

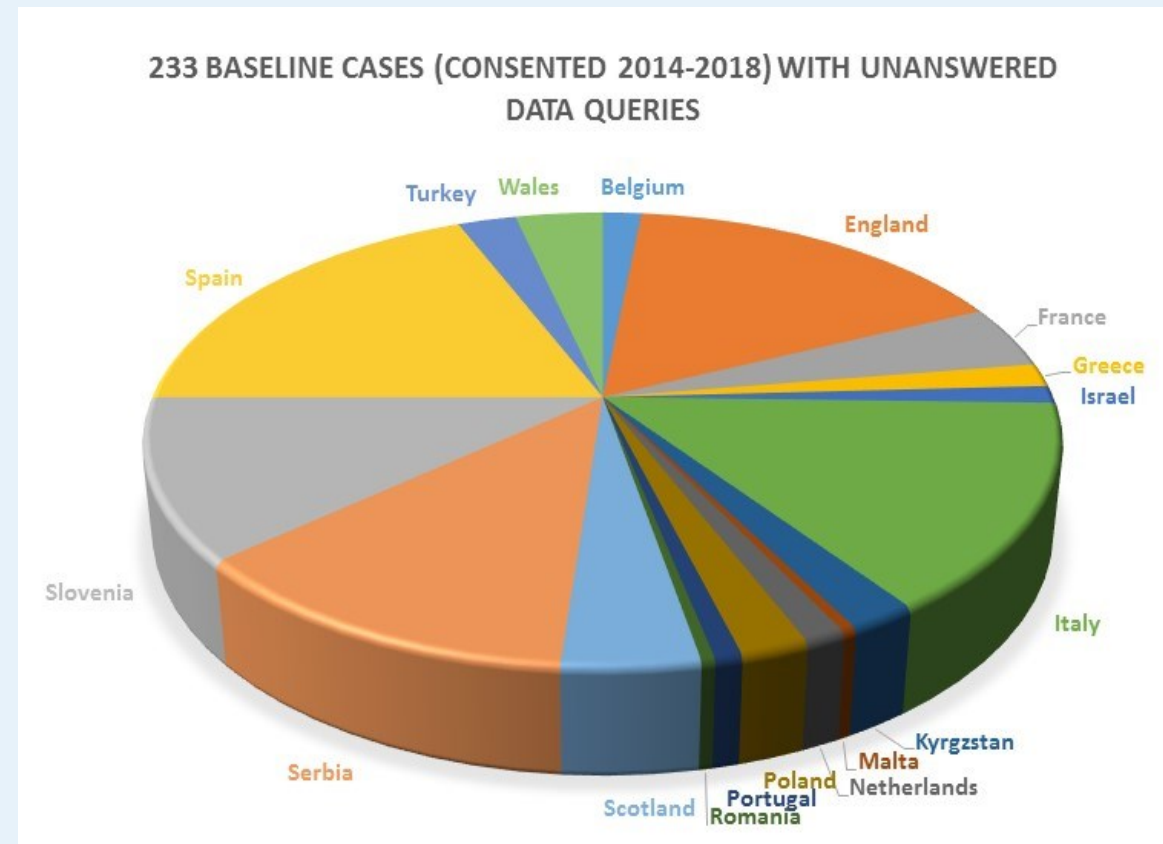
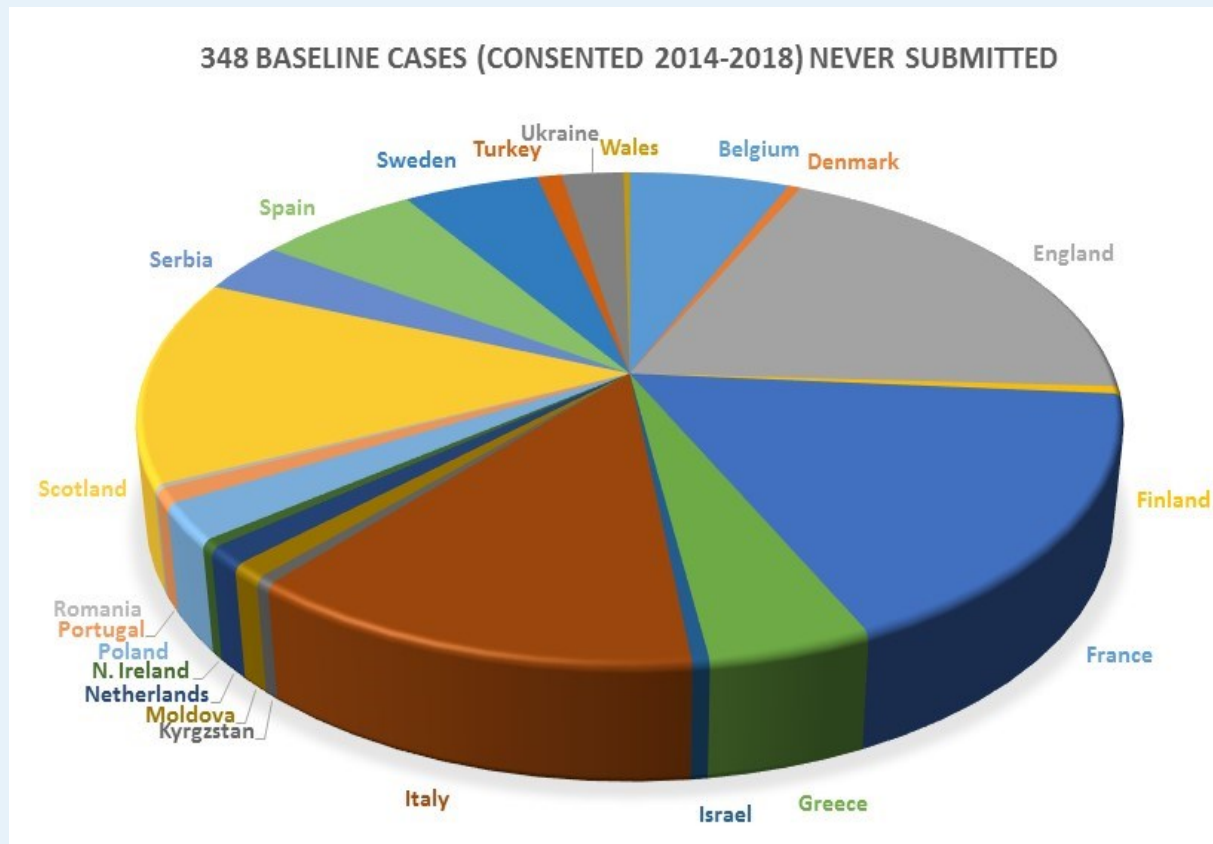
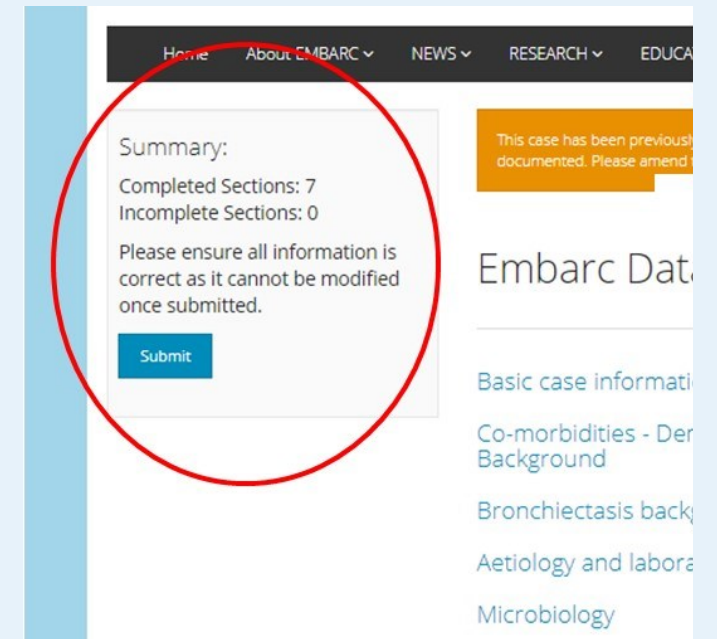


EMBARC registry

We would like to give a massive thank you to all who continue to recruit new patients to the registry. It is amazing to see the continued dedication in bronchiectasis research especially as we have recently passed the 14,000th EU patient bringing us to a global total of 16,000!

Please remember only the cases which are fully submitted to the registry contribute to data analysis as it is only then that the data can be verified. Unfortunately we are aware of data belonging to **581** patients consented between 2014 and 2018 which cannot yet contribute to analysis as they are still waiting for full submission. 40% of these cases are needing data queries resolved leaving 60% having never before been submitted.

Ideally, cases should not spend more than 3months in the unsubmitted section. Please contact the study coordinator, m.l.crichton@dundee.ac.uk if assistance is required or if any cases need removed from the EMBARC eCRF system.



European Ntm & Bronchiectasis Workshop

July 6th – 8th, 2019
Vienna

The first European NTM and Bronchiectasis workshop was held in July in Vienna. The workshop proved a great success covering many interesting topics from diagnosis and treatments to epidemiology and radiology.

For anyone who could not make the workshop or wishes to review the materials, video recordings of the sessions can be accessed via www.ntmbronchiectasis.org

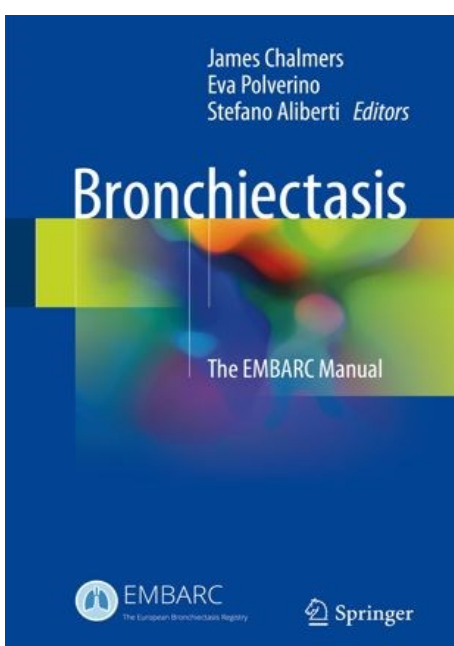
The pulmonary NTM registry is now underway. If your centre specialises in pulmonary NTM and would like to take part in this sub-study, please contact info@bronchiectasis.eu

The European Lung Foundation are also interested in hearing patient experience in being diagnosed with bronchiectasis and/or NTM. Please direct your patients to the [ELF website](http://elf.org) where they can complete the survey anonymously.

The European NTM Registry

4th World Bronchiectasis & NTM Conference
Barcelona
2 - 4 July 2020

Organising Secretariat: www.embarc.eu



The EMBARC Manual

The EMBARC manual is still proving popular and is available for free download. Individual chapters can be downloaded or the book in its entirety. For more information or to download your own copy please visit

<https://link.springer.com/book/10.1007%2F978-3-319-61452-6#about>

THE LANCET Respiratory Medicine

THE LANCET Global Health

We are extremely proud to announce the simultaneous publications of three papers in the Lancet journals.

Congratulations to the EMBARC India team who published their first report from the Indian bronchiectasis registry, the largest national dataset for bronchiectasis in the world. Remarkable differences were found between bronchiectasis patients in India compared to those in Europe and the United States. The findings were published in the Lancet Global Health.

A further two papers were simultaneously published in the Lancet Respiratory Medicine. These saw Dr Jose Altenburg lead a meta-analysis on the use of macrolides in bronchiectasis patients while another meta-analysis on inhaled antibiotics was led by EMBARC fellow, Irena Laska.

In addition to these, we are happy to announce the first report from the Australian Bronchiectasis Registry has now also been published in Respiratory Medicine. Links to all of these publications can be found on the next page amongst many other publications from EMBARC contributors.



Patient Priorities

The ELF Patient Priorities website has been specifically designed for patients with the help of the European bronchiectasis patient support group. The website contains lots of patient friendly information in the form of videos, lay guidelines and documents translated into multiple languages. The most recent addition sees the completion of the new "Drugs in development" section which gives an overview of bronchiectasis research and is kept current to show ongoing trials. A patient checklist has also been designed based on the European Bronchiectasis Guidelines 2017 and made freely available on the site. This document lists what most bronchiectasis patients should expect from their care. Please encourage your patients to visit the site for accredited information www.europeanlunginfo.org/bronchiectasis

EMBARC Presents at ERS 2019

Monday 30th

Session 257 **Poster discussion** 10:45 - 12:45

Clinical and translational studies of bronchiectasis and non-TB mycobacterial infection

- PA2163 Risk factors for new *P. aeruginosa* isolation in bronchiectasis- data from the European Bronchiectasis Registry (EMBARC) P. Burgel (France)
- PA2170 Inflammatory molecular endotypes in bronchiectasis A. Shoemark (UK)

Session 297 **Thematic poster** 12:50-14:40

Phenotypes and endotypes of bronchiectasis

- PA 2877 Phenotyping of adult patients with bronchiectasis and Yellow-Nail-Syndrome (YNS)- data from the German and the European Bronchiectasis Registries (PROGNOSIS and EMBARC) I. Pink (Germany)

Session 300 **Thematic poster** 12:50-14:40

Clinical investigations of non-TB mycobacterial infection

- PA2937 New isolation of non-tuberculous mycobacteria in patients with bronchiectasis - data from the European Bronchiectasis Registry (EMBARC) F. Ringshausen (Germany)

Tuesday 1st

Session 504 **Oral presentation** 14:45-16:45

Advances in bronchiectasis and non-TB mycobacterial infections

- 16:00 Determinants of survival in the European Bronchiectasis Registry (EMBARC) S. Aliberti (Italy)



Zambon Invitation to ERS Meeting

For anyone attending ERS 2019, the Zambon team, sponsors of the PROMIS trials, are holding an Investigator update and discussion meeting. They will review and discuss key aspects for the successful delivery of the trial based on real life experience to-date including the patient profile, recruitment and retention strategies, and management/reporting of exacerbations, all from the perspective of the investigator site team. They will also provide an update on status, timelines and key changes in the programme. Speakers include Lucy Morgan, James Chalmers, Charlie Haworth and Felix Ringshausen. If you are currently taking part in the study (or interested in taking part) and attending the ERS meeting they cordially invite you and your colleagues to attend.

DATE: Monday 30th September 2019
VENUE: Melia Barajas Hotel close to ERS venue
TIMING: 5.15-7.00 PM (refreshments provided)



Publications

Call for Data Applications

If you have a research question which can be answered using the EMBARC dataset and wish to access EMBARC data please complete a data applications form and send to the research coordinator, info@bronchiectasis.eu
Data request forms can be downloaded from the EMBARC website or accessed from this link.

