



# EMBARC Newsletter

## Welcome to the 2<sup>nd</sup> edition of the EMBARC Newsletter!

We are excited to bring you the latest updates and achievements from the EMBARC community!

In this edition, we're showcasing the recent success of our "Educated and Empowered" webinar in celebration of World Bronchiectasis Day, and a key milestone for the EMBARC community - the 10<sup>th</sup> anniversary of the EMBARC registry!

It's also almost time to pack our bags and head to Amsterdam for the European Respiratory Society Congress! We'll be sharing the details of some not-to-be-missed bronchiectasis sessions and how EMBARC will be present at this year's congress.

We are also happy to spotlight 3 recently published EMBARC publications!

This issue also includes some exciting research initiatives, including the launch of a new patient survey that we would very much appreciate your help in encouraging your bronchiectasis patients to take part in, and our new 'Bronchiectasis Empowerment Pack' aimed at people with bronchiectasis and clinicians to educate and facilitate empowering discussions.

As always, we will also be sharing EMBARC project updates, insights and key 'dates for the diary' to keep you both informed and inspired.

We are sure you will agree, there's something here for everyone.

We thank you for being a part of our journey and for your continued support.

Please enjoy this edition of the newsletter.

With best wishes,



## EMBARC

The European Bronchiectasis Registry





## Celebrating World Bronchiectasis Day 2025

On July 1<sup>st</sup> 2025, we celebrated **World Bronchiectasis Day** - a day which aims to call attention to the growing burden of this lesser-known respiratory disease and the urgent need for increased awareness, diagnosis and improved care to reduce the burden of bronchiectasis for patients and their families.

To celebrate the day, we collaborated with the [European Lung Foundation](#) to host a **Bronchiectasis Question Time webinar** aimed at patients, their caregivers and those looking to learn more about bronchiectasis.

The 1-hour webinar - titled **'Educated and Empowered: how to take control of your bronchiectasis'** - saw an expert panel consisting of patient representatives and EMBARC members answer pre-submitted questions.

**266 people from 38 countries** attended the event - an increase from last year's event!

Our panel answered **22 pre-submitted questions** during the webinar, with **>80 patient questions answered live** via the Q&A chat.

The event was incredibly well received by attendees, including both the patient community and healthcare professionals:



*"Being recently diagnosed, it was a revelation to hear from so many experts and someone actually in the same boat as me"*

*"A better insight on condition from perspective of the health care professionals but also from someone who lives with this condition. For me, as a GP, was a very valuable experience."*



**We would like to thank all of those who attended, and our expert panelists for their participation and contribution to the success of the event!**

The recording of the Educated and Empowered webinar (with subtitles), as well as previous Bronchiectasis Question Time events, are available to watch [here](#).





## Celebrating the 10<sup>th</sup> Anniversary of the EMBARC Registry at ERS 2025!

We're proud to share that **25 EMBARC abstracts** have been accepted for presentation at the European Respiratory Society (ERS) Congress 2025, reflecting the strength and momentum of bronchiectasis research.

**2025 also marks 10 years of the EMBARC registry!** We are incredibly proud of the collaborative research community that we have created and the impact that the EMBARC registry has made in progressing bronchiectasis research over the past 10 years.

We are particularly excited to celebrate this milestone with our EMBARC community at the upcoming ERS 2025 meeting. In honour of this anniversary, the congress are hosting a special themed oral session titled...



***'A new era for bronchiectasis: 10 years of progress in global management'***



The session, featuring key EMBARC community members, will delve into how our understanding of bronchiectasis has developed since 2015 and what the future holds for advancements in bronchiectasis research.

This session will take place on **Monday 29<sup>th</sup> September at 14:15-15:00 CEST**.

