



Over the past few months we have seen an absolutely amazing commitment to the registry as recruitment figures continue to rise far beyond the 2020 target of 10,000 bronchiectasis patients. Not only have existing sites continued the hard work of ongoing recruitment but we have had the pleasure of setting up sites in Austria, Denmark, Sweden, Finland and Ukraine, bringing the number of participating countries to our current total of 33! We are proud to be working with you all and can only see good prospects for bronchiectasis research develop from such a massively important collaboration.



Embarc is also pleased to announce the launch of the European NTM Registry. This aims to recruit at least 800 patients with non-tuberculous mycobacterial disease. Patients enrolled in the registry may have bronchiectasis but the study is also enrolling patients without bronchiectasis. We are currently contacting sites to determine their interest in participating in this sub-study. Please contact us if you would like further information.

### \*\*\*IMPORTANT\*\*\*

Participants must be 18+ years at consent for eligibility.

Consent must be done face to face, by-proxy is not permitted.

Inhaled short acting bronchodilators do not need documented unless they are nebulised, in this case, all short acting bronchodilators should be recorded as salbutamol/albuterol.

Radiology data for new recruitment should be taken from CT scans prior to consent date, any data after this will be captured in the follow-up CRF.

Please check spirometry, microbiology, CT and QOL-B data is not that from the previous year—it must be new data taken since the previous data collection.

Please ensure any respiratory medication classed as "other" is documented in the additional notes if it is not available in the drop down menu. Please check the drop down menu for drug name and not brand name.

Please only record information relevant to bronchiectasis in the additional note, Recording of medication not requested in the CRF is not required.

The below table is for easy reference only. We acknowledge there are many more inhaler brands but have listed the most widely known to reduce the number of data queries. Salbutamol, Terbutaline and Ipratropium are short acting bronchodilators and do not require CRF capture.

	Drug	Trade		Drug	Trade
SABA (20mins to peak, acting for 3-6hrs)	Salbutamol	Ventolin	ICS/LABA	Fluticasone / Salmeterol	• Seretide • Sirdupla
	Terbutaline	Bricanyl		Beclomethasone / Formoterol	Fostair
SAMA (60min to peak, acting for 6-9hrs)	Ipratropium	Atrovent	LABA/LAMA (acting 6-8hrs)	Budesonide / Formoterol	• Symbicort • Duoresp • Spiromax
				Fluticasone / Vilanterol	• Relvar Ellipta • Breo Ellipta
ICS	Budesonide	Pulmicort	LABA/LAMA (acting 6-8hrs)	Fluticasone / Formoterol	Flutiform
	Fluticasone	Flovent		Indacaterol / Glycopyrronium	Ultibro Breezhaler
	Beclomethasone	• QVAR • Clenil Modulite		Formoterol / Acridinium	Duaklir
	Mometasone	Asmanex Twisthaler		Olodaterol / Tiotropium	Spiolto Respimat
LABA (acting for 12-24hrs)	Olodaterol	Striverdi Respimat	SABA/SAMA	Formoterol / Ipratropium	Combivent Respimat
	Indacaterol	Onbrez		Albuterol / Ipratropium	
	Formoterol	• Oxeze • Foradil			
	Salmeterol	Serevent			
LAMA (acting for up to 24hrs)	Glycopyrronium	Seebri	<ul style="list-style-type: none"> <li>SA - Short Acting (reliever)</li> <li>LA - Short Acting (preventer)</li> <li>BA- Beta2 Agonist (actively opens)</li> <li>MA- Muscarinic antagonist (anti cholinergic) (prevents closing)</li> <li>ICS: Inhaled Corticosteroid (reduces inflammation)</li> </ul>		
	Tiotropium	Spiriva			
	Acridinium	Eklira Genuair			
	Umeclidinium	Incruse Ellipta			

It is the responsibility of eligible centres to raise invoices for their recruitment.

The central team will not send reminders.

All invoices must be in English and addressed to;

The European Bronchiectasis Registry  
Clinical Research Centre  
James Arrott Drive  
University of Dundee  
Ninewells Hospital and Medical School  
Dundee DD1 9SY, UK

Alternatively, they can be emailed directly to the study coordinator; [m.l.crichton@dundee.ac.uk](mailto:m.l.crichton@dundee.ac.uk)

Please do not send invoices directly to the finance department.