- ◊ **Bronchiectasis insanity: Doing the same thing over and over again and expecting different results?**
Metersky M, Chalmers J
F1000Res. 2019 Mar 15;8. pii: F1000 Faculty Rev-293. doi: 10.12688/f1000research.17295.1. eCollection 2019.
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- ◊ **Bronchiectasis phenotypes.**
Chang-Macchiu P, Traversi L, Polverino E.
Curr Opin Pulm Med. 2019 Mar 18. doi: 10.1097/MCP.0000000000000569. [Epub ahead of print]
<https://insights.ovid.com/pubmed?pmid=30893106>
- ◊ **A systematic review of pharmacotherapeutic clinical trial end-points for bronchiectasis in adults.**
Crichton ML, Aliberti S, Chalmers JD.
Eur Respir Rev. 2019 Mar 14;28(151). pii: 180108. doi: 10.1183/16000617.0108-2018. Print 2019 Mar 31. Review.
<https://err.ersjournals.com/content/28/151/180108.long>
- ◊ **Chronic Bacterial Infection Prevalence, Risk Factors, and Characteristics: A Bronchiectasis Population-Based Prospective Study.**
Amorim A, Meira L, Redondo M, Ribeiro M, Castro R, Rodrigues M, Martins N, Hespanhol V.
J Clin Med. 2019 Mar 6;8(3). pii: E315. doi: 10.3390/jcm8030315.
<https://www.mdpi.com/2077-0383/8/3/315>
- ◊ **The economic burden of bronchiectasis – known and unknown: a systematic review**
Goeminne PC, Hernandez F, Diel R, Filonenko A, Hughes R, Juelich F, Solomon GM, Upton A, Wichmann K, Xu W, Chalmers JD.
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- ◊ **National Survey on the Management of Adult Bronchiectasis in Belgium.**
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- ◊ **British Thoracic Society guideline for bronchiectasis in adults.**
Hill AT, Sullivan AL, Chalmers JD, De Soya A, Elborn SJ, Floto AR, Gruffydd-Jones K, Harvey A, Haworth CS, Hiscocks E, Hurst JR, Johnson C, Kelleher PW, Bedi P, Payne K, Saleh H, Sreaton NJ, Smith M, Tunney M, Whitters D, Wilson R, Loebinger MR.
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https://thorax.bmj.com/content/74/Suppl_1/1.long
- ◊ **Updated BTS Adult Bronchiectasis Guideline 2018: a multidisciplinary approach to comprehensive care.**
Hill AT, Welham SA, Sullivan AL, Loebinger MR.
Thorax. 2019 Jan;74(1):1-3. doi: 10.1136/thoraxjnl-2018-212468.
<https://thorax.bmj.com/content/74/1/1.long>
- ◊ **Economic burden of bronchiectasis in Germany.**
Diel R, Chalmers JD, Rabe KF, Nienhaus A, Loddenkemper R, Ringshausen FC.
Eur Respir J. 2019 Feb 28;53(2). pii: 1802033. doi: 10.1183/13993003.02033-2018. Print 2019 Feb.
<https://erj.ersjournals.com/content/53/2/1802033.long>
- ◊ **Feasibility of computerized adventitious respiratory sounds to assess the effects of airway clearance techniques in patients with bronchiectasis.**
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Physiother Theory Pract. 2019 Jan 23;1-11. doi: 10.1080/09593985.2019.1566945. [Epub ahead of print]
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- ◊ **Inhaled liposomal ciprofloxacin in patients with non-cystic fibrosis bronchiectasis and chronic lung infection with Pseudomonas aeruginosa (ORBIT-3 and ORBIT-4): two phase 3, randomised controlled trials.**
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- ◊ **Low transmission risk of Pseudomonas aeruginosa in a bronchiectasis clinic based on the knowledge of bacterial population biology.**
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- ◊ **Atypical Mycobacteria in Bronchiectasis. When do we Treat it?**
Perez-Miranda J, Traversi L, Polverino E.
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- ◊ **Advances in bronchiectasis.**
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- ◊ **A point-of-care neutrophil elastase activity assay identifies bronchiectasis severity, airway infection and risk of exacerbation.**
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- ◊ **Mucoid Pseudomonas aeruginosa alters sputum viscoelasticity in patients with non-cystic fibrosis bronchiectasis.**
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- ◊ **Soluble P-selectin in Acute Exacerbations and Stable Bronchiectasis in Adults.**
Raúl Méndez, Antonio Moscardó, Ana Latorre, Laura Feced, Paula González-Jiménez, Alba Piró, Victoria Alcaraz-Serrano, Giulia Scioscia, Rosanel Amaro, Antoni Torres, Rosario Menéndez
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- ◊ **Bronchiectasis in India: results from the European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC) and Respiratory Research Network of India Registry.**
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- ◊ **Efficacy and safety of tobramycin inhalation powder in bronchiectasis patients with P. aeruginosa infection: Design of a dose-finding study (iBEST-1).**
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