



## 10,000 Patients Recruited!!!

In 2014 the idea of creating a pan-European specialist bronchiectasis network containing the first registry for bronchiectasis patients was set in motion. EMBARC set off on a mission to recruit 10,000 bronchiectasis patients to the registry from across 20 EU countries by 01/10/2020. The first patient was enrolled into the registry on 02/03/2015. From then on, the EMBARC team, with support from the European Respiratory Society, European Lung Foundation and Innovative Medicines Initiative, were overwhelmed by the interest from investigators across the globe. Over the course of the following two years 478 healthcare professionals across 61 countries registered on the website to be part of the network. 200 centres joined the registry from across 27 countries contributing to the 10,000 patients.

### Congratulations!

On 05/09/2017 Dr Pieter Goeminne from AZ Nikolaas in Belgium recruited the 10,000th patient to the registry thus smashing the 2020 target three years ahead of schedule!

Congratulations to Dr Goeminne and the Belgian team and as always, a massive thanks to everyone supporting EMBARC.



Although we have now passed the target of 10,000, we still remain open to recruiting new patients. Our focus now however, is the annual follow-up data so that the first longitudinal dataset in bronchiectasis can be made available.

## EMBARC presents at ERS 2017

During the annual European Respiratory Society congress, representatives of EMBARC presented the ongoing projects which EMBARC is involved with.



First and foremost, the much needed and long awaited European Respiratory Society guidelines for the management of adult bronchiectasis. This presentation received a great response as Dr Eva Polverino talked us through the 9 PICO topics of highest importance in bronchiectasis care with advice on how they should be dealt with. We are also proud to share that these 9 topics were decided upon with the help of the ELF Patient Advisory Group. The taskforce creating these guidelines was the first to include patients as full voting members! Click [here](#) to view the new bronchiectasis guidelines.

The NTM registry steering committee had further discussions on the development of the NTM registry which will be a sub-study of EMBARC. If you have not already expressed interest in the NTM registry and wish to take part, please contact [info@bronchiectasis.eu](mailto:info@bronchiectasis.eu) for further information and a feasibility form.

The ELF patient advisory group met to finalise the new ELF bronchiectasis patient information page which has recently been launched. To view the page click [here](#). They also discussed the ongoing work towards creating a new patient powered registry. This will also utilise the EMBARC platform and allow patients to consent online and enter their health data directly, unlike the physicians doing it for them in the main registry.



## \*\*\*\*\* 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.
- \* **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.

## Publications

- ◇ *European Respiratory Society guidelines for the management of adult bronchiectasis.*  
Eva Polverino, Pieter C. Goeminne, Melissa J. McDonnell, Stefano Aliberti, Sara E. Marshall, Michael R. Loebinger, Marlene Murriss, Rafael Cantón, Antoni Torres, Katerina Dimakou, Anthony De Soya, Adam T. Hill, Charles S. Haworth, Montserrat Vendrell, Felix C. Ringshausen, Dragan Subotic, Robert Wilson, Jordi Vilaró, Bjorn Stallberg, Tobias Welte, Gernot Rohde, Francesco Blasi, Stuart Elborn, Marta Almagro, Alan Timothy, Thomas Ruddy, Thomy Tonia, David Rigau, James D. Chalmers  
European Respiratory Journal 2017 50: 1700629; DOI: 10.1183/13993003.00629-2017  
<http://erj.ersjournals.com/content/50/3/1700629.long>
- ◇ *Sensitization to Aspergillus fumigatus as a risk factor for bronchiectasis in COPD.*  
Stephanie Everaerts, Katrien Lagrou, Adriana Dubbeldam, Natalie Lorent, Kristina Vermeersch, Erna Van Hoeyveld, Xavier Bossuyt, Lieven J Dupont, Bart M Vanaudenaerde, and Wim Janssens  
Int J Chron Obstruct Pulmon Dis. 2017; 12: 2629–2638. Published online 2017 Aug 31. doi: 10.2147/COPD.S141695  
<https://www.ncbi.nlm.nih.gov/pubmed/28919731>
- ◇ *Patient participation in ERS guidelines and research projects: the EMBARC experience.*  
James D. Chalmers, Alan Timothy, Eva Polverino, Marta Almagro, Thomas Ruddy, Pippa Powell, and Jeanette Boyd, on behalf of the European Multicentre Bronchiectasis and Research Collaboration (EMBARC), the European Lung Foundation (ELF) and the EMBARC/ELF patient advisory group  
Breathe (Sheff). 2017 Sep; 13(3): 194–207. Doi: 10.1183/20734735.009517  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5584721/>
- ◇ *The European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC): experiences from a successful ERS Clinical Research Collaboration.*  
James D. Chalmers, Megan Crichton, Pieter C. Goeminne, Michael R. Loebinger, Charles Haworth, Marta Almagro, Montserrat Vendrell, Anthony De Soya, Raja Dhar, Lucy Morgan, Francesco Blasi, Stefano Aliberti, Jeanette Boyd, and Eva Polverino, on behalf of EMBARC, the European Lung Foundation (ELF) and the EMBARC/ELF patient advisory group  
Breathe (Sheff). 2017 Sep; 13(3): 180–192. doi: 10.1183/20734735.005117. Review.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5584712/>
- ◇ *The role of non-invasive modalities for assessing inflammation in patients with non-cystic fibrosis bronchiectasis.*  
Stamatoula Tsirikika, Katerina Dimakou, Andriana I. Papaioannou, Georgios Hillas, Loukas Thanos, Kostantinos Kostikas, Stelios Loukides, Spyros Papiros, Nikolaos Koulