ Yes
- ☐ No – clinically not suitable
- ☐ No – patient declined evaluation

If yes, transplant type offered evaluation for:

- ☐ Lung
- ☐ Liver
- ☐ Other:

Has the patient been evaluated for transplant?

- ☐ Yes
- ☐ No
- ☐ Waiting for first evaluation

If yes, what was the outcome of the transplant evaluation?

- ☐ Accepted
- ☐ Deferred
- ☐ Declined
- ☐ Awaiting decision from transplant team

If accepted:

Date placed onto active transplant waiting list __ / __ / ____

Was the patient removed from the active transplant waiting list?

- ☐ Yes
- ☐ No

If yes:

Date removed from active transplant waiting list __ / __ / ____

Reason for leaving waiting list

- ☐ Patient decision
- ☐ Clinical status improved
- ☐ Clinical status declined

10.3ii Received transplant?

- ☐ Yes
- ☐ No

If yes:

Transplant date __ / __ / ____

Transplant centre

- ☐ Addenbrooke's Hospital, Cambridge
- ☐ Edinburgh Royal Infirmary, Edinburgh
- ☐ Freeman Hospital, Newcastle
- ☐ Great Ormond Street Hospital, London
- ☐ Harefield Hospital, London
- ☐ Nottingham City Hospital, Nottingham
- ☐ Papworth Hospital, Cambridge
- ☐ Queen Elizabeth Hospital, Birmingham
- ☐ Royal Free Hospital, London
- ☐ St James' University Hospital, Leeds
- ☐ Wythenshawe Hospital, Manchester
- ☐ Other:

Transplant type(s):

- ☐ Bilateral lung
- ☐ Heart and lung
- ☐ Lobe from cadaver
- ☐ Lobe from living donor
- ☐ Liver
- ☐ Other:

10.3iii Within 12 months of surgery, select any complications suffered:

- ☐ None
- ☐ Bronchiolitis obliterans
- ☐ Lymphoproliferative disorder
- ☐ Renal failure
- ☐ Atypical infection
- ☐ Other:
- ☐ Unknown

Appendix A – CFQ-R

A1 – CFQ-R domain scores

Please enter the scores (0-100) for each of the CFQ-R domains. You can learn more, and calculate the scores, by navigating to an external website **here**. Alternatively, you can fill in the relevant questionnaire and the domain scores will be calculated upon completion.

You can enter multiple CFQ-R surveys per year, which can also be viewed, edited or created via the patient's 'Demographics' section from the Patient Management screen.

1	Physical	_____	☐ Not available
2	Vitality	_____	☐ Not available
3	Emotion	_____	☐ Not available
4	Eat	_____	☐ Not available
5	Treat	_____	☐ Not available
6	Health	_____	☐ Not available
7	Social	_____	☐ Not available
8	Body	_____	☐ Not available
9	Role	_____	☐ Not available
10	Weight	_____	☐ Not available
11	Respiratory	_____	☐ Not available
12	Digestive	_____	☐ Not available
13	School	_____	☐ Not available

A2 – CFQ-R questionnaire for adolescents / adults (age 14 and over)

Understanding the impact of your illness and treatments on your everyday life can help your healthcare team keep track of your health and adjust your treatments. For this reason, this questionnaire was specifically developed for people who have cystic fibrosis. Thank you for your willingness to complete this form.

The following questions are about the current state of your health, as you perceive it. This information will allow us to better understand how you feel in your everyday life. Please answer all the questions. There are no right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your situation.

Section I. Demographics

A What is your date of birth? __ / __ / ____

B What is your gender?

- ☐ Male
- ☐ Female

C During the past two weeks, have you been on holiday or out of school or work for reasons NOT related to your health?

- ☐ Yes
- ☐ No

D What is your current marital status?

- ☐ Single/never married
- ☐ Married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Remarried
- ☐ With a partner

E Which of the following best describes your racial background?

- ☐ White (British)
- ☐ White (Irish)
- ☐ White (Other)
- ☐ Mixed (White and Black Caribbean)
- ☐ Mixed (White and Black African)
- ☐ Mixed (White and Asian)
- ☐ Mixed (Other)
- ☐ Other (Chinese)
- ☐ Prefer not to say
- ☐ Black (Caribbean)
- ☐ Black (African)
- ☐ Black (Other)
- ☐ Asian (Indian)
- ☐ Asian (Pakistani)
- ☐ Asian (Bangladeshi)
- ☐ Asian (Other)
- ☐ Other (Any other ethnic group)
- ☐ Not known

F What is the highest level of education you have completed?

