



**Essential Data is data which is deemed by the study team as crucial in achieving the objectives of the registry. Specifying an *essential data* set does not imply in any way the additional data points are optional. In the absence of essential data or sufficient data quantity, the case may be rejected from the registry. Cases rejected from the registry do not receive payment/accruals associated with the recruitment. The decision of the co-ordinating centre on whether to accept a submitted case is considered final. The obligation to provide quality data, and discretion of the co-ordinating centre to accept or decline cases is outlined in the site contracts.**

### **Essential Data Points;**

**Radiology** – Confirm patient eligibility by recording the Date and Type of CT imaging used to confirm bronchiectasis diagnosis. If any radiology data is missing or there is uncertainty surrounding the scan please contact the central team [info@bronchiectasis.eu](mailto:info@bronchiectasis.eu)

**Microbiology** – Enter all (stable, exacerbation and mycobacterial) respiratory samples tested in the previous 12 months. Please do not enter data more than 12 months old. It is expected at least one sample should be provided as annual sputum culture is part of bronchiectasis standard care (UK British Thoracic Society guidelines). It is acknowledged that some patients do not produce sputum spontaneously, however consistent absence of sputum culture data from cases will be queried.

**Spirometry** – Please enter the most recent spirometry data from the previous 12 months. As per European Respiratory Society spirometry guidelines, height and weight are expected to be updated at the time of spirometry. Please do not enter data more than 12 months old.

**Exacerbation history** - Please communicate with the patient to find out exacerbation data including the number of hospital admissions and emergency department visits (respiratory related only). Hospital records can be used if absolutely necessary but patient source is much preferred.

**In order to reduce the amount of system queries please ensure the patients are actively involved in the collection of their data. The majority of data collected in this CRF will be available in the patient notes, however we have outlined below some data fields in which we would prefer and expect patients to be able to answer at the time of consent and during clinic visits, thus providing the most accurate up to date information. These data points are termed Patient Response Questions.**

### **Patient Response Question;**

- All questions asked in the **Bronchiectasis Background Information** page except spirometry which is covered above in *Essential Data*
- **Medical History** such as history of Tuberculosis, Whooping Cough, HIV, Gastro-oesophageal reflux disease
- Use of **Long term Oxygen therapy**
- **Influenza Vaccination** received in the previous 12 months
- All **Physiotherapy and Activity Questions**



## EMBARC Case Report Form Baseline

Version 3.0 April 2016

### BASIC CASE INFORMATION

Case Identifier: \_\_\_\_\_ Date of patient consent: \_\_\_\_\_ (dd/mm/yyyy)

- Eligibility criteria:
- Has a CT chest scan consistent with bronchiectasis
  - Is over 18 years old
  - Does not have known cystic fibrosis
  - Has not had a previous heart or lung transplant
  - Has given signed consent to inclusion in the study

Gender:  Male  Female

Date of birth: \_\_\_\_\_ (dd/mm/yyyy)

Center: \_\_\_\_\_

- Ethnicity
- White European
  - Gypsy/traveller
  - Other white ethnic group
  - Hispanic
  - Indian, Pakistani, Bangladeshi or other South Asian ethnic group
  - Chinese European/Other Chinese ethnic group
  - Other Asian ethnic group
  - Black European/Black African/other black ethnic group
  - Other African
  - Caribbean/other Caribbean ethnic group
  - Arab European/Other Arab ethnic group
  - Other ethnicity
  - Not recorded/declined

How long has the patient had bronchiectasis?

Unknown

10-14 years

< 5 years

15-20 years

5-9 years

>20 years



## CO-MORBIDITIES

**Please record Comorbidities the patient is known to have**

### Cardiovascular diseases

**Yes**     **No**

*If yes;*

- Myocardial infarction  Yes     No
- Angina  Yes     No
- Stroke or Transient Ischaemic Attack  Yes     No
- Coronary artery bypass graft  Yes     No
- Congestive cardiac failure  Yes     No
- Pulmonary hypertension  Yes     No
- Atrial fibrillation  Yes     No
- Others \_\_\_\_\_  Yes     No

