EMBARC Case Report Form

Version 1.1, February 2015

For definitions please refer to the user guide

BASIC CASE INFORMATION

Hospital number or identifier_____

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 consent to inclusion in the study

Gender: ☐ Male ☐ Female Date of birth: _____ (dd/mm/yyyy)

Ethnicity
- ☐ White European
- ☐ Gyspy/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

Center: _____

How long has the patient had bronchiectasis?
- ☐ Unknown
- ☐ < 5 years
- ☐ 5-10 years
- ☐ 11-15 years
- ☐ 16-20 years
- ☐ >20 years

Date of patient visit: _____ (dd/mm/yyyy)

CO-MORBIDITIES

Comorbidities

Cardiovascular diseases ☐ Yes ☐ No ☐ Unknown

- Myocardial infarction ☐ Yes ☐ No ☐ Unknown
- Angina ☐ Yes ☐ No ☐ Unknown
- Stroke or Transient ischaemic attack ☐ Yes ☐ No ☐ Unknown
- Coronary artery bypass graft ☐ Yes ☐ No ☐ Unknown
- Congestive cardiac failure ☐ Yes ☐ No ☐ Unknown
- Pulmonary hypertension ☐ Yes ☐ No ☐ Unknown
- Atrial fibrillation ☐ Yes ☐ No ☐ Unknown
- Systemic hypertension ☐ Yes ☐ No ☐ Unknown
- Others_____

Liver Cirrhosis ☐ Yes ☐ No ☐ Unknown

Osteoporosis ☐ Yes ☐ No ☐ Unknown

Depression ☐ Yes ☐ No ☐ Unknown

Anxiety ☐ Yes ☐ No ☐ Unknown

Chronic renal failure ☐ Yes ☐ No ☐ Unknown

- Haemodialysis ☐ Yes ☐ No ☐ Unknown

Neoplastic disease ☐ Yes ☐ No ☐ Unknown

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

Diabetes ☐ Yes ☐ No ☐ Unknown

- Type ☐ Type I ☐ Type II ☐ Not Known
- Treatment ☐ Insulin ☐ Sulphonylurea ☐ Metformin ☐ Other ☐ Not Known

Non respiratory medications

Statin	☐ Yes	☐ No	☐ Unknown
Angiotensin-converting -enzyme inhibitor	☐ Yes	☐ No	☐ Unknown
Angiotensin II receptor blocker	☐ Yes	☐ No	☐ Unknown
Aspirin	☐ Yes	☐ No	☐ Unknown
Clopidogrel	☐ Yes	☐ No	☐ Unknown
Warfarin/Oral anticoagulants	☐ Yes	☐ No	☐ Unknown
β-Blocker	☐ Yes	☐ No	☐ Unknown
Proton pump inhibitor	☐ Yes	☐ No	☐ Unknown

Additional medications can be recorded in the respiratory treatments section.

BRONCHIECTASIS BACKGROUND INFORMATION

Weight (Kg) _____ ☐ N/A Height (cm) _____ ☐ N/A

FEV_1 L (recorded)_____ ☐ N/A FVC L (recorded)_____ ☐ N/A

Were any additional lung function tests performed? ☐ Yes ☐ No ☐ Unknown

Total Lung Capacity (L)_____ ☐ N/A Diffusing capacity (DLCO) (L)_____ ☐ N/A

Residual Volume (L)_____ ☐ N/A Inspiratory capacity (DLCO) (L)_____ ☐ N/A

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

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)
☐ N/A

Asthma: ☐ Yes ☐ No ☐ Unknown COPD: ☐ Yes ☐ No ☐ Unknown

Nasal polyps: ☐ Yes ☐ No ☐ Unknown Rhinosinusitis: ☐ Yes ☐ No ☐ Unknown

Sputum color when stable:
☐ Mucoid
☐ Mucopurulent
☐ Purulent

Usual daily sputum volume:
_____(ml/day) ☐ N/A

Smoking status:
☐ Current
☐ Ex
☐ Never

Approximate Pack years:
☐ 0
☐ 0-5
☐ 6-10
☐ 11-20
☐ 21-40
☐ More than 40
☐ Unknown