- ☐ Some secondary school or less
- ☐ GCSEs/ O-levels
- ☐ A/AS-levels
- ☐ Other higher education
- ☐ University degree
- ☐ Professional qualification or post-graduate study

G Which of the following best describes your current work or school status?

- ☐ Attending school outside the home
- ☐ Taking educational courses at home
- ☐ Seeking work
- ☐ Working full or part time (either outside the home or at a home-based business)
- ☐ Full time homemaker
- ☐ Not attending school or working due to my health
- ☐ Not working for other reasons

Section II. Quality of Life

During the past two weeks, to what extent have you had difficulty:

1 Performing vigorous activities such as running or playing sports

- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

2 Walking as fast as others

- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

3 Carrying or lifting heavy things such as books, shopping, or school bags

- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

4 Climbing one flight of stairs

- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

5 Climbing stairs as fast as others
- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

During the past two weeks, indicate how often:

6 You felt well
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

7 You felt worried
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

8 You felt useless
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

9 You felt tired
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

10 You felt full of energy
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

11 You felt exhausted
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

12 You felt sad
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

Thinking about the state of your health over the last two weeks:

13 To what extent do you have difficulty walking?
- ☐ You can walk a long time without getting tired
- ☐ You can walk a long time but you get tired
- ☐ You cannot walk a long time because you get tired quickly
- ☐ You avoid walking whenever possible because it's too tiring for you

14 How do you feel about eating?
- ☐ Just thinking about food makes you feel sick
- ☐ You never enjoy eating
- ☐ You are sometimes able to enjoy eating
- ☐ You are always able to enjoy eating

15 To what extent do your treatments make your daily life more difficult?
- ☐ Not at all
- ☐ A little
- ☐ Moderately
- ☐ A lot

16 How much time do you currently spend each day on your treatments?
- ☐ A lot
- ☐ Some
- ☐ A little
- ☐ Not very much

17 How difficult is it for you to do your treatments (including medications) each day?
- ☐ Not at all
- ☐ A little
- ☐ Moderately
- ☐ Very

18 How do you think your health is now?
- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

Thinking about your health during the last two weeks, indicate the extent to which each sentence is true or false for you:

19 I have trouble recovering after physical effort
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

20 I have to limit vigorous activities such as running or playing sports
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

21 I have to force myself to eat
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

22 I have to stay at home more than I want to
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

23 I feel comfortable discussing my illness with others
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

24 I think I am too thin
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

25 I think I look different from others my age
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

26 I feel bad about my physical appearance
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

27 People are afraid that I may be contagious
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

28 I get together with my friends a lot
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

29 I think my coughing bothers others
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

30 I feel comfortable going out at night
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

31 I often feel lonely
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

32 I feel healthy
- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

33 It is difficult to make plans for the future (for example, going to college, getting married, getting promoted at work, etc.)

- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

34 I lead a normal life

- ☐ Very true
- ☐ Somewhat true
- ☐ Somewhat false
- ☐ Very false

Section III. School, Work, or Daily Activities

35 To what extent did you have trouble keeping up with your schoolwork, professional work, or other daily activities during the past two weeks?

- ☐ You have had no trouble keeping up
- ☐ You have managed to keep up but it's been difficult
- ☐ You have been behind
- ☐ You have not been able to do these activities at all

36 How often were you absent from school, work, or unable to complete daily activities during the last two weeks because of your illness or treatments?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

37 How often does CF get in the way of meeting your school, work, or personal goals?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

38 How often does CF interfere with getting out of the house to run errands such as shopping or going to the bank?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

Section IV. Symptom Difficulties

Indicate how you have been feeling during the past two weeks:

39 Have you had trouble gaining weight?
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

40 Have you been congested?
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

41 Have you been coughing during the day?
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

42 Have you had to cough up mucus?
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

43 Has your mucus been mostly:
- ☐ Clear
- ☐ Clear to yellow
- ☐ Yellowish-green
- ☐ Green with traces of blood
- ☐ Don’t know

How often in the past two weeks:

44 Have you been wheezing?
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

45 Have you had trouble breathing?
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

46 Have you woken up during the night because you were coughing?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

47 Have you had problems with wind?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

48 Have you had diarrhoea?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

49 Have you had abdominal pain?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

50 Have you had eating problems?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

A3 – CFQ-R questionnaire for 12-13 year olds (self-report format)

These questions are for children like you who have cystic fibrosis. Your answers will help us understand what this disease is like and how your treatments help you. So, answering these questions will help you and others like you in the future.