### Liver Cirrhosis

Yes     No

### Osteoporosis

Yes     No

### Depression

Yes     No

### Anxiety

Yes     No

### Chronic renal failure

**Yes**     **No**

*If yes;*

- Haemodialysis  Yes     No

### Neoplastic disease

**Yes**     **No**

*If yes;*

- Active  Yes     No
- Haematological  Yes     No
- Site
  - Lung     Breast     Prostate
  - Colon     Pancreas     Bone
  - Skin     Brain     Other
  - Unknown

### Diabetes

**Yes**     **No**

*If yes;*

- Type  Type I     Type II     Unknown
- Treatment  Insulin     Sulphonylurea
- Metformin     Other



## NON RESPIRATORY MEDICATIONS

**Please record currently prescribed Non respiratory medications**

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| Statin  | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Angiotensin-converting-enzyme inhibitor         | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Angiotensin II receptor blocker                 | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Aspirin   | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Non-aspirin platelet inhibitors eg, Clopidogrel | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Warfarin/Oral anticoagulants                    | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| $\beta$ -Blocker                                | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Proton pump inhibitor                           | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

*Additional medications can be recorded in the respiratory treatments section.*



## BRONCHIECTASIS BACKGROUND INFORMATION

\*\*\*\*\*

**Spirometry, MRC score and Exacerbation history are deemed Essential Data. This data must not be more than 12 months old and must be updated annually. Cases may be rejected from the registry in the absence of Essential Data.**

\*\*\*\*\*

Weight (Kg) \_\_\_\_\_  N/A      Height (cm) \_\_\_\_\_  N/A      BMI (Kg/m<sup>2</sup>) \_\_\_\_\_  N/A  
*(BMI as autocalculated by eCRF)*

FEV<sub>1</sub> L (recorded) \_\_\_\_\_  N/A      FEV<sub>1</sub> L (% predicted) \_\_\_\_\_  N/A  
*(% predicted values as autocalculated by eCRF)*

FVC L (recorded) \_\_\_\_\_  N/A      FVC L (% predicted) \_\_\_\_\_  N/A  
*(% predicted values as autocalculated by eCRF)*

Bronchodilator Status       Pre-Bronchodilator  
    Post-Bronchodilator  
    Unknown  
*(where possible, post-bronchodilator values are preferred)*

If spirometry has not been completed in the past 12months, please give a reason in the box below

Are any additional lung function tests available?       Yes       No

*If yes;*

Total Lung Capacity (L) \_\_\_\_\_  N/A      Diffusing capacity (DLCO) (L) \_\_\_\_\_  N/A

Residual Volume (L) \_\_\_\_\_  N/A      Inspiratory capacity (DLCO) (L) \_\_\_\_\_  N/A

Modified MRC dyspnoea score:

- 0 (I only get breathless with strenuous exercise)
- 1 (I get short of breath when hurrying on level ground or walking up a slight hill)
- 2 (On the level ground I walk slower than people of the same age because of breathlessness or I have to stop for breath when walking at my own pace on the level)
- 3 (I stop for breath after walking about 100 yards or after a few minutes on the level ground)
- 4 (I am too breathless to leave the house or I am breathless when dressing)



Asthma:  Yes  No

COPD:  Yes  No

Nasal polyps:  Yes  No

Rhinosinusitis:  Yes  No

Sputum color when stable:  Mucoid  
 Mucopurulent  
 Purulent  
 Purulent (severe)

Usual daily sputum volume: \_\_\_\_\_(ml/day)

Smoking status:  Current  
 Ex  
 Never

Approximate Pack years:  0 - 4  21 - 40  
 5 - 9  More than 40  
 10 - 20

Number of exacerbations **not** requiring secondary care in the last year:

0  1  2  3  4  5  6  7  8  9  10  11  12

Source of this data:

Patient history  Antibiotic prescription data  Hospital records

Number of exacerbations requiring **hospital admission** in the last year:

0  1  2  3  4  5  6  7  8  9  10  11  12

Source of this data:

Patient history  Antibiotic prescription data  Hospital records

Number of respiratory related **emergency department visits not resulting in hospitalisation** in the last year:

0  1  2  3  4  5  6  7  8  9  10  11  12

Source of this data:

Patient history  Antibiotic prescription data  Hospital records

Has the patient ever been hospitalised for bronchiectasis?  Yes  No

Has the patient received outpatient intravenous antibiotics in the last year?  Yes  No

Has the patient ever had major haemoptysis requiring hospital admission?  Yes  No

Has the patient participated in a clinical trial for bronchiectasis (other than the registry)?  Yes  No



### QOL-B QUESTIONNAIRE

Is QoL-B Questionnaire data available?  Yes  No

*If yes, complete the following:*

English-UK  Danish-Denmark  Dutch-Belgium  Dutch-Netherlands  Finnish   
 French-Belgium  French-France  German  Hungarian  Italian  Lithuanian   
 Norwegian  Polish  Portuguese  Romanian  Russian-Israel  Russian- Russia   
 Serbian  Spanish-Latin  Spanish-Spain

Date of completion: \_\_\_\_\_ (dd/mm/yyyy)

Q1 _____	Q2 _____	Q3 _____	Q4 _____	Q5 _____
Q6 _____	Q7 _____	Q8 _____	Q9 _____	Q10 _____
Q11 _____	Q12 _____	Q13 _____	Q14 _____	Q15 _____
Q16 _____	Q17 _____	Q18 _____	Q19 _____	Q20 _____
Q21 _____	Q22 _____	Q23 _____	Q24 _____	Q25 _____
Q26 _____	Q27 _____	Q28 _____	Q29 _____	Q30 _____
Q31 _____	Q32 _____	Q33 _____	Q34 _____	Q35 _____
Q36 _____	Q37 _____			



## AETIOLOGY AND LABORATORY TESTING

**Has the patient evidence of testing for the following underlying disorders:**

### ABPA

*If yes;*

- |                               |                                   |                                 |                                     |                                     |  |
|-------------------------------|-----------------------------------|---------------------------------|-------------------------------------|-------------------------------------|--|
|                               | <input type="checkbox"/> Yes      | <input type="checkbox"/> No     |                                     |                                     |  |
| - Serum eosinophil count      | <input type="checkbox"/> Elevated | <input type="checkbox"/> Normal | <input type="checkbox"/> Not tested |                                     |  |
| - Total IgE                   | _____iu/mL                        | <input type="checkbox"/> Normal | <input type="checkbox"/> Elevated   | <input type="checkbox"/> Not tested |  |
| - Specific IgE to aspergillus | <input type="checkbox"/> Raised   | <input type="checkbox"/> Normal | <input type="checkbox"/> Not tested |                                     |  |
| - Aspergillus IgG             | <input type="checkbox"/> Raised   | <input type="checkbox"/> Normal | <input type="checkbox"/> Not tested |                                     |  |
| - Aspergillus Skin prick test | <input type="checkbox"/> Raised   | <input type="checkbox"/> Normal | <input type="checkbox"/> Not tested |                                     |  |

### Cystic Fibrosis

*If yes;*

- |              |                                       |  |  |
|--------------|---------------------------------------|--|--|
|              | <input type="checkbox"/> Yes          | <input type="checkbox"/> No            |  |
| - Sweat test | <input type="checkbox"/> Positive     | <input type="checkbox"/> Intermediate  |  |
|              | <input type="checkbox"/> Negative     | <input type="checkbox"/> Not performed |  |
| - Genetics   | <input type="checkbox"/> Homozygous   | <input type="checkbox"/> Heterozygous  |  |
|              | <input type="checkbox"/> No mutations | <input type="checkbox"/> Not performed |  |