Questions or comments? E-mail us at [info@bronchiectasis.eu](mailto:info@bronchiectasis.eu)



EUROPEAN RESPIRATORY SOCIETY every breath counts

### \*\*\*\*\* Frequently Asked Questions \*\*\*\*\*

- My patient is no longer in follow-up/has died, how do I proceed?**  
Every patient entering the registry should have at least one follow-up review. The review CRF will ask whether the patient is still alive and if they are still being followed-up. All new information which has been captured about the patient should be updated in the review CRF until the date of discharge/death ie. all pages of the eCRF must be completed. Once the review has been submitted to show patient is no longer in follow up or has died, no further follow-up cases will be required.
- My patient has had no tests done in the past 12months, how do I record this?**  
If there has been no change to comorbidities/ concomitant medications/ aetiology testing etc, "NO" should be selected to show this.  
\*\*Please remember all patients should be submitting at least one sputum sample (regardless of exacerbation) and undergoing spirometry testing at least once per year as per standards bronchiectasis care.
- Why do I have an exclamation mark next to some of my cases?**  
Exclamation marks will appear next to cases when a review is due. Amber represents 9months past the consent date and this will turn red at 12months. We cannot stress the importance of the review data to the registry.
- How often should I create a review and for how long is follow-up?**  
Reviews are mandatory for all patients entered to the registry and should be updated annually (every 12months) until 2020.
- The CRF page will not complete or allow me to submit the case.**  
When a page does not "complete", please select "CHECK COMPLETENESS" at the bottom of the page for advice on which data set is at fault.  
\*\* In the exception of MRC score for patients who have died or withdrawn and therefore cannot be contacted, please enter the same score as previous year.
- Is a CT angiogram acceptable for inclusion criteria?**  
A CT Pulmonary angiogram is eligible as it has a similar resolution to an HRCT- it should be entered under CT Thorax.  
If it is an angiogram ie the test used for diagnosing the source of haemoptysis or some other CT protocol then it is not eligible.
- Can I include patients with traction bronchiectasis?**  
No, the protocol specifically excludes traction bronchiectasis due to another pathology.
- How do I calculate the QOL-B results?**  
You do not need to do this, the eCRF will automatically do this for you. Please select the answers from the drop down menu which correspond to the patients' answers.  
\*\*It is preferred that QOL-B questionnaires are done in clinic/study visit and not returned by post.

## Publications

Risk factors for multidrug-resistant pathogens in bronchiectasis exacerbations  
Menéndez R, Méndez R, Polverino E, Rosales-Mayor E, Amara-Elorri I, Reyes S, Sahuquillo-Arce JM, Fernández-Barat L, Alcaraz V, Torres A.  
BMC Infect Dis. 2017 Sep 30;17(1):659. doi: 10.1186/s12879-017-2754-5.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5622549/>

Factors associated with hospitalizations in bronchiectasis exacerbations: a one-year follow-up study  
Menéndez R, Méndez R, Polverino E, Rosales-Mayor E, Amara-Elorri I, Reyes S, Posadas T, Fernández-Barat L, Torres A.  
Respir Res. 2017 Sep 30;18(1):176. doi: 10.1186/s12931-017-0659-x.  
<https://respiratory-research.biomedcentral.com/articles/10.1186/s12931-017-0659-x>

The respiratory threat posed by multidrug resistant Gram-negative bacteria.  
Rodrigo-Troyano A, Sibila O.  
Respirology. 2017 Oct;22(7):1288-1299. doi: 10.1111/resp.13115. Epub 2017 Jul 6. Review.  
<https://www.ncbi.nlm.nih.gov/pubmed/28681941>

Correlates and assessment of excess cardiovascular risk in bronchiectasis  
Aarash D, Saleh, Bessie Kwok, Jeremy S. Brown, John R. Hurst  
European Respiratory Journal 2017 50: 1701127; DOI: 10.1183/13993003.01127-2017  
<http://erj.ersjournals.com/content/50/5/1701127.long>

Cough and bronchiectasis  
PaulMcCallion/AnthonyDe Soya  
Pulmonary Pharmacology & Therapeutics Volume 47, December 2017, Pages 77-83  
<https://doi.org/10.1016/j.pupt.2017.04.010>