Please answer all the questions. There are no right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your situation.

A What is your date of birth? __ / __ / ____

B Are you…
- ☐ Male
- ☐ Female

C During the past two weeks, have you been on holiday or out of school for reasons NOT related to your health?
- ☐ Yes
- ☐ No

D Which of the following best describes your racial background?
- ☐ White (British)
- ☐ White (Irish)
- ☐ White (Other)
- ☐ Mixed (White and Black Caribbean)
- ☐ Mixed (White and Black African)
- ☐ Mixed (White and Asian)
- ☐ Mixed (Other)
- ☐ Other (Chinese)
- ☐ Prefer not to say
- ☐ Black (Caribbean)
- ☐ Black (African)
- ☐ Black (Other)
- ☐ Asian (Indian)
- ☐ Asian (Pakistani)
- ☐ Asian (Bangladeshi)
- ☐ Asian (Other)
- ☐ Other (Any other ethnic group)
- ☐ Not known

E What year are you in now at school? If it's summer, the year you just finished.
- ☐ Reception
- ☐ Year 1
- ☐ Year 2
- ☐ Year 3
- ☐ Year 4
- ☐ Year 5
- ☐ Year 6
- ☐ Year 7
- ☐ Not in school

In the past two weeks:

1 You were able to walk as fast as others
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

2 You were able to climb stairs as fast as others
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

3 You were able to run, jump and climb as you wanted
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

4 You were able to run as quickly and for as long as others
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

5 You were able to participate in sports that you enjoy (e.g., swimming, football, dancing or others)
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

6 You had difficulty carrying or lifting heavy things such as books, your school bag, or a rucksack
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

And during these past two weeks, indicate how often:

7 You felt tired
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

8 You felt mad
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

9 You felt grouchy
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

10 You felt worried
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

11 You felt sad
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

12 You had trouble falling asleep
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

13 You had bad dreams or nightmares
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

14 You felt good about yourself
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

15 You had trouble eating
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

And during these past two weeks, indicate how often:

16 You had to stop fun activities to do your treatments
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

17 You were forced to eat
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

During the past two weeks:

18 You were able to do all of your treatments
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

19 You enjoyed eating
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

20 You got together with friends a lot
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

21 You stayed at home more than you wanted to

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

22 You felt comfortable sleeping away from home (at a friend or family member's house or elsewhere)

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

23 You felt left out

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

24 You often invited friends to your house

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

25 You were teased by other children

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

26 You felt comfortable discussing your illness with others (friends, teachers)

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

27 You thought you were too short

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

28 You thought you were too thin
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

29 You thought you were physically different from others your age
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

30 Doing your treatments bothered you
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

Let us know how often in the past two weeks:

31 You coughed during the day
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

32 You woke up during the night because you were coughing
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

33 You had to cough up mucus
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

34 You had trouble breathing
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

35 Your stomach hurt

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

A4 – CFQ-R questionnaire for 6-13 year olds (completed by parent/carer)

Understanding the impact of your child's illness and treatments on his or her everyday life can help your healthcare team keep track of your child's health and adjust his or her treatments. For this reason, we have developed a quality of life questionnaire specifically for parents of children with cystic fibrosis. We thank you for your willingness to complete this questionnaire.

Instructions: The following questions are about the current state of your child's health, as he or she perceives it. This information will allow us to better understand how he or she feels in everyday life.

Please answer all the questions. There are no right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your child's situation.

Section I. Demographics

A What is your child's date of birth? __ / __ / ____

B What is your relationship to the child?

- ☐ Mother
- ☐ Father
- ☐ Grandmother
- ☐ Grandfather
- ☐ Other (please describe):
- ☐ Other relative
- ☐ Foster mother
- ☐ Foster father

C Which of the following best describes your child's racial background?

