CFRI
The Cystic Fibrosis Registry of Ireland

WOODVIEW HOUSE, UCD-Belfield, Dublin 4, D04 V1W8, Ireland
Phone: +353 1 716 3177 Fax: +353 1 716 3186
Web: www.cfri.ie Email: info@cfri.ie
Charity Number: CRA 20065638 CHY 22249
Company Number: 635291

# CONFIDENTIAL – PROPERTY OF CFRI CLG

# CFRI VARIABLE LIST – VERSION 3.2

**24/07/2023**

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Contents

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| | 1. ENROLMENT FORM | Notes |
|---|---|---|
| | CFRI ID | Auto-generated number |
| | Date enrolled | DD/MM/YYYY. Auto-generated. |
| | First name | Text |
| | Last name | Text |
| | Date of birth | DD/MM/YYYY |
| | Sex | Male/female |
| | Label for patient record | Text. Auto-populated. |
| | Patient consented to inclusion in CFRI | Yes/No |
| | Date consent refused | DD/MM/YYYY |
| | CFRI CLG consent (& assent) form(s) signed? | Yes/Not yet |
| | Informed consent provided by | Self/Other |
| | Date of written informed consent | DD/MM/YYYY |
| | Date consent received by CFRI | DD/MM/YYYY |
| | Assent | Yes/No |

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| 2. CORE DATA FORM | | Notes |
|---|---|---|
| 2.1 | **Demography** | |
| 2.1.1 | *Patient status* | |
| | Patient status | Alive/deceased/lost to follow-up/discharged from CFSPID follow-up. |
| | Is the patient dead? | Yes/no |
| | Date of death | DD/MM/YYYY |
| | Age of death | DD/MM/YYYY |
| | Cause of death | Respiratory/Cardiorespiratory<br>Liver disease/liver Failure<br>Other CF-related (please specify)<br>Transplant related<br>Trauma<br>Suicide<br>Cancer<br>Non-CF related (please specify)<br>Missing, variable not collected yet |
| | Place of death | |
| | Is the patient lost to follow-up? | Yes/no |
| | Date of lost to follow-up | DD/MM/YYYY. Auto-generate with date of last encounter. |
| | Cause of lost to follow-up | Emigrated<br>Poor attendance<br>Other<br>Missing, variable not collected yet |
| | Has the patient been discharged? | Yes/no |
| | Date of discharge? | DD/MM/YYYY |
| 2.1.2 | *Patient's identity* | |
| | CFRI registry ID | Auto-generated |
| | Individual Health Identifier (IHI) | Text |
| | Sex | Male/female. Auto-generated from enrolment form |
| | Date of birth | DD/MM/YYYY. Auto-generated from enrolment form |
| | Previous name (if different) | Text |
| | Country of birth | Dropdown: all country list |
| 2.1.3 | *Address* | |
| | Address | Text |
| | City/town | Text |
| | County | Dropdown: all Irish county list |
| | Eircode | Text |
| 2.1.4 | *Ethnicity* | Dropdown:<br><br>White Irish<br>White Irish Traveller<br>Other White Background<br>Black Irish<br>Black African<br>Other Black Background<br>Pakistani<br>Indian<br>Chinese |

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| | | Other (please specify |
|---|---|---|
| 2.2 | **CFRI consent** | |
| 2.2.1 | *Consent & assent* | |
| | Consent form signed? | Consent given<br>Consent refused<br>Consent Withdrawn |
| | Reason for refusal | Text |
| | Informed consent provided by | Self/other |
| | Date of written informed consent | DD/MM/YYYY |
| | Date consent received by CFRI | DD/MM/YYYY |
| | Assent | Yes/no |
| 2.2.2 | *CFRI re-consent* | |
| | *Re-consent due-date | DD/MM/YYYY |
| | Re-consent form signed | Not yet<br>Consent given |
| | Date of written informed re-consent | DD/MM/YYYY |
| | Reason for re-consent refusal | Text |
| | Reason for consent withdrawal | Text |
| 2.3.4 | *Medical care* | |
| | Current CF centre | Dropdown: all Irish CF centres list. Will auto-generate when patient is enrolled & change is patient is transferred. |
| | Medical record number (MRN) | Text |
| | Date chart last reviewed | DD/MM/YYYY |
| | Does the patient attend another hospital? | Yes/no. Auto-generated from share/transfer tab. |
| | Other hospital name | Auto-generated from share/transfer tab. |
| | Medical record number (MRN) (other hospital | Text |

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| | 3. DIAGNOSTIC FORM | Notes |
|---|---|---|
| 3.1 | **Diagnosis** | |
| | Diagnosis confirmed? | CF<br>CFSPID<br>CF diagnosis reversed |
| | Date of CF diagnosis | DD/MM/YYYY |
| | Age at CF diagnosis | Auto-generated |
| | Date of CFSPID diagnosis | DD/MM/YYYY |
| | Age at CFSPID diagnosis | Auto-generated |
| 3.1.1 | *New-born bloodspot screening* | |
| | New-born bloodspot screening | Yes<br>Not done<br>Unknown<br>Performed, results positive<br>Performed, results negative<br>Performed, results unknown |
| | Date of new-born screening | DD/MM/YYYY |
| | IRT concentration | Numeric (up to 2 decimal places) |
| 3..1.2 | *Sweat test* | |
| | Sweat test taken? | Yes<br>Not done<br>Unknown |
| | Hospital sweat test performed | Dropdown: all Irish CF centres list. |
| | Date of sweat test | DD/MM/YYYY |
| | Sweat conductivity | Numeric (up to 2 decimal places) |
| * | Chloride concentration | Numeric (up to 2 decimal places) |
| | Sodium concentration | Numeric (up to 2 decimal places) |
| 3.1.3 | *Nasal Potential Difference (NPD)* | |
| | Trans-epithelial NPD done? | No<br>Yes<br>Unknown<br>Missing, variable not collected yet |
| | Date of NPD test | DD/MM/YYYY |
| | NPD value | Numeric (up to 2 decimal places) |
| 3.1.4 | *Intestinal Current Measurement* | |
| | Has ICM been taken? | No<br>Yes<br>Unknown<br>Missing, variable not collected yet |
| | Date of ICM | DD/MM/YYYY |
| | CF-typical ICM value | No<br>Yes<br>Unknown<br>Indeterminate |
| 3.2 | **CFTR Genotype** | |
| | Has patient been genotyped? | No<br>Yes<br>Missing (variable not collected) |
| 3.2.1 | *Mutation 1* | |
| | Date of first mutation reported | DD/MM/YYYY |

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| | | |
|---|---|---|
| | *First mutation | Dropdown: ECFS CFTR2 list.<br>If other please specify |
| | Poly-T tract | 5T<br>7T<br>9T<br>Other (please specify if Other)<br>Unknown |
| | Polymorphic TG repeat | TG9<br>TG10<br>TG11<br>TG12<br>TG13<br>Other (please specify if Other)<br>Unknown |
| 3.2.2 | *Mutation 2* | |
| | Date of second mutation reported | DD/MM/YYYY |
| | *Second mutation | Dropdown: ECFS CFTR2 list.<br>If other please specify |
| | Poly-T tract | 5T<br>7T<br>9T<br>Other (please specify if Other)<br>Unknown |
| | *Polymorphic TG repeat | TG9<br>TG10<br>TG11<br>TG12<br>TG13<br>Other (please specify if Other)<br>Unknown |
| 3.3 | **CF History** | |
| | Diagnosis suggested by the following clinical sign/symptom(s) at first of CF work-up (select all that apply)<br>*Below options will be available when symptom(s) selected* | Newborn screening (auto-filled from CF diagnosis)<br>Family history<br>Meconium ileus<br>Sinopulmonary disease<br>Gastrointestinal and Nutritional abnormalities<br>Other |
| | Family history | Text |
| | Meconium ileus | Meconium Ileus managed medically<br>Meconium Ileus needing surgery<br>Meconium Ileus unknown if operated<br>Other neonatal intestinal and/or bowel obstruction<br>if Yes, please specify |
| | Sinopulmonary disease | Acute respiratory infection/ Persistent lower respiratory symptom<br>Digital Clubbing<br>Sinus Disease and/or Nasal polyps<br>Other (please specify) |
| | Gastrointestinal and nutritional abnormalities | Diabetes mellitus<br>Edema and/or hypoproteinemia/hypoalbuminemia<br>Failure to thrive and/or malnutrition<br>Hepato-Biliary Disease<br>Pancreatitis (Not explained by other etiologies)<br>Prolonged jaundice<br>Rectal prolapse |