No of exacerbations in last year:
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10 ☐11 ☐12 ☐Unknown
Source of this data:
☐Patient history ☐Antibiotic prescription data ☐Hospital records

No of hospital admissions for respiratory infections in last year:
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10 ☐11 ☐12 ☐Unknown
Source of this data:
☐Patient history ☐Antibiotic prescription data ☐Hospital records

No of Emergency Department visits in last year:
(Please record outpatient exacerbations, hospital admissions and emergency department visits that do not result in hospital admission separately)
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10 ☐11 ☐12 ☐Unknown
Source of this data:
☐Patient history ☐Antibiotic prescription data ☐Hospital records

Has the patient ever been hospitalised for bronchiectasis? ☐Yes ☐No ☐Unknown

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

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

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

☐ QoL-B Questionnaire *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 had testing for the following underlying disorders:

ABPA ☐ Yes ☐ No ☐ Unknown

Serum eosinophil count	☐ Elevated ☐ Normal ☐ Not tested
Total IgE	____iu/mL ☐ Norma ☐ Elevated ☐ Unknown
Specific IgE to aspergillus	☐ Raised ☐ Normal ☐ Not tested
Aspergillus IgG	☐ Raised ☐ Normal ☐ Not tested
Aspergillus Skin prick test	☐ Raised ☐ Normal ☐ Not tested

Cystic Fibrosis ☐ Yes ☐ No ☐ Unknown

Sweat test	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
Genetics	☐ Homozygous ☐ Heterozygous ☐ No mutations ☐ Not performed ☐ Unknown

Serum Immunoglobulins ☐ Yes ☐ No ☐ Unknown

Serum level IgM	☐ Normal ☐ Low ☐ High ☐ Not tested
Serum level IgG	☐ Normal ☐ Low ☐ High ☐ Not tested
Serum level IgA	☐ Normal ☐ Low ☐ High ☐ Not tested
Serum level IgG1	☐ Normal ☐ Low ☐ High ☐ Not tested
Serum level IgG2	☐ Normal ☐ Low ☐ High ☐ Not tested
Serum level IgG3	☐ Normal ☐ Low ☐ High ☐ Not tested
Serum level IgG4	☐ Normal ☐ Low ☐ High ☐ Not tested

α-1 antitrypsin deficiency ☐ Yes ☐ No ☐ Unknown

Level	☐ Normal ☐ Low ☐ High ☐ Not tested
Genetics	☐ PiMM (Normal) ☐ PiMS ☐ PiSS ☐ PiMZ ☐ PiSZ ☐ PiZZ ☐ Not performed

Functional antibodies to Pneumococcal/H influenza vaccine ☐ Yes ☐ No ☐ Unknown

Result	☐ Normal ☐ Abnormal ☐ Not performed ☐ Unknown

Serum electrophoresis ☐ Yes ☐ No ☐ Unknown

Result	☐ Normal ☐ Abnormal ☐ Not performed ☐ Unknown

Tests of ciliary function ☐ Yes ☐ No ☐ Unknown

Nasal eNO	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
Saccharin test	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
Scintigraphic mucociliary clearence	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
Biopsy for electron microscopy	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
Biopsy for analysis of ciliary beat patter/frequency	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
Genetics	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown

Bronchoscopy ☐ Yes ☐ No ☐ Unknown

Autoantibody testing ☐ Yes ☐ No ☐ Unknown

CCP screen results	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
ANA screen results	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
ENA screen results	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
ANCA	☐ Positive ☐ Intermediate ☐ Negative ☐ Not performed ☐ Unknown
Additional tests performed	_____

Does the patient have a history of any of the following:

Pneumonia ☐ Yes ☐ No ☐ Unknown

Whooping cough/pertussis ☐ Yes ☐ No ☐ Unknown

Other childhood/respiratory infection ☐ Yes ☐ No ☐ Unknown

Tuberculosis	☐ Yes	☐ No	☐ Unknown
Infection	☐ Current	☐ Previous	☐ Unknown
Treatment received	☐ Yes	☐ No	☐ Unknown

Atypical mycobacterial infection	☐ Yes	☐ No	☐ Unknown
Infection	☐ Current	☐ Previous	☐ Unknown
Treatment received	☐ Yes	☐ No	☐ Unknown

Rheumatoid arthritis ☐ Yes ☐ No ☐ Unknown

Other connective tissue disease ☐ Yes ☐ No ☐ Unknown

☐ Systemic lupus erythematosus ☐ Sjogrens syndrome ☐ Systemic sclerosis/scleroderma
☐ Poly/dermatomyositis ☐ Ehlers_danlos syndrome ☐ Juvenile idiopathic asthritis
☐ Mixed connective tissue disease ☐ Relapsing polychondritis ☐ Stills disease ☐ Other ☐ Unknown

Inflammatory bowel disease ☐ Yes ☐ No ☐ Unknown

Ulcerative colitis ☐ Yes ☐ No ☐ Unknown
Crohns disease ☐ Yes ☐ No ☐ Unknown

HIV ☐ Yes ☐ No ☐ Unknown

Immunodeficiency ☐ Yes ☐ No ☐ Unknown

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, eneteropathy, 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 ☐ Unknown
Aspiration	☐ Yes ☐ No ☐ Unknown
Gastro-oesophageal reflux disease	☐ Yes ☐ No ☐ Unknown
Congenital airway abnormality	☐ Yes ☐ No ☐ Unknown Please specify:_____
Foreign body inhalation or obstruction	☐ Yes ☐ No ☐ Unknown

After investigation, the underlying aetiology determined was:

☐ Idiopathic
☐ Post-infective
☐ Post-tuberculous
☐ ABPA
☐ Rheumatoid arthritis
☐ Connective tissue disease
☐ Inflammatory bowel disease
☐ Aspiration
☐ Gastroesophageal reflux disease
☐ Non-tuberculous mycobacteria
☐ COPD
☐ Asthma
☐ Primary ciliary dyskinesia

☐ Kartagener syndrome
☐ Youngs Syndrome
☐ Alpha-1-antitrypsin deficiency
☐ Common variable immunodeficinecy
☐ X-linked agammaglobulinaemia
☐ IgA deficiency
☐ IgG subclass deficiency
☐ Specific antibody deficiency
☐ HIV
☐ Williams-Campbell Syndrome
☐ Marfan Syndrome
☐ Mounier-Kuhn syndrome
☐ Yellow nail syndrome

Other aetiology (please specify):_____

MICROBIOLOGY

Have any microbiology samples been obtained for this patient? ☐ 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 (include negative cultures)

Date of sample: _____ (mm/yyyy) ☐ N/A

Source: ☐ Sputum ☐ BAL ☐ Induced sputum ☐ Throat swab

☐ No organism isolated
☐ Organism:_____

Antibiotic: Sensitive:_____
Sensitive:_____
Sensitive:_____
Sensitive:_____
Sensitive:_____
Resistant:_____
Resistant:_____
Resistant:_____
Resistant:_____

☐ Organism:_____

Antibiotic: Sensitive:_____
Sensitive:_____
Sensitive:_____
Sensitive:_____
Resistant:_____
Resistant:_____
Resistant:_____

Has the patient ever grown Pseudomonas aeruginosa? ☐ Yes ☐ No ☐ Unknown

How long ago was the most recent isolation of Pseudomonas? ☐ Present ☐ Last 2 years ☐ Last 5 years ☐ Last 10 years ☐ More than 10 years

Type: ☐ Mucoid ☐ Non-mucoid ☐ Unknown

Has the patient ever had nebulised, oral or intravenous antibiotics aimed at eradication of pseudomonas?
☐ Yes ☐ No ☐ Unknown