- ☐ White (British)
- ☐ White (Irish)
- ☐ White (Other)
- ☐ Mixed (White and Black Caribbean)
- ☐ Mixed (White and Black African)
- ☐ Mixed (White and Asian)
- ☐ Mixed (Other)
- ☐ Other (Chinese)
- ☐ Prefer not to say
- ☐ Black (Caribbean)
- ☐ Black (African)
- ☐ Black (Other)
- ☐ Asian (Indian)
- ☐ Asian (Pakistani)
- ☐ Asian (Bangladeshi)
- ☐ Asian (Other)
- ☐ Other (Any other ethnic group)
- ☐ Not known

D During the past two weeks, has your child been on holiday or out of school for reasons NOT related to their health?

- ☐ Yes
- ☐ No

Section II. Quality of Life

To what extent has your child had difficulty:

1 Performing vigorous activities such as running or playing sports
- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

2 Walking as fast as others
- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

3 Climbing stairs as fast as others
- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

4 Carrying or lifting heavy objects such as books, a school bag, or rucksack
- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

5 Climbing several flights of stairs
- ☐ A lot of difficulty
- ☐ Some difficulty
- ☐ A little difficulty
- ☐ No difficulty

During the past two weeks, indicate how often your child:

6 Seemed happy
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

7 Seemed worried
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

8 Seemed tired
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

9 Seemed short-tempered
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

10 Seemed well
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

11 Seemed grouchy
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

12 Seemed full of energy
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

13 Was absent or late for school or other activities because of his/her illness or treatments
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

Thinking about the state of your child's health over the past two weeks, indicate:

14 The extent to which your child participated in sports and other physical activities, such as P.E. (physical education)

- ☐ Has not participated in physical activities
- ☐ Has participated less than usual in sports
- ☐ Has participated as much as usual but with some difficulty
- ☐ Has been able to participate in physical activities without any difficulty

15 The extent to which your child has difficulty walking

- ☐ He or she can walk a long time without getting tired
- ☐ He or she can walk a long time but gets tired
- ☐ He or she cannot walk a long time, because he or she gets tired quickly
- ☐ He or she avoids walking whenever possible, because it's too tiring for him or her

Thinking about your child's state of health during the past two weeks, indicate the extent to which each sentence is true or false for your child:

16 My child has trouble recovering after physical effort

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

17 Mealtimes are a struggle

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

18 My child's treatments get in the way of his/her activities

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

19 My child feels small compared to other kids the same age

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

20 My child feels physically different from other kids the same age
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

21 My child thinks that he/she is too thin
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

22 My child feels healthy
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

23 My child tends to be withdrawn
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

24 My child leads a normal life
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

25 My child has less fun than usual
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

26 My child has trouble getting along with others
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

27 My child has trouble concentrating
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

28 My child is able to keep up with his/her school work or holiday activities
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

29 My child is not doing as well as usual in school or holiday activities
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

30 My child spends a lot of time on his/her treatments everyday
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

31 How difficult is it for your child to do his/her treatments (including medications) each day?
- ☐ Not at all
- ☐ A little
- ☐ Moderately
- ☐ Very

32 How do you think your child's health is now?
- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

Section III. Symptom Difficulties

The next set of questions is designed to determine the frequency with which your child has certain respiratory difficulties, such as coughing or shortness of breath.

Please indicate how your child has been feeling during the past two weeks:

33 My child had trouble gaining weight
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

34 My child was congested
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

35 My child coughed during the day
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

36 My child had to cough up mucus
- ☐ A great deal
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

37 My child's mucus has been mostly:
- ☐ Clear
- ☐ Clear to yellow
- ☐ Yellowish-green
- ☐ Green with traces of blood
- ☐ Don’t know

During the past two weeks:

38 My child wheezed
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

39 My child had trouble breathing
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

40 My child woke up during the night because he/she was coughing
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

41 My child had wind
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

42 My child had diarrhoea
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

43 My child had abdominal pain
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

44 My child has had eating problems
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

A5 – CFQ-R questionnaire for 6-11 year olds (interviewer format)

This questionnaire is formatted for use by an interviewer. Please use this format for younger children. For older children who seem able to read and answer the questions on their own, such as 12 and 13 year olds, use this questionnaire in its self-report format.

There are directions for the interviewer for each section of the questionnaire. Directions that you should read to the child are indicated by quotation marks. Directions that you are to follow are underlined and set in italics.

Interviewer: *Please ask the following questions*

A What is your date of birth? __ / __ / ____

B Are you…
- ☐ Male
- ☐ Female

C During the past two weeks, have you been on holiday or out of school for reasons NOT related to your health?
- ☐ Yes
- ☐ No

D Which of the following best describes your racial background?
- ☐ White (British)
- ☐ White (Irish)
- ☐ White (Other)
- ☐ Mixed (White and Black Caribbean)
- ☐ Mixed (White and Black African)
- ☐ Mixed (White and Asian)
- ☐ Mixed (Other)
- ☐ Other (Chinese)
- ☐ Prefer not to say
- ☐ Black (Caribbean)
- ☐ Black (African)
- ☐ Black (Other)
- ☐ Asian (Indian)
- ☐ Asian (Pakistani)
- ☐ Asian (Bangladeshi)
- ☐ Asian (Other)
- ☐ Other (Any other ethnic group)
- ☐ Not known

E What year are you in now at school? If it's summer, the year you just finished.
- ☐ Reception
- ☐ Year 1
- ☐ Year 2
- ☐ Year 3
- ☐ Year 4
- ☐ Year 5
- ☐ Year 6
- ☐ Year 7
- ☐ Not in school

Interviewer: *Please read the following to the child:*

"These questions are for children like you who have cystic fibrosis. Your answers will help us understand what this disease is like and how your treatments help you. So, answering these questions will help you and others like you in the future."

"For each question that I ask, choose one of the answers on the cards I'm about to show you."

Present the orange card to the child.

"Look at this card and read with me what it says: **very true, mostly true, somewhat true, not at all true**."

"Here's an example: If I asked you if it is **very true, mostly true, somewhat true, not at all true** that elephants can fly, which one of the four answers on the card would you choose?"

Present the blue card to the child.

"Now, look at this card and read with me what it says: **always / often / sometimes / never**."

"Here's another example: If I asked you if you go to the moon **always, often, sometimes, or never**, which answer on the card would you choose?"

Present the orange card to the child.

"Now, I will ask you some questions about your everyday life."

"**Tell me if you find the statements I read to you to be** very true, mostly true, somewhat true, or not at all true."

Please tick the box indicating the child's response.

During the past **two weeks**:

1 You were able to walk as fast as others

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

2 You were able to climb stairs as fast as others
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

3 You were able to run, jump and climb as you wanted
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

4 You were able to run as quickly and for as long as others
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

5 You were able to participate in sports that you enjoy (e.g., swimming, football, dancing or others)
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

6 You had difficulty carrying or lifting heavy things such as books, your school bag, or a rucksack
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

Interviewer: *Present the blue card to the child.*

Please tick the box indicating the child's response.

And during these past **two weeks**, tell me how often:

7 You felt tired
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

8 You felt mad
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

9 You felt grouchy
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

10 You felt worried
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

11 You felt sad
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

12 You had trouble falling asleep
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

13 You had bad dreams or nightmares
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

14 You felt good about yourself
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

15 You had trouble eating
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

16 You had to stop fun activities to do your treatments
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

17 You were forced to eat
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

Interviewer: *Present the orange card to the child.*

"**Now tell me if you find the statements I read to you to be** very true, mostly true, somewhat true, or not at all true."

During the past **two weeks**:

18 You were able to do all of your treatments
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

19 You enjoyed eating
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

20 You got together with friends a lot
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

21 You stayed at home more than you wanted to

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

22 You felt comfortable sleeping away from home (at a friend or family member's house or elsewhere)

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

During the past **two weeks**:

23 You felt left out

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

24 You often invited friends to your house

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

25 You were teased by other children

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

26 You felt comfortable discussing your illness with others (friends, teachers)

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

27 You thought you were too short

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

28 You thought you were too thin
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

29 You thought you were physically different from others your age
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

30 Doing your treatments bothered you
- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ Not at all true

Interviewer: *Present the blue card to the child again*

Tell me how often in the past **two weeks**:

31 You coughed during the day
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

32 You woke up during the night because you were coughing
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

33 You had to cough up mucus
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

34 You had trouble breathing
- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

35 Your stomach hurt

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Never

Appendix B – exercise tests

B1 – shuttle test

Test date __ / __ / ____

Level achieved ____ ☐ Not known

Additional distance achieved ____ metres ☐ Not known

Heart rate

a. Maximal heart rate ____ beats per minute ☐ Not known

b. Resting heart rate ____ beats per minute ☐ Not known

O2 saturation

a. O2 saturations (resting/baseline) ____% ☐ Not known

b. O2 saturations (lowest) ____% ☐ Not known

Recovery time ____ minutes ☐ Not known

Supplemental O2 required? ☐ Yes ☐ No ☐ Not known

BORG scale ☐ 0-10 scale ☐ 6-20 scale ☐ Not done

0-10 scale:

a. Modified BORG (0-10) – baseline

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

b. Modified BORG (0-10) – maximal

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

6-20 scale:

a. BORG (6-20) – baseline

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

b. BORG (6-20) – maximal

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

B2 – 6 minute walk test

Test date __ / __ / ____

Distance achieved ____ metres ☐ Not known

Heart rate

a. Maximal heart rate ____ beats per minute ☐ Not known

b. Resting heart rate ____ beats per minute ☐ Not known

O2 saturation

a. O2 saturations (resting/baseline) ____% ☐ Not known

b. O2 saturations (lowest) ____% ☐ Not known

Recovery time ____ minutes ☐ Not known

BORG scale ☐ 0-10 scale ☐ 6-20 scale ☐ Not done

0-10 scale:

a. Modified BORG (0-10) – baseline

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

b. Modified BORG (0-10) – maximal

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

6-20 scale:

a. BORG (6-20) – baseline

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

b. BORG (6-20) – maximal

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

B3 – step test

Test date __ / __ / ____

Level achieved ____ ☐ Not known

Heart rate

a. Maximal heart rate ____ beats per minute ☐ Not known

b. Resting heart rate ____ beats per minute ☐ Not known

O2 saturation

a. O2 saturations (resting/baseline) ____% ☐ Not known

b. O2 saturations (lowest) ____% ☐ Not known

Recovery time ____ minutes ☐ Not known

BORG scale ☐ 0-10 scale ☐ 6-20 scale ☐ Not done

0-10 scale:

a. Modified BORG (0-10) – baseline

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

b. Modified BORG (0-10) – maximal

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

6-20 scale:

a. BORG (6-20) – baseline

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

b. BORG (6-20) – maximal

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

B4 – CPET

Test date __ / __ / ____

CPET method used ☐ Bike ☐ Treadmill

VO2 tests

a. Absolute VO2max/peak ____ l/min ☐ Not known

b. Relative VO2max/peak ____ ml/kg/min ☐ Not known

c. Peak power output (bike) ____ watts ☐ Not known

d. Anaerobic threshold ____ %VO2max ☐ Not known

O2 saturation

a. O2 saturations (resting/baseline) ____% ☐ Not known

b. O2 saturations (lowest) ____% ☐ Not known

Recovery time ____ minutes ☐ Not known

BORG scale ☐ 0-10 scale ☐ 6-20 scale ☐ Not done

0-10 scale:

a. Modified BORG (0-10) – baseline

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

b. Modified BORG (0-10) – maximal

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

6-20 scale:

a. BORG (6-20) – baseline

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

b. BORG (6-20) – maximal

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

B5 – other exercise test

Test date __ / __ / ____

Please give details of test:

VO2 tests

a. Absolute VO2max/peak ____ l/min ☐ Not known

O2 saturation

a. O2 saturations (resting/baseline) ____% ☐ Not known

b. O2 saturations (lowest) ____% ☐ Not known

Recovery time ____ minutes ☐ Not known

BORG scale ☐ 0-10 scale ☐ 6-20 scale ☐ Not done

0-10 scale:

a. Modified BORG (0-10) – baseline

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

b. Modified BORG (0-10) – maximal

☐ 0 – nothing at all
☐ 0.5 – very, very slight (just noticeable)
☐ 1 – very slight
☐ 2 – slight
☐ 3 – moderate
☐ 4 – somewhat severe
☐ 5 – severe
☐ 6
☐ 7 – very severe
☐ 8
☐ 9 – very, very severe (almost maximal)
☐ 10 – maximal

6-20 scale:

a. BORG (6-20) – baseline

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion

b. BORG (6-20) – maximal

- ☐ 6 – no exertion at all
- ☐ 7 – extremely light
- ☐ 8
- ☐ 9 – very light
- ☐ 10
- ☐ 11 – light
- ☐ 12
- ☐ 13 – somewhat hard
- ☐ 14
- ☐ 15 – hard
- ☐ 16
- ☐ 17 – very hard
- ☐ 18
- ☐ 19 – extremely hard
- ☐ 20 – maximal exertion