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| | | |
|---|---|---|
| | | Steattorrhoea and/or abnormal stools and/or malabsorption<br>Other |
| | Other | Prenatal Screening (CVS, Amino)<br>CBAVD (Absent vas deferens) or related abnormalities<br>Delayed puberty<br>Electrolyte imbalance/dehydration<br>Infertility/GU abnormalities<br>Other symptom(s) |

| **4. TRANSPLANT STATUS FORM** | | Notes |
|---|---|---|
| | Current transplant status | Not referred for transplant<br>Referred, waiting for assessment<br>Assessed, waiting for decision<br>Decision made, unsuitable<br>Decision made, on active list<br>Patient refused to consider transplant<br>Patient removed from transplant list<br>Transplant |
| 4.1 | **Transplant history** | |
| | Date of transplant | DD/MM/YYYY |
| | Type of transplant received | Double lung<br>Unilateral lung<br>Heart & Lung<br>Lobes<br>Liver<br>Kidney<br>Pancreas<br>Other (please specify) |
| | Comment | Text |

| **5. FOR CFRI OFFICIAL USE ONLY** | | Notes |
|---|---|---|
| | Comments | Text |

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| 6. | **ENCOUNTER FORM** | Notes |
|---|---|---|
| 6.1 | **Encounter data** | |
| 6.1.1 | *Encounter visit date* | |
| | Date of encounter | DD/MM/YYYY |
| | Type of encounter | Routine CF Review<br>Drop-in Visit<br>Annual Review<br>Virtual Encounter<br>Other type of visit (please specify) |
| 6.1.2 | *Team review history* | |
| | Patient seen by CF consultant (or doctor) at this visit | Yes/no |
| | Patient seen by CF nurse at this visit | Yes/no |
| | Patient seen by a dietitian/nutritionist at this visit | Yes/no |
| | Patient seen by a physiotherapist at this visit | Yes/no |
| | Patient seen by a social worker at this visit | Yes/no |
| | Patient seen by a psychologist at this visit | Yes/no |

| 7. | **ANTHROPOMETRY FORM** | Notes |
|---|---|---|
| | Height (cm) | Numeric (no decimals) |
| | Height centile, height Z-score | Auto-calculated |
| | Weight (kg) | Numeric (up to 1 decimal place) |
| | Weight centile, weight Z-score | Auto-calculated |
| | BMI | Auto-calculated |
| | BMI centile, BMI Z-score | Auto-calculated |

| 8. | **SPIROMETRY FORM** | Notes |
|---|---|---|
| 8.1 | **Today's PFTs** | *(If multiple tests taken, record maximum test result)* |
| | PFTs performed this encounter | Not done<br>Unable to perform reliable test<br>Yes |
| | FEV1 | Numeric (up to 2 decimal places) |
| | FVC | Numeric (up to 2 decimal places) |
| | FEF 25-75% | Numeric (up to 2 decimal places) |
| 8.2 | **LCI** | |
| | LCI performed this visit | Not done<br>Unable to perform reliable test<br>Yes |
| | Date of LCI | DD/MM/YYYY |
| | Type of device | Ecomedics Exhalyzer D N2-Washout<br>Ecomedics Exhalyzer SF6 (Tracer gas 4%)<br>Innovision Innocor<br>NDD Easyone Pro |
| | LCI technique | SBW<br>MBW<br>Unknown |
| | LCI value | Numeric (no decimals) |