### Serum Immunoglobulins

*If yes;*

- |                    |                                 |                              |                               |                                     |  |
|--------------------|---------------------------------|------------------------------|-------------------------------|-------------------------------------|--|
|                    | <input type="checkbox"/> Yes    | <input type="checkbox"/> No  |                               |                                     |  |
| - Serum level IgM  | <input type="checkbox"/> Normal | <input type="checkbox"/> Low | <input type="checkbox"/> High | <input type="checkbox"/> Not tested |  |
| - Serum level IgG  | <input type="checkbox"/> Normal | <input type="checkbox"/> Low | <input type="checkbox"/> High | <input type="checkbox"/> Not tested |  |
| - Serum level IgA  | <input type="checkbox"/> Normal | <input type="checkbox"/> Low | <input type="checkbox"/> High | <input type="checkbox"/> Not tested |  |
| - Serum level IgG1 | <input type="checkbox"/> Normal | <input type="checkbox"/> Low | <input type="checkbox"/> High | <input type="checkbox"/> Not tested |  |
| - Serum level IgG2 | <input type="checkbox"/> Normal | <input type="checkbox"/> Low | <input type="checkbox"/> High | <input type="checkbox"/> Not tested |  |
| - Serum level IgG3 | <input type="checkbox"/> Normal | <input type="checkbox"/> Low | <input type="checkbox"/> High | <input type="checkbox"/> Not tested |  |
| - Serum level IgG4 | <input type="checkbox"/> Normal | <input type="checkbox"/> Low | <input type="checkbox"/> High | <input type="checkbox"/> Not tested |  |

### $\alpha$ -1 antitrypsin deficiency

*If yes;*

- |            |  |                               |  |
|------------|--|-------------------------------|--|
|            | <input type="checkbox"/> Yes           | <input type="checkbox"/> No   |  |
| - Level    | <input type="checkbox"/> Normal        | <input type="checkbox"/> Low  | <input type="checkbox"/> High <input type="checkbox"/> Not tested    |
| - Genetics | <input type="checkbox"/> PiMM (Normal) | <input type="checkbox"/> PiMS | <input type="checkbox"/> PiSS  |
|            | <input type="checkbox"/> PiMZ          | <input type="checkbox"/> PiSZ | <input type="checkbox"/> PiZZ <input type="checkbox"/> Not performed |

### Functional antibodies to Pneumococcal/H influenza vaccine

*If yes;*

- |          |                                 |                                   |
|----------|---------------------------------|-----------------------------------|
|          | <input type="checkbox"/> Yes    | <input type="checkbox"/> No       |
| - Result | <input type="checkbox"/> Normal | <input type="checkbox"/> Abnormal |

### Serum electrophoresis

*If yes;*

- |          |                                 |                                   |
|----------|---------------------------------|-----------------------------------|
|          | <input type="checkbox"/> Yes    | <input type="checkbox"/> No       |
| - Result | <input type="checkbox"/> Normal | <input type="checkbox"/> Abnormal |





### Tests of ciliary function

*If yes;*

- Nasal eNO
- Saccharin test
- Scintigraphic mucociliary clearance
- Biopsy for electron microscopy
- Biopsy for analysis of ciliary beat patten/frequency
- Genetics

Yes     No

- Positive    Intermediate    Negative
- Not performed
- Positive    Intermediate    Negative
- Not performed
- Positive    Intermediate    Negative
- Not performed
- Positive    Intermediate    Negative
- Not performed
- Positive    Intermediate    Negative
- Not performed
- Positive    Intermediate    Negative
- Not performed

### Bronchoscopy

Yes     No

### Autoantibody testing

*If yes;*

- CCP screen results
- ANA screen results
- ENA screen results
- ANCA
- Additional tests performed

Yes     No

- Positive    Intermediate    Negative
  - Not performed
  - Positive    Intermediate    Negative
  - Not performed
  - Positive    Intermediate    Negative
  - Not performed
  - Positive    Intermediate    Negative
  - Not performed
-



## Does the patient have a known history of any of the following?

**Pneumonia**  Yes  No

**Whooping cough/pertussis**  Yes  No

**Other childhood/respiratory infection**  Yes  No

**Tuberculosis**  **Yes**  **No**

*If yes;*

- Infection  Current  Previous
- Treatment received  Yes  No  Unknown

**Atypical mycobacterial infection**  **Yes**  **No**

*If yes;*

- Infection  Current  Previous
- Treatment received  Yes  No  Unknown

**Rheumatoid arthritis**  Yes  No

**Other connective tissue disease**  **Yes**  **No**

*If yes;*

- |  |   |
|--|---|
| <input type="checkbox"/> Systemic lupus erythematosus    | <input type="checkbox"/> Sjogrens syndrome          |
| <input type="checkbox"/> Systemic sclerosis/scleroderma  | <input type="checkbox"/> Poly/dermatomyositis       |
| <input type="checkbox"/> Ehlers_danlos syndrome          | <input type="checkbox"/> Juvenile idiopathic asthma |
| <input type="checkbox"/> Mixed connective tissue disease | <input type="checkbox"/> Relapsing polychondritis   |
| <input type="checkbox"/> Stills disease                  | <input type="checkbox"/> Other                      |