We are also happy to share that **EMBARC will have an exhibition stand** at the congress! Be sure to stop by, say 'hello!' and:

- ◆ Take a journey through the EMBARC registry's 10 year history
  - ◆ Learn more about the EMBARC registry and biobank
  - ◆ Meet and connect with EMBARC researchers
  - ◆ Listen to expert talks
- ◆ Explore how to get involved in EMBARC - whether you're a clinician, researcher, or industry partner

We hope to connect with you all and celebrate this milestone together at ERS 2025!





## EMBARC-BRIDGE Electronic Data Collection is live!



For sites involved in the BRIDGE study, you can now begin to upload the clinical data for the patients you have recruited in recent months.

Details will be sent to sites with information regarding accessing and uploading data to the database.

If you have any questions, please contact [respiratoryresearchgroup@dundee.ac.uk](mailto:respiratoryresearchgroup@dundee.ac.uk)

## Are you interested in utilising EMBARC data and/or samples for your research?

The EMBARC registry and EMBARC-BRIDGE biobank are valuable resources developed to support high-quality, collaborative research into bronchiectasis.

As such, we offer a selection of samples to support research, including:



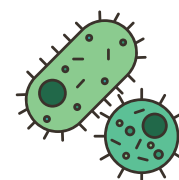
**Clinical Data**



**Biological Samples**



**Biological Datasets**



**Bacterial Isolates**

We are also able to provide scientific advice and statistical support with research.

If you are interested in accessing these resources for an upcoming research project, please complete the relevant application forms below (also available on our [website](#)).

[Request EMBARC Clinical Data](#)

[Request EMBARC-BRIDGE Samples](#)

[Request EMBARC-BRIDGE Datasets](#)

[Request EMBARC Bacterial Isolates](#)





## Launch of an EMBARC/ELF Patient Survey: 'Untold Stories of Bronchiectasis'

In collaboration with the European Lung Foundation (ELF), we are excited to launch a **new multilingual patient survey** aiming to better understand the experiences of those living with bronchiectasis in areas that are often under-researched or overlooked in clinical practice, including:



**Gut health and digestion**



**Fertility, Menopause and Hormonal Changes**



**Co-existing conditions**



**Use of Herbal and Complimentary Therapies**

The survey takes ~15-20 minutes to complete and is anonymous.

The survey is available in **8 languages** ([English](#), [Italian](#), [Spanish](#), [French](#), [German](#), [Portuguese](#), [Hebrew](#), and [Arabic](#)).

**SURVEY DEADLINE: 30th October 2025**



**EMBARC Clinicians and Researchers**  
Please help us share the survey with the patient community!



**Share the details of the survey** with your patients and bronchiectasis networks



**Download and display/share our multilingual flyers** in your clinics, waiting rooms, newsletters, or online communities.



**Encourage your patients to participate** in the survey and share their experiences

Your support will help ensure we hear from a diverse range of patients and uncover valuable insights that could improve care and research directions.

## ‘Bronchiectasis Empowerment Pack’

In collaboration with the European Lung Foundation, we have designed a **shared resource designed for both patients and clinicians** to support open communication, promote shared decision-making, and ensure that everyone involved in managing bronchiectasis has access to trusted, practical information.



**For  
clinicians**

This pack is a learning tool for bronchiectasis that can build knowledge. It supports informed decisions and encourages collaborative healthcare.

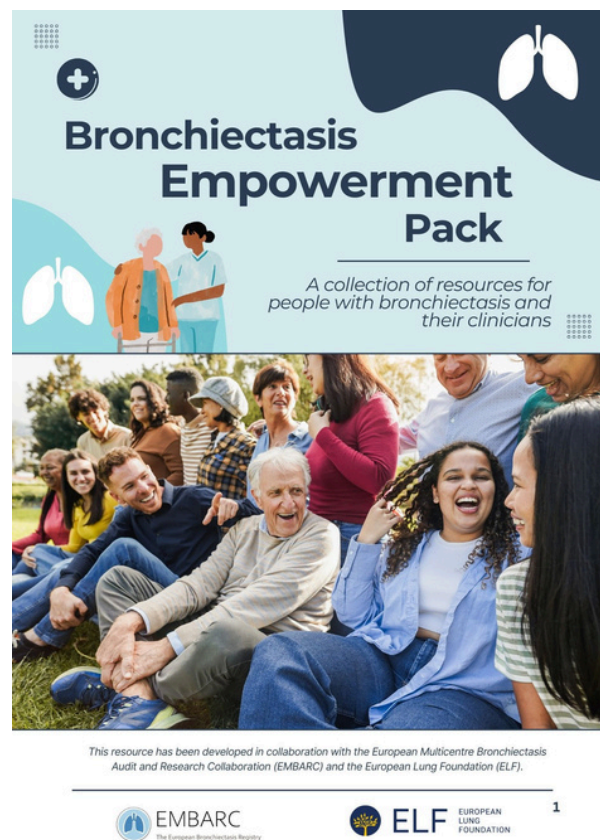
This pack offers clear information about bronchiectasis, including tips, tools, and resources to help manage the condition and take an active role in your care.



**For  
patients**

We hope this pack acts as a starting point for conversations, planning, and confidence-building.

**We encourage you to [download and share this resource pack](#) with your patients and online communities!**





We are thrilled to have **published 3 new EMBARC publications!**

**Endotypes of *Pseudomonas aeruginosa* infection in Bronchiectasis Are Associated with Inhaled Antibiotic Response: Results from Two Randomised, Double-blind, Placebo-controlled Phase III Trials (ORBIT-3 and ORBIT-4)**



Rebecca Hull et al. AJRCCM. Published Online: July 2025. [doi: 10.1164/rccm.202501-0159OC](https://doi.org/10.1164/rccm.202501-0159OC).

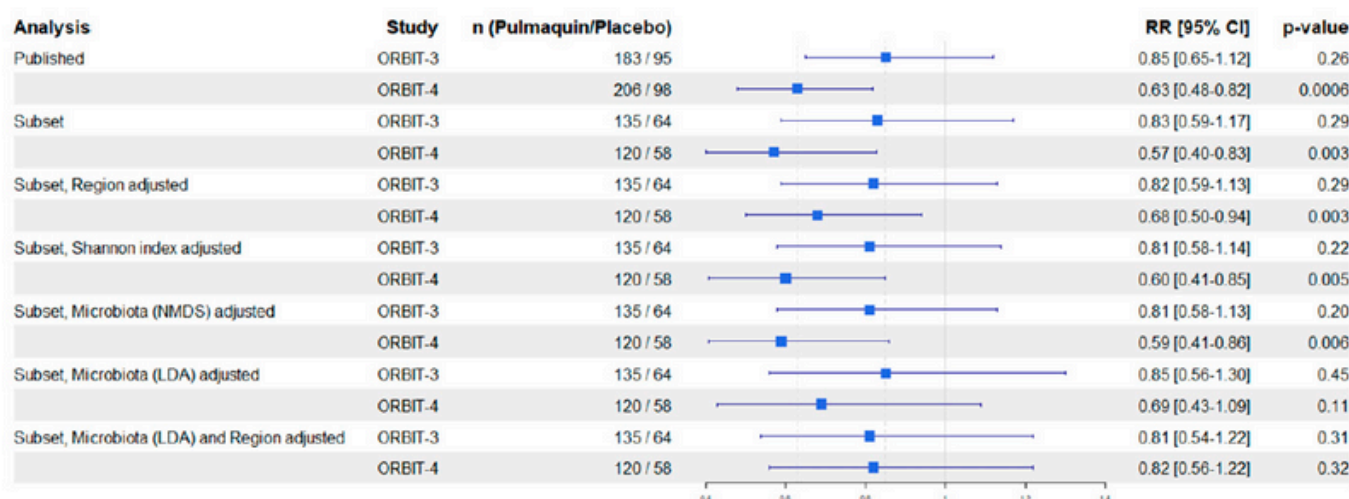
This research utilised sputum samples from those enrolled in the [ORBIT-3 and ORBIT-4 trials](#) ([Haworth et al., 2019](#)) - replicate randomised Phase III trials investigating the efficacy of inhaled ciprofloxacin in those with bronchiectasis with chronic *Pseudomonas* infection which reported inconsistent results, not explained by differences in patient characteristics between the trials.

Here, Hull et al. performed 16S rRNA sequencing, proteomics and inflammatory marker quantification to profile a global cohort of bronchiectasis patients with chronic *P. aeruginosa* infection and investigate if different microbial and inflammatory endotypes are linked to antibiotic response.

The results show that patients with chronic *P. aeruginosa* infection demonstrate heterogeneous microbiota and inflammatory profiles, which differ in their associations with exacerbation frequency and response to inhaled antibiotic treatment. Geographic differences were also observed.

After accounting for differences in microbiota profile and geographical region, the treatment effect of inhaled antibiotics in both trials appeared similar and matched findings from previous meta-analyses of trials of inhaled antibiotics - identifying these variables as potentially important confounders of inhaled antibiotic response. **This study not only deepens our understanding of why replicate trials can produce inconsistent results but also suggests a way to make antibiotic trials more consistent, emphasising the importance of disease endotypes in clinical research.**

To read the full article, click [here](#).



Taken from Hull et al., 2025.

## Greater disease severity in adults with paediatric-onset versus adult-onset bronchiectasis: a multicenter EMBARC registry study



Luai Khalaili et al. ERJ. Published Online: July 2025. [doi.org/10.1183/13993003.00665-2025](https://doi.org/10.1183/13993003.00665-2025)

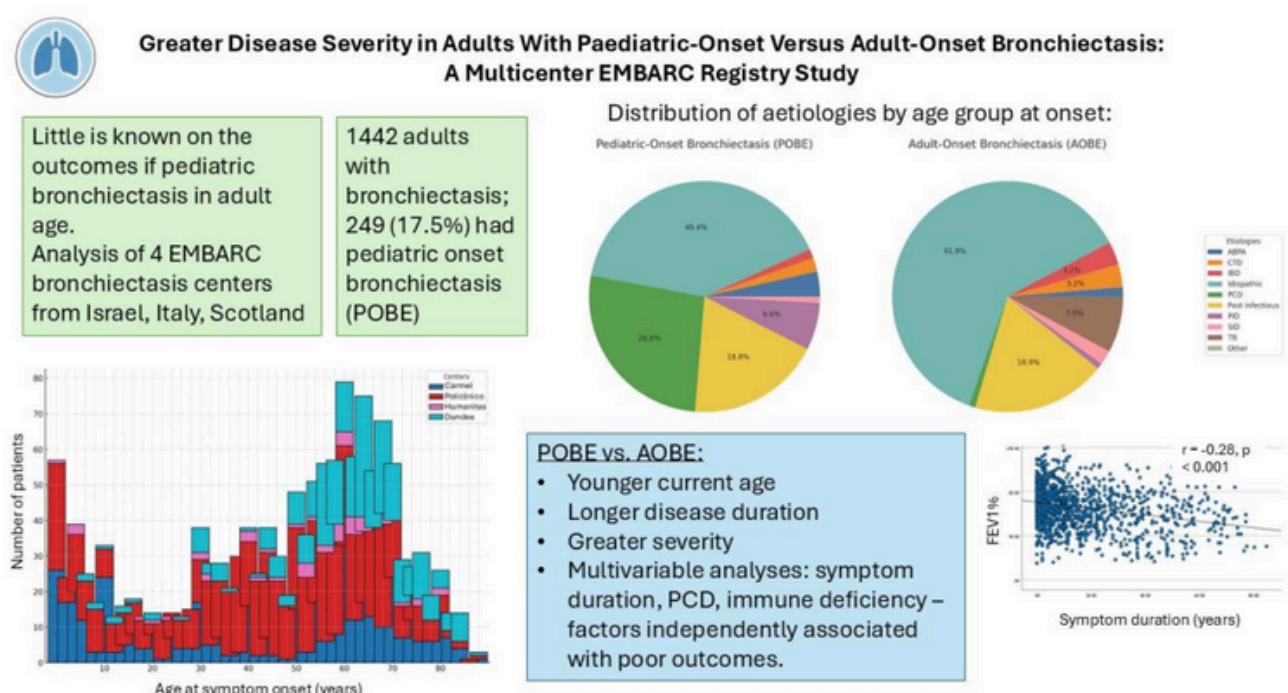
Heterogeneity in bronchiectasis creates challenges with diagnosis and management. Young adults with bronchiectasis, as well as older adults with POBE, may differ from those with AOB, requiring differing approaches to disease self-management. The proportion of adult bronchiectasis cases attributed to POBE, as well as the characteristics of those with POBE, is currently unclear.

This research utilised data from 1,422 individuals with bronchiectasis enrolled across 4 centres contributing to the EMBARC registry to compare disease characteristics between those with paediatric-onset bronchiectasis (POBE) and adult-onset bronchiectasis (AOBE).

Here, Khalaili et al report POBE accounted for 17.5% of this bronchiectasis cohort, with those with POBE having a younger age at enrollment, longer disease/symptom duration and increased severity - including worsened lung function, radiological severity, infection burden and exacerbations.

This study advances our understanding of POBE, highlighting POBE as a significant contributor of disease burden in bronchiectasis - **advocating for appropriate transitioning programs directed at young adults with bronchiectasis to mitigate disease progression**. This study also highlights that conventional bronchiectasis severity assessment scores may underestimate severity in young people with POBE - a finding that warrants further investigation.

To read the full article, click [here](#).



Taken from Khalaili et al., 2025.





## Sputum metagenomics in bronchiectasis reveals pan-European variation: an EMBARC-BRIDGE study.



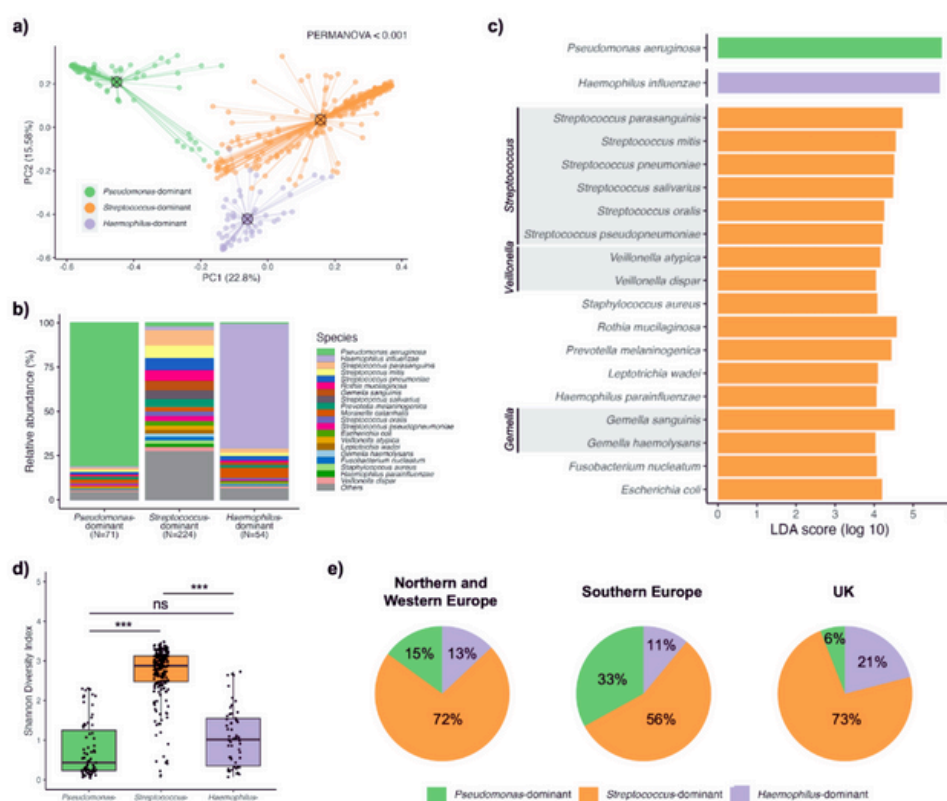
Kai Xian Thng, et al. ERJ. Published Online: May 2025. [doi.org/10.1183/13993003.00054-2025](https://doi.org/10.1183/13993003.00054-2025)

This research used next generation metagenomic sequencing to assess the sputum microbiome and antimicrobial resistance gene profiles, or "resistomes", of 349 participants with bronchiectasis enrolled in the multicentre, observational EMBARC-BRIDGE study.

Previous analysis of the EMBARC Registry reported geographic variation in sputum microbiology across Europe ([Chalmers et al., 2023](#)), and observations of failed replicate pan-European clinical trials in bronchiectasis emphasise an inherent heterogeneity among European bronchiectasis patients. However, there is currently a lack of literature comparing variation in the microbiome across geographical regions.

Here, Thng et al. confirm and expand on earlier findings showing geographic differences in the bronchiectasis airway microbiome, using metagenomics. Metagenomics revealed three microbial clusters, each dominated by *Pseudomonas*, *Streptococcus* or *Haemophilus*, with variable distribution across Europe. The authors also validated the existence of known bronchiectasis resistotypes (RT1 & RT2) ([Mac Aogain et al., 2024](#)) and reported diversity in the distribution of resistome profiles across Europe. This study provides critical insight into the local and regional antimicrobial resistance trends - **highlighting the important implications of the variable distribution of pathogens and antimicrobial resistance profiles for clinical practice across Europe.**

To read the full article, click [here](#).



Taken from Thng et al., 2025.



# GENERAL ANNOUNCEMENTS

## The ✨ FUTURE ✨ of EMBARC

We are in the process of launching **FUTURE** - an **EMBARC network for Early Career Researchers (ECRs)**.

The programme aims to establish a collaborative research network for ECRs interested in bronchiectasis research to:

- ✓ Drive EMBARC-related research projects
- ✓ Strengthen mentorship and career development opportunities
- ✓ Encourage continued education and patient advocacy among ECRs.

If you are an ECR - or know an ECR - who may be interested in FUTURE, please register interest [here](#).

## Dates for the Diary



### ERS Research Seminar

*'Dissecting similarities and differences of exacerbations across different chronic airway diseases'*

**22-23 Jan 2026 | Barcelona, Spain**

**[REGISTER](#) BY: 21 SEPT 2025**

## EMBARC-BRIDGE

We currently have...

 **>1,500 patients from 25 sites** 

enrolled in the EMBARC-BRIDGE study!

If your site is interested in taking part in **BRIDGE**, please register your interest on the following [form](#) or contact [contact@bronchiectasis.net](mailto:contact@bronchiectasis.net) for more information.

If you are interested in collaborating and/or working with **EMBARC samples/resources**, please submit your request on the following [form](#).



**Have you got something you would like to share with the EMBARC community?**



If so, please email your submission with a short description to [contact@bronchiectasis.net](mailto:contact@bronchiectasis.net)

*Thank you for reading!*



[www.bronchiectasis.net](http://www.bronchiectasis.net)



[contact@bronchiectasis.net](mailto:contact@bronchiectasis.net)



EMBARC - The European  
Bronchiectasis Network