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| 9. COMPLICATIONS FORM | | Notes |
|---|---|---|
| | | For most options in column below dropdown:<br>Yes<br>No<br>Unknown |
| 9.1 | **Respiratory (cardio) complications** | Allergic Bronchopulmonary Aspergillosis (ABPA) treated / Allergic Bronchopulmonary Aspergillosis (ABPA) untreated / Asthma / Cardiovascular Disease (including Heart failure) / Haemoptysis – Haemoptysis other / Haemoptysis Massive haemoptysis (>240ml/day or >100 ml/day for several days) / Nasal polyp / Pneumothorax-not requiring chest drain / Pneumothorax-requiring chest drain / Sinus Disease (symptomatic) / Other respiratory related complications (please specify) |
| 9.2 | **Gastrointestinal (GI) complications** | Constipation/abdominal pain / Distal Intestinal Obstruction Syndrome (DIOS) / Gallbladder disease / GERD (Gastro-Oesophageal Reflux Disease) / GI Bleed Req hospital non variceal / GI Bleed Req hospital variceal / Liver enzymes elevated / Pancreatic insufficiency / Pancreatitis / Rectal prolapse / Peptic ulcer disease / Other GI related complications |
| 9.3 | **CF-related liver disease** | Dropdown: CF Related Liver disease-stage unspecified / CF Related Liver disease-Non-cirrhosis / CF Related Liver disease-cirrhosis without portal / Hypertension/hypersplenism / CF Related Liver disease-cirrhosis, hypertension unknown / CF Related Liver disease-cirrhosis with portal hypertension/hypersplenism / Other liver disease (please specify) |
| 9.4 | **Other liver disease** | Hepatitis / Wilson Disease / Bleeding disorder / other (please specify) |
| 9.5 | **Diabetes status** | CFRD, Diet and Insulin Control / CFRD, Diet Control Gestational diabetes / Impaired Glucose Tolerance / Type I diabetes |
| 9.6 | **Bone and joint complications** | Arthritis/Arthropathy / Bone fracture / Osteopenia /Osteoporosis / Scoliosis / Other bone and joints related complications (please specify) |
| 9.7 | **Other complications** | Anxiety disorder / cardiac arrhythmias / tumor/cancer (specify type) / chronic pain / cholesterolaemia / depression / cataract / eye disease / gall stones / hearing loss / pulmonary arterial hypertension / Hypertension with cholesterolemia / Hypertension without cholesterolemia / Kidney stone / Renal disease-GFR <50% / Renal disease-Microalbuminaria / Renal disease-Nephrolithiasis / Renal disease-Proteinurea / Renal disease-requiring dialysis / Tinnitus / Salt Loss Syndrome / Splenomegaly / other (please specify) |

| 10. REGULAR MEDICATIONS FORM | | Notes |
|---|---|---|
| | Have there been any changes to the regular medication(s)? (Select all that apply) | Regular Pulmonary Medication / Gastro-intestinal/Nutrition Medication / CF related Diabetes (CFRD) Control Medication / Nutrition supplement / Osteoporosis/Osteopenia treatment medication / Post-Transplant Medication / Other regular medications |
| 10.1 | **Regular pulmonary medications** | If yes: |

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|---|---|---|
| | Maintenance antibiotics<br>Maintenance antifungal<br>Bronchodilator<br>Mucolytic<br>Corticosteroid<br>Maintenance Nasal Preparation | If yes, please indicate:<br>Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date |
| 10.2 | **Gastro-intestinal/Nutritional medications** | If yes: |
| | Pancreatic Enzyme Replacement Therapy<br>H2 Blockers<br>Proton Pump Inhibitors (PPIs)<br>Other Antacids<br>Vitamins/minerals<br>Appetite stimulants<br>CFLD medication<br>DIOS/Constipation medication | If yes, please indicate:<br>Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date |
| 10.3 | **CF-related Diabetes (CFRD) control medication** | |
| | Hypoglycaemic agent<br>Insulin | If yes, please indicate:<br>Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date |
| 10.4 | **Nutritional supplements form** | |
| | Feeding route | Oral Nutritional Supplement (ONS) / Nasogastric tube (NG tube) / Gastrostomy tube/button (G-Tube) |
| | Feeding regime | If yes, please indicate:<br>Textbox: input regime name<br>Indicate: Bolus (yes/no) / start date / continuing / stop date |
| 10.5 | **Osteoporosis/osteopenia treatment form** | |
| | Bisphosphonates<br>Other osteoporosis/osteopenia | If yes, please indicate:<br>Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date |
| 10.6 | **Post-transplant medication** | |
| | If yes, please indicate: | Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date |
| 10.7 | **CFTR Modulators** | |
| | If yes, please indicate: | Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date / reason ended |
| | Reason ended: | Dropdown:<br>Non-compliance<br>Required prohibited medication<br>Pregnancy<br>Withdrawal of consent<br>Physical decision<br>Switch to another drug<br>Lack of efficacy<br>Other (please specify)<br>AE/ Intolerance (please specify) |
| | Date of pre-initialisation sweat test | DD/MM/YYYY |
| | Chloride concentration | Numeric |
| 10.8 | **Other chronic medications** | Notes |
| | Antidepressants | Dropdown: generic drug name lists |

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|---|---|---|
| | Anti-Hypertensive medication<br>NSAID Anti-inflammatory Drug<br>Miscellaneous medication | Indicate: Route* / start date / continuing / stop date |
| ** Route options: PO, via NG, Intravenous (IV), Inhaled, Nebulised, nasal spray, via PEG, other route (please specify), subcutaneous, intramuscular* | | |

| **11. MICROBIOLOGY FORM** | | Notes |
|---|---|---|
| 11.1 | **Pathogens since last visit** | |
| | Was a sample attempted | Yes/no |
| 11.2 | **Pathogens results** | |
| | Culture result | Culture positive<br>Culture negative<br>Insufficient specimen/contaminated |
| | Date of specimen | DD/MM/YYYY |
| | Specimen type (type & autofill) | Axial swab<br>BAL<br>Cough swab<br>Groin swab<br>Nasal swab<br>Other Sample<br>Throat swab<br>Not Specified<br>Sputum Culture<br>Unknown |
| | Microorganism found | Dropdown: All culture types, including insufficient specimen, no growth, contaminated, culture negative options |

| **12. LAB INVESTIGATIONS** | | | Notes |
|---|---|---|---|
| | | Please select appropriate lab annual assessment tests (select all that apply) | Haematology<br>Biochemistry<br>Endocrinology<br>Immunology<br>Vitamins/Minerals<br>Pancreatic status |
| **Haematology** | 12.1 | *Full blood count* | |
| | | Date of collection,<br>WBC<br>Haemoglobin (Hb)<br>EOS | DD/MM/YYYY<br>Numeric<br>Numeric<br>Numeric |
| | 12.2 | *Coagulation* | |
| | | Date of collection<br>Prothrombin time<br>INR<br>APTT | DD/MM/YYYY<br>Numeric<br>Numeric<br>Numeric |