**Inflammatory bowel disease**  **Yes**  **No**

*If yes;*

- Ulcerative colitis  Yes  No
- Crohns disease  Yes  No

**HIV**  Yes  No



### Immunodeficiency

*If yes;*

Yes

No

- B-cell deficiencies:

- Common variable immunodeficiency
- X-linked agammaglobulinaemia
- Thymoma with antibody deficiency
- Hyper IgM syndrome
- Activate PI3K-delta syndrome
- Selective IgA deficiency
- IgG subclass deficiency
- Specific antibody deficiency
- Other

- T-cell and combined deficiencies

- Severe combined immunodeficiency
- DiGeorge syndrome
- X-linked lymphoproliferative syndrome
- Hyper IgM syndrome (CD40 ligand)
- MHC class II deficiency
- Ataxia-telangiectasis
- Wiskott-Aldrich syndrome
- Chronic mucocutaneous candidiasis
- TAP deficiency
- IPEX (immune dysfunction, polyendocrinopathy, enteropathy, X-linked)
- ALPS (autoimmune lymphoproliferative syndrome)
- WHIM syndrome
- Other

- Secondary immunodeficiencies

- Chronic Lymphocytic leukemia
- Multiple Myeloma
- Immunodeficiency associated with haematological malignancy
- Immunodeficiency secondary to systemic chemotherapy
- Immunodeficiency secondary to immunosuppressive drugs
- Stem cell transplantation
- Solid organ transplantation
- Other



- Phagocyte deficiencies
  - Chronic granulomatous disease
  - Familial Haemophagocytic lymphohistiocytosis
  - Congenital agranulocytosis
  - Cyclic neutropenia
  - Leucocyte adhesion deficiency
  - Chediak-Higashi syndrome
  - Griscelli's syndrome
  - Hyper IgE syndrome
  - Interferon gamma/IL-12 rec
  - Other cytokine deficiencies
  
- Complement deficiencies
  - Mannose binding lectin (MBL) deficiency
  - Properdin deficiency
  - Complement C3 deficiency
  - Terminal complement component deficiency
  - Other

**Primary ciliary dyskinesia**  Yes  No

**Aspiration**  Yes  No

**Gastro-oesophageal reflux disease**  Yes  No

**Congenital airway abnormality**  Yes  No

If yes, please specify: \_\_\_\_\_

**Foreign body inhalation or obstruction**  Yes  No

**After investigation, the underlying aetiology determined was:**

- |  |  |
|--|--|
| <input type="checkbox"/> Idiopathic                      | <input type="checkbox"/> Alpha-1-antitrypsin deficiency            |
| <input type="checkbox"/> Post-infective                  | <input type="checkbox"/> Common variable immunodeficiency          |
| <input type="checkbox"/> Post-tuberculous                | <input type="checkbox"/> X-linked agammaglobulinaemia              |
| <input type="checkbox"/> ABPA                            | <input type="checkbox"/> IgA deficiency                            |
| <input type="checkbox"/> Rheumatoid arthritis            | <input type="checkbox"/> IgG subclass deficiency                   |
| <input type="checkbox"/> Connective tissue disease       | <input type="checkbox"/> Specific antibody deficiency              |
| <input type="checkbox"/> Inflammatory bowel disease      | <input type="checkbox"/> HIV                                       |
| <input type="checkbox"/> Aspiration                      | <input type="checkbox"/> Williams-Campbell Syndrome                |
| <input type="checkbox"/> Gastroesophageal reflux disease | <input type="checkbox"/> Marfan Syndrome                           |
| <input type="checkbox"/> Non-tuberculous mycobacteria    | <input type="checkbox"/> Mounier-Kuhn syndrome                     |
| <input type="checkbox"/> COPD                            | <input type="checkbox"/> Yellow nail syndrome                      |
| <input type="checkbox"/> Asthma                          | <input type="checkbox"/> HTLV-1 infection                          |
| <input type="checkbox"/> Primary ciliary dyskinesia      | <input type="checkbox"/> Chronic neonatal lung disease             |
| <input type="checkbox"/> Kartagener syndrome             | <input type="checkbox"/> Neonatal ventilation for prematurity      |
| <input type="checkbox"/> Youngs Syndrome                 | <input type="checkbox"/> Pink Disease (infantile mercury exposure) |

Other aetiology (please specify): \_\_\_\_\_



## MICROBIOLOGY

\*\*\*\*\*

**Microbiology is deemed Essential Data.**

**This data must not be more than 12 months old and must be updated annually.**

**Cases may be rejected from the registry in the absence of Essential Data.**

\*\*\*\*\*

Have any microbiology samples been obtained in the past 12 months?  Yes  No

*If yes, complete the following:*

*Samples are divided into those performed when clinically stable and those performed during exacerbations. If it is uncertain whether patients were stable or not at the time of sampling please record under "clinically stable".*

### While clinically stable

*Please provide details of all sputum results while stable over the last 12 months including negative cultures (use additional sheets where necessary)*

Date of sample: \_\_\_\_\_ (mm/yyyy)

Source:

Sputum

Induced sputum

BAL

Throat swab

No organism isolated

Organism: \_\_\_\_\_

Antibiotic: Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Organism: \_\_\_\_\_

Antibiotic: Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_



### During exacerbations

Please provide details of all sputum results during exacerbations over the last 12 months  
(use additional sheets where necessary)

Date of sample: \_\_\_\_\_ (mm/yyyy)

Source:

Sputum

Induced sputum

BAL

Throat swab

No organism isolated

Organism: \_\_\_\_\_

Antibiotic: Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Organism: \_\_\_\_\_

Antibiotic: Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Sensitive: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

Resistant: \_\_\_\_\_

### Mycobacterial samples

Please provide details of all sputum results for acid fast bacilli/mycobacterial culture over the last 12 months (use additional sheets where necessary).

Date of sample: \_\_\_\_\_ (mm/yyyy)

Source:

Sputum

Induced sputum

BAL

Throat swab

No organism isolated

Organism: \_\_\_\_\_

**Is there evidence the patient has ever grown *Pseudomonas aeruginosa*?**  Yes  No

*If yes;*

How long ago was the most recent isolation of *Pseudomonas*?

Present

Last 10 years

Last 2 years

Over 10 years

Last 5 years

Last 10 years

Type:  Mucoïd  Non-mucoïd  Unknown

Has the patient ever had nebulised, oral or intravenous antibiotics aimed at eradication of *pseudomonas*?

Yes

No



## RADIOLOGY

\*\*\*\*\*

**Patients must have a diagnosis of bronchiectasis confirmed by CT imaging.  
Cases will be rejected from the registry without CT confirmed diagnosis.**

\*\*\*\*\*

Date of CT scan: \_\_\_\_\_ (dd/mm/yyyy)

Type of imaging:     High resolution CT scan (HRCT)  
                               CT Thorax

Is there CT evidence of Bronchiectasis in;

**Right upper lobe:**     No Bronchiectasis  
                               Cylindrical  
                               Varicose  
                               Cystic  
                               Unknown Severity

**Left upper lobe:**     No Bronchiectasis  
                               Cylindrical  
                               Varicose  
                               Cystic  
                               Unknown Severity

**Right middle lobe:**  No Bronchiectasis  
                               Cylindrical  
                               Varicose  
                               Cystic  
                               Unknown Severity

**Lingula:**             No Bronchiectasis  
                               Cylindrical  
                               Varicose  
                               Cystic  
                               Unknown Severity

**Right lower lobe:**     No Bronchiectasis  
                               Cylindrical  
                               Varicose  
                               Cystic  
                               Unknown Severity

**Left lower lobe:**     No Bronchiectasis  
                               Cylindrical  
                               Varicose  
                               Cystic  
                               Unknown Severity



## RESPIRATORY TREATMENTS

Long term oxygen therapy:  Yes  No

Non invasive ventilation:  Yes  No

Oral theophylline:  Yes  No

**The patient has regular respiratory treatments:**  Yes  No

*If yes;*

### Respiratory Medications

- |  |             |
|--|-------------|
| <input type="checkbox"/> Inhaled steroid   | Drug: _____ |
| <input type="checkbox"/> Inhaled steroid/Long acting beta agonist                | Drug: _____ |
| <input type="checkbox"/> Intravenous immunoglobulin                              | Drug: _____ |
| <input type="checkbox"/> Itraconazole  | Drug: _____ |
| <input type="checkbox"/> Leukotriene receptor antagonist                         | Drug: _____ |
| <input type="checkbox"/> Long acting anti-muscarinic                             | Drug: _____ |
| <input type="checkbox"/> Long acting beta agonist/Long acting<br>anti-muscarinic | Drug: _____ |
| <input type="checkbox"/> Long acting beta agonist                                | Drug: _____ |
| <input type="checkbox"/> Long term (>28 days) Oral corticosteroids               | Drug: _____ |
| <input type="checkbox"/> Monoclonal antibody                                     | Drug: _____ |
| <input type="checkbox"/> Mucolytic   | Drug: _____ |
| <input type="checkbox"/> Nebulised bronchodilators                               | Drug: _____ |

### Antibiotic Medications

- |  |             |
|--|-------------|
| <input type="checkbox"/> Inhaled/Nebulised antibiotics         | Drug: _____ |
| <input type="checkbox"/> Long term (>28 days) Oral antibiotics | Drug: _____ |
| <input type="checkbox"/> Cyclical antibiotic therapy           | Drug: _____ |

### Physiotherapy Adjuncts

- DNAase
- Inhaled mannitol
- Nebulised Hypertonic saline
- Nebulised Normal saline
- Sodium Hyaluronate

### Vaccination

- Is there evidence the patient has ever received;
- |  |                              |                             |
|--|------------------------------|-----------------------------|
| Pneumococcal polysaccharide vaccine (e.g.: PSV23):               | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Pneumococcal conjugate vaccine (e.g.: PCV13):                    | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| In the last year has the patient received Influenza vaccination: | <input type="checkbox"/> Yes | <input type="checkbox"/> No |





## PHYSIOTHERAPY AND ACTIVITY

Does the patient practice regular chest physiotherapy?  Yes  No

*If yes;*

- Manual airway clearance:
- Active cycle of breathing technique
  - Autogenic drainage
  - Postural drainage
  - Assisted cough
  - Manual vibration
  - Percussion
  - ELTGOL
  - Regular physical exercise
  - None

- Devices:
- Positive expiratory pressure (PEP) device
  - Flutter device
  - Cornet
  - Acapella
  - Mechanical vibration
  - Percussionnaire
  - High frequency chest wall oscillation
  - Other
  - None

- Has the patient attended pulmonary rehabilitation?  Yes
- Not referred
  - Not fit due to co-morbidities
  - Patient refused
  - Patient failed to attend

## ADDITIONAL INFORMATION

Provide any additional required information in the free text provided:

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## Disclaimer

In using this paper case report form to record identifiable patient data, the user accepts all responsibility for the secure storage of this data and disposal of this data in accordance with local ethical approvals and policies.

## Acknowledgements

EMBARC is a European Respiratory Society Clinical Research Collaboration.

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- Innovative Medicines Initiative
- European Respiratory Society
- The United States COPD Foundation Bronchiectasis Registry
- Bronch-UK, the UK bronchiectasis network
- The European Cystic Fibrosis Society
- Italian Society of Respiratory Medicine (SIP)
- Lung Foundation of Australia
- The European Lung Foundation
- Bayer HealthCare
- Novartis Pharma AG
- Aradigm Corporation
- The Prospective German Non-CF Bronchiectasis (PROGNOSIS) Registry
- The Group for Research and Education in Pneumo-Infectious Diseases (GREPI), France

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