Sex bias in diagnostic delay in bronchiectasis: An analysis of the Spanish Historical Registry of Bronchiectasis  
Rosa Ma Girón, Javier de Gracia Roldán, Casilda Oliveira, Montserrat Vendrell, Miguel Ángel Martínez-García, David de la Rosa, Luis Máz, Julio Ancochea, Liliana Vázquez, Luis Borderías, Eva Polverino, Eva Martínez-Moragón, Olga Rajas, Joan B Soriano  
Chronic Respiratory Disease, vol. 14, 4: pp. 360-369. First Published April 10, 2017.  
[http://journals.sagepub.com/doi/abs/10.1177/1479972317702139?url\\_ver=Z39.88-2003&rft\\_id=ori:rid:crossref.org&rft\\_datcr\\_pub%3Dpubmed](http://journals.sagepub.com/doi/abs/10.1177/1479972317702139?url_ver=Z39.88-2003&rft_id=ori:rid:crossref.org&rft_datcr_pub%3Dpubmed)

Oral versus inhaled antibiotics for bronchiectasis.  
Spencer S, Felix LM, Milan SJ, Normansell R, Goeminne PC, Chalmers JD, Donovan T.  
Cochrane Database Syst Rev. 2018 Mar 27;3.CD012406. doi: 10.1002/14651858.CD012406.pub2. Review.  
<http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD012406.pub2>  
abstractId=DE41775D01670084045A9D88C7EE1A0E\_103101

Moving forward: Bronchiectasis and chronic suppurative lung disease in children and adults in the 21st century.  
Hill AT, Chang AB.  
Respirology. 2018 Mar 25. doi: 10.1111/resp.13296. [Epub ahead of print] Review. No abstract available.  
<https://onlinelibrary.wiley.com/doi/full/10.1111/resp.13296>

Prevalence, risk factors and prognosis of Non tuberculous mycobacteria infection among people with bronchiectasis: a population survey.  
Shteinberg M, Stein N, Adir Y, Ken-Dror S, Shitrit D, Bendayan D, Fuks L, Saliba W.  
Eur Respir J. 2018 Mar 15. pii: 1702469. doi: 10.1183/13993003.02469-2017. [Epub ahead of print] No abstract  
<http://erj.ersjournals.com/content/early/2018/03/01/13993003.02469-2017.long>

Macrolide antibiotics for bronchiectasis  
Kelly C, Chalmers JD, Crossingham I, Reiph N, Felix LM, Evans DJ, Milan SJ, Spencer S.  
Cochrane Database Syst Rev. 2018 Mar 27;3.CD012406. doi: 10.1002/14651858.CD012406.pub2. Review.  
<http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD012406.pub2>  
abstractId=1C7A4576F719CE992CEB5445F0883A7\_10103

The annual prognostic ability of FACED and E-FACED scores to predict mortality in patients with bronchiectasis.  
de la Rosa Carrillo D, Athanasio R, Girón Moreno RM, Máz Carro L, Oliveira C, de Gracia J, Vendrell M, Prados Sánchez C, Gramblícka G, Corso Pereira M, Lundgren F, Fernandes De Figueiredo M, Arancibia F, Rached S, Martínez-García MA.  
ERJ Open Res. 2018 Mar 6;4(1). pii: 00139-2017. doi: 10.1183/23120541.00139-2017. eCollection 2018 Jan.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5838357/>

Identification of Pseudomonas aeruginosa and airway bacterial colonization by an electronic nose in bronchiectasis  
Suarez-Cuartín G, Giner J, Merino JL, Rodrigo-Troyano A, Felíu A, Perea L, Sanchez-Reus F, Castillo D, Plaza V, Chalmers JD, Sibila O.  
Respir Med. 2018 Mar;136:111-117. doi: 10.1016/j.rmed.2018.02.008. Epub 2018 Feb 13.  
<https://www.sciencedirect.com/science/article/pii/S0954611118300374?via%3Dihub>

Information and education provision in bronchiectasis: co-development and evaluation of a novel patient-driven resource in a digital era.  
Hester KLM, Newton J, Ropley T, Ryan V, De Soya A.  
Eur Respir J. 2018 Mar 1. pii: 1702402. doi: 10.1183/13993003.02402-2017. [Epub ahead of print] No abstract available.  
<http://erj.ersjournals.com/content/51/4/1702402.long>

Bronchiectasis Exacerbations Are Heart-Breaking.  
Chalmers JD.  
Ann Am Thorac Soc. 2018 Mar;15(3):301-303. doi: 10.1513/AnnalsATS.201710-832ED. No abstract available.  
[https://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201710-832ED?url\\_ver=Z39.88-2003&rft\\_id=ori%3Arid%3ACrossref.org&rft\\_datcr\\_pub%3Dpubmed](https://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201710-832ED?url_ver=Z39.88-2003&rft_id=ori%3Arid%3ACrossref.org&rft_datcr_pub%3Dpubmed)