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|---|---|---|---|
| **Biochemistry** | 12.3 | *Liver function tests* | |
| | | Date of collection<br>Total protein<br>Serum albumin<br>Total bilirubin<br>Alk phos<br>Gamma GT<br>ALT<br>AST | DD/MM/YYYY<br>Numeric<br>Numeric<br>Numeric<br>Numeric<br>Numeric<br>Numeric<br>Numeric |
| | 12.4 | *Miscellaneous* | |
| | | Date of collection<br>Serum amylase<br>Ferritin | DD/MM/YYYY<br>Numeric<br>Numeric |
| | 12.5 | *Renal function tests* | |
| | | Urea<br>Serum creatinine | Numeric<br>Numeric |
| **Endocrinology** | 12.6 | *Glucose tolerance test* | |
| | | Date of collection<br>Fasting glucose<br>30 min glucose<br>60 min glucose<br>90 min glucose<br>2 hr PP glucose | DD/MM/YYYY<br>Numeric<br>Numeric<br>Numeric<br>Numeric<br>Numeric |
| | 12.7 | *Haemoglobin A1C* | |
| | | Date of collect<br>HbA1c (IFCC) | DD/MM/YYYY<br>Numeric |
| | 12.8 | *Immunology* | |
| | | Date of collection<br>IgA<br>IgG<br>IgM<br>IgE<br>IgE Rast Aspergillus titre<br>Aspergillus Fumigatus Ab | DD/MM/YYYY<br>Numeric<br>Numeric<br>Numeric<br>Numeric<br>Numeric<br>Numeric |
| | 12.9 | *Vitamins/Minerals* | |
| | | Date of collection<br>Vitamin A<br>Vitamin D (1,25-Dihydroxy-vitamin D serum)<br>Vitamin E | DD/MM/YYYY<br>Numeric<br>Numeric<br><br>Numeric |
| | 12.10 | *Pancreatic status* | |
| | | Date of collection<br>Faecal elastase<br>Faecal fat | DD/MM/YYYY<br>Numeric<br>Numeric |
| | 12.11 | *Sweat test* | |
| | | Date of collection<br>Chloride concentration | DD/MM/YYYY<br>Numeric |

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| | 13. RADIOLOGY FORM | Notes |
|---|---|---|
| | Please select appropriate lab annual assessment radiology (select all that apply) | Chest X-Ray<br>HRCT Thorax<br>DEXA scan<br>Abdominal ultrasound |
| 13.1 | **Chest X-ray** | If selected |
| | Date performed<br>Check X-ray report (required for CFSPID) | DD/MM/YYYY<br>Textbox |
| 13.2 | **HRCT Thorax** | If selected |
| | Chest CT scan report date<br>CT scan report (required for CFSPID)<br>CT scoring system used<br>CT score | DD/MM/YYYY<br>Textbox<br>Brody, Pragma, Other (please specify)<br>Textbox |
| 13.3 | **DEXA scan** | If selected |
| | Date performed<br>Femur T-Score<br>Femur Z-Score<br>Lumbar spine T-Score<br>Lumbar spine Z-Score<br>DEXA conclusion | DD/MM/YYYY<br>Numeric<br>Numeric<br>Numeric<br>Numeric<br>Normal bone density<br>Lower bone mass / Osteopenia (T-score 1.5 to -2.49) /<br>Osteoporosis (T-score -2.5 or less) |
| 13.4 | **Abdominal ultrasound** | If selected |
| | Date of performed<br>Abdominal U/S indication | DD/MM/YYYY<br>Normal<br>Increased heterogeneity<br>Fatty Liver<br>Splenomegaly<br>Cirrhosis<br>Portal hypertension<br>Varices<br>Gallstones |

| | 14. ACUTE CARE | Notes |
|---|---|---|
| 14.1 | **Acute antibiotics** | |
| | Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date | |
| | Indication | Exacerbation of RTI<br>Exacerbation therapy<br>Other (please specify) |
| 14.2 | **Acute antifungal** | |
| | Dropdown: generic drug name lists<br>Indicate: Route* / start date / continuing / stop date | |

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Charity Number: CRA 20065638 CHY 22249
Company Number: 635291

| | | |
|---|---|---|
| | Indication | Exacerbation of RTI<br>Exacerbation therapy<br>Other (please specify) |
| 14.3 | **Hospitalisation** | |
| | Admission date<br>Continuing<br>Discharge date | DD/MM/YYYY<br>Tick box<br>DD/MM/YYYY |
| | Reason for admission | Elective Admission for IV therapy<br>Elective surgery<br>CF related-Haemoptysis<br>CF related-Pneumothorax<br>CF related-DIOBs<br>Pulmonary Exacerbation<br>CF related-End Stage Lung Disease<br>Transplant related<br>Other CF related (please specify) |
| | In ICU<br>ICU start date<br>ICU end date | Yes/No<br>DD/MM/YYYY<br>DD/MM/YYYY |