During exacerbations

Please provide details of all sputum results during exacerbations over the last 12 months

Date of sample: _____ (mm/yyyy) ☐ N/A Source: ☐ Sputum ☐ BAL ☐ Induced sputum ☐ Throat swab

☐ No organism isolated
☐ Organism:_____ Antibiotic: Sensitive:_____
Sensitive:_____
Sensitive:_____
Sensitive:_____
Sensitive:_____
Resistant:_____
Resistant:_____
Resistant:_____
Resistant:_____

☐ Organism:_____ Antibiotic: Sensitive:_____
Sensitive:_____
Sensitive:_____
Sensitive:_____
Sensitive:_____
Resistant:_____
Resistant:_____
Resistant:_____
Resistant:_____

Mycobacterial samples

Please provide details of all sputum results for acid fast bacilli/mycobacterial culture over the last 12 months

Date of sample: _____ (mm/yyyy) ☐ N/A Source: ☐ Sputum ☐ BAL ☐ Induced sputum ☐ Throat swab

☐ No organism isolated
☐ Organism:_____ Macrolide sensitivity: ☐ Yes ☐ No ☐ Unknown

RADIOLOGY

CT scan available for this patient? ☐ Yes ☐ No

If yes:

Date of CT scan: _____ (dd/mm/yyyy) ☐ Unknown

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

Right upper lobe:
☐ Cylindrical
☐ Varicose
☐ Cystic
☐ Unknown

Right middle lobe:
☐ Cylindrical
☐ Varicose
☐ Cystic
☐ Unknown

Right lower lobe:
☐ Cylindrical
☐ Varicose
☐ Cystic
☐ Unknown

Left upper lobe:
☐ Cylindrical
☐ Varicose
☐ Cystic
☐ Unknown

Lingula:
☐ Cylindrical
☐ Varicose
☐ Cystic
☐ Unknown

Left Lower lobe:
☐ Cylindrical
☐ Varicose
☐ Cystic
☐ Unknown

RESPIRATORY TREATMENTS

The patient has regular respiratory treatments: ☐ Yes ☐ No *(if yes, complete below)*

Long term oxygen therapy: ☐ Yes ☐ No ☐ Unknown

Non invasive ventilation: ☐ Yes ☐ No ☐ Unknown

Respiratory Medications

☐ Inhaled steroid Drug:_____
☐ Inhaled steroid/Long acting beta agonist Drug:_____
☐ Itraconazole Drug:_____
☐ Leukotriene receptor antagonist Drug:_____
☐ Long acting anti-muscarinic Drug:_____
☐ Long acting beta agonist Drug:_____
☐ Long term (>28 days) Oral corticosteroids Drug:_____
☐ Monoclonal antibody Drug:_____
☐ Mucolytic Drug:_____
☐ Nebulised bronchodilators Drug:_____
☐ Oral theophylline Drug:_____

Antibiotic Medications

☐ Inhaled/Nebulised antibiotics Drug:_____
☐ Long term (>28 days) Oral antibiotics Drug:_____
☐ Cyclical antibiotic therapy Drug:_____

Physiotherapy Adjuncts

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

Vaccination

Has the patient ever received?
Pneumococcal polysaccharide vaccine (e.g.: PSV23): ☐ Yes ☐ No ☐ Unknown
Pneumococcal conjugate vaccine (e.g.: PCV13): ☐ Yes ☐ No ☐ Unknown
In the last year has the patient received Influenza vaccination: ☐ Yes ☐ No ☐ Unknown

Physiotherapy and activity

Does the patient practice regular chest physiotherapy? ☐ Yes ☐ No ☐ Unknown

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

Devices:
- ☐ Positive expiratory pressure (PEP) device
- ☐ Flutter device
- ☐ Cornet
- ☐ Acapella
- ☐ Mechanical vibration
- ☐ Percussionaire
- ☐ 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
- ☐ Unknown

ADDITIONAL INFORMATION

Provide any additional required information in the free text provided:

_____
_____
_____
_____
_____
_____
_____