Bronchiectasis update.  
O'Donnell AE.  
Curr Opin Infect Dis. 2018 Apr;31(2):194-198. doi: 10.1097/QCO.0000000000000445.  
<https://insights.ovid.com/pubmed?pmid=29489526>

Bronchiectasis: new therapies and new perspectives.  
Chalmers JD, Chotirmall SH.  
Lancet Respir Med. 2018 Feb 22. pii: S2213-2600(18)30053-5. doi: 10.1016/S2213-2600(18)30053-5. [Epub ahead of print] Review.  
<https://www.sciencedirect.com/science/article/pii/S2213260018300535?via%3Dihub>

Aspergillus fumigatus Detection and Risk Factors in Patients with COPD-Bronchiectasis Overlap.  
Everaerts S, Lagrou K, Vermeersch K, Dupont LJ, Vanaudenaerde BM, Janssens W.  
Int J Mol Sci. 2018 Feb 9;19(2). pii: E523. doi: 10.3390/ijms19020523.  
<http://www.mdpi.com/1422-0067/19/2/523>

Pseudomonas aeruginosa infection and exacerbations in bronchiectasis: more questions than answers.  
Martínez-García MA.  
Eur Respir J. 2018 Jan 31;51(2). pii: 1702497. doi: 10.1183/13993003.02497-2017. Print 2018 Feb. No abstract available  
<http://erj.ersjournals.com/content/51/2/1702497.long>

The independent contribution of Pseudomonas aeruginosa infection to long-term clinical outcomes in bronchiectasis.  
Araújo D, Shteinberg M, Aliberti S, Goeminne PC, Hill AT, Fardon TC, Obradovic D, Stone G, Trautmann M, Davis A, Dimakou K, Polverino E, De Soya A, McDonnell MJ, Chalmers JD.  
Eur Respir J. 2018 Jan 31;51(2). pii: 1701953. doi: 10.1183/13993003.01953-2017. Print 2018 Feb.  
<http://erj.ersjournals.com/content/51/2/1701953.long>

RESPIRE: breathing new life into bronchiectasis.  
Chotirmall SH, Chalmers JD.  
Eur Respir J. 2018 Jan 25;51(1). pii: 1702444. doi: 10.1183/13993003.02444-2017. Print 2018 Jan. No abstract available.  
<http://erj.ersjournals.com/content/51/1/1702444.long>

RESPIRE 1: a phase III placebo-controlled randomised trial of ciprofloxacin dry powder for inhalation in non-cystic fibrosis bronchiectasis.  
De Soya A, Aksamit T, Bandel TJ, Criollo M, Elborn JS, Opershall E, Polverino E, Roth K, Winthrop KL, Wilson R.  
Eur Respir J. 2018 Jan 25;51(1). pii: 1702052. doi: 10.1183/13993003.02052-2017. Print 2018 Jan.  
<http://erj.ersjournals.com/content/51/1/1702052.long>

RESPIRE 2: a phase III placebo-controlled randomised trial of ciprofloxacin dry powder for inhalation in non-cystic fibrosis bronchiectasis.  
Aksamit T, De Soya A, Bandel TJ, Criollo M, Elborn JS, Opershall E, Polverino E, Roth K, Winthrop KL, Wilson R.  
Eur Respir J. 2018 Jan 25;51(1). pii: 1702053. doi: 10.1183/13993003.02053-2017. Print 2018 Jan.  
<http://erj.ersjournals.com/content/51/1/1702053.long>

Upper airway involvement in bronchiectasis is marked by early onset and allergic features.  
Shteinberg M, Nassrallah N, Jrbashyan J, Uri N, Stein N, Adir Y.  
ERJ Open Res. 2018 Jan 19;4(1). pii: 00115-2017. doi: 10.1183/23120541.00115-2017. eCollection 2018 Jan.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5773814/>

Characterisation of the "Frequent Exacerbator Phenotype" in Bronchiectasis.  
Chalmers JD, Aliberti S, Filonenko A, Shteinberg M, Goeminne PC, Hill AT, Fardon TC, Obradovic D, Gerlinger C, Sotgiu G, Opershall E, Rutherford RM, Dimakou K, Polverino E, De Soya A, McDonnell MJ.  
Am J Respir Crit Care Med. 2018 Jan 22. doi: 10.1164/rccm.201711-2202OC. [Epub ahead of print]  
<https://www.atsjournals.org/doi/abs/10.1164/rccm.201711-2202OC>