| **15. PHYSIOTHERAPY** | | Notes |
|---|---|---|
| | Record the physiotherapy the patient reports receiving (select all that apply) | Airway Clearance Technique (ACT)<br>Oxygen therapy<br>Non-Invasive Positive Pressure Ventilation Therapy (NIV)<br>Exercise/Activity<br>Exercise Tolerance Test |
| 15.1 | **Airway Clearance Technique (ACT)** | If selected |
| | ACT modalities | Dropdown (if other, please specify) |
| 15.2 | **Oxygen therapy** | If selected |
| | Does the patient use portable oxygen device?<br><br>Home oxygen therapy<br>Oxygen therapy modalities | Yes/no/unknown<br><br>Yes/no/unknown<br>Dropdown: overnight, ambulation, continuous, other (please specify) |
| 15.3 | **Non-Invasive Positive Pressure Ventilation Therapy (NIV)** | If selected |
| | Does the patient use Bi-level Positive Airway Pressure (BiPAP) modality for NIV<br>IPAP<br>EPAP<br>Does the patient use CPAP modality for NIV | Yes/no/unknown<br><br>Numeric<br>Numeric<br>Yes/no |
| 15.4 | **Exercise/activity** | If selected |
| | Exercise/Activity<br><br>Name<br>Frequency<br>Duration (minutes) | Type I (Vigorous >6 MET, Type II (Moderate 3-6 MET), Type III (Light < 3 MET)<br>Dropdown: activity list<br>1-3 times/week, 3-5 times/week, >5 times/week, Daily, Unknown<br>Textbox |
| 15.5 | **Exercise tolerance test** | If selected |
| | Type of Exercise Test | Cardiopulmonary Exercise Test<br>Modified Shuffle Walk Test<br>Three-Minute Step Test |

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| | | |
|---|---|---|
| | | Six-Minute Walk Test |
| | Testing protocol | Cycle Ergometer<br>Treadmill |
| | Ramp | Numeric |
| | Supplemental oxygen requirement<br>if yes, please specify flow | Yes/No<br>Numeric |
| 15.5.1 | *VO2 (peak)* | VO2 (Peak)<br>VO2 (Peak) % predict |
| 15.5.2 | *Anaerobic threshold* | Anaerobic threshold<br>Anaerobic threshold % predict |
| 15.5.3 | *Heart rate / blood pressure / SPO2 / BORG* | Pre-Test (Rest)<br>During Test (Max)<br>Post-Test |
| 15.5.4 | *MET* | Pre-Test (Rest)<br>During Test (Max)<br>Post-Test<br>Max minute ventilation (MMV)<br>Ventilation (max exercise)<br>Breathing Reserve<br>Respiratory exchange ratio<br>Oxygen-pulse (O2/HR)<br>PETCO2<br>EqCO2<br>EqO2<br>Distance walked during test<br>Steps taken during test |

| **16. PREGNANCY** | | Notes |
|---|---|---|
| | Please indicate if the patient is current pregnant | Yes/no/unknown |
| | Please indicate if the patient's pregnancy outcome is a live birth | Yes/no |

| **17. CLINICAL TRIALS** | | Notes |
|---|---|---|
| | Please indicate if the patient is currently participating in a clinical trial | Yes/no/unknown |
| | Clinical trial number/code | Textbox |
| | Start date | DD/MM/YYYY |
| | Stop date | DD/MM/YYYY |

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**VERSION HISTORY**

| Version | Date updated | Updates made |
|---|---|---|
| V2 | n/a | Original 2019 document |
| V3 | 26/07/2022 | Fully reviewed based on implementation of new system |
| V3.1 | 16/09/2022 | Addition of sweat chloride test information (CFTRm & lab investigations) |
| V3.2 | 24/07/2023 | Removal of data fields for consenter first & last name in enrolment & core data forms<br>Update of letterhead |