Treating Cough Due to Non-CF and CF Bronchiectasis With Nonpharmacological Airway Clearance: CHEST Expert Panel Report.  
Hill AT, Barker AF, Bolser DC, Davenport P, Ireland B, Chang AB, Mazzone SB, McGarvey L.  
Chest. 2018 Jan 31. pii: S0012-3692(18)30091-6. doi: 10.1016/j.chest.2018.01.014. [Epub ahead of print]  
[http://journal.chestnet.org/article/S0012-3692\(18\)30091-6/fulltext](http://journal.chestnet.org/article/S0012-3692(18)30091-6/fulltext)

The Prevalence and Significance of Staphylococcus aureus in Patients with Non-Cystic Fibrosis Bronchiectasis.  
Metersky ML, Aksamit TR, Barker A, Choate R, Daley CL, Daniels LA, DiMango A, Eden E, Griffith D, Johnson M, Knowles M, O'Donnell AE, Olivier K, Salathe M, Thomashow B, Tino G, Turino G, Winthrop KL, Mannino D.  
Ann Am Thorac Soc. 2018 Mar;15(3):365-370. doi: 10.1513/AnnalsATS.201706-426OC.  
[https://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201706-426OC?url\\_ver=Z39.88-2003&rft\\_id=ori%3Arid%3ACrossref.org&rft\\_datcr\\_pub%3Dpubmed](https://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201706-426OC?url_ver=Z39.88-2003&rft_id=ori%3Arid%3ACrossref.org&rft_datcr_pub%3Dpubmed)

Cross-infection risk in patients with bronchiectasis: a position statement from the European Bronchiectasis Network (EMBARC), EMBARC/ELF patient advisory group and European Reference Network (ERN-Lung) Bronchiectasis Network.  
Chalmers JD, Ringshausen FC, Harris B, Elborn JS, Posthumus A, Haworth CS, Pilkington N, Polverino E, Ruddy T, Aliberti S, Goeminne PC, Winstanley C, De Soya A.  
Eur Respir J. 2018 Jan 11;51(1). pii: 1701928. doi: 10.1183/13993003.01928-2017. Print 2018 Jan. No abstract  
<http://erj.ersjournals.com/content/51/1/1701928.long>

Long-term benefits of airway clearance in bronchiectasis: a randomised placebo-controlled trial.  
Murof G, de Gracia J, Buxó M, Alvarez A, Vendrell M.  
Eur Respir J. 2018 Jan 11;51(1). pii: 1701928. doi: 10.1183/13993003.01928-2017. Print 2018 Jan.  
<http://erj.ersjournals.com/content/51/1/1701928.long>

Macrolides, mucocactive drugs and adherence to the management of bronchiectasis.  
Chalmers JD, Polverino E; European Respiratory Society Bronchiectasis Guidelines Task Force.  
Eur Respir J. 2018 Jan 4;51(1). pii: 1702033. doi: 10.1183/13993003.02033-2017. Print 2018 Jan. No abstract available.  
<http://erj.ersjournals.com/content/51/1/1702033.long>

Spanish Guidelines on the Evaluation and Diagnosis of Bronchiectasis in Adults.  
Martínez-García MA, Máz L, Oliveira C, Girón RM, de la Rosa D, Blanco M, Cantón R, Vendrell M, Polverino E, de Gracia J, Prados C.  
Arch Bronconeumol. 2018 Feb;54(2):79-87. doi: 10.1016/j.arbres.2017.07.015. Epub 2017 Nov 9. English, Spanish.  
<http://www.archbronconeumol.org/en/spanish-guidelines-on-evaluation-diagnosis/articulo/S157921291730383X/>

Spanish Guidelines on Treatment of Bronchiectasis in Adults.  
Martínez-García MA, Máz L, Oliveira C, Girón RM, de la Rosa D, Blanco M, Cantón R, Vendrell M, Polverino E, de Gracia J, Prados C.  
Arch Bronconeumol. 2018 Feb;54(2):88-98. doi: 10.1016/j.arbres.2017.07.016. Epub 2017 Nov 9. English, Spanish.  
<http://www.archbronconeumol.org/en/pdf/S1579212917303841/S300/>

Bronchiectasis: Rising from its own ashes.  
Martínez-García MA, de la Rosa-Carrillo D.  
Arch Bronconeumol. 2018 Feb;54(2):59-60. doi: 10.1016/j.arbres.2017.06.022. Epub 2017 Aug 1. English, Spanish. No abstract available.  
<http://www.archbronconeumol.org/bronchiectasis-rising-from-its-own-ashes/articulo/S1579212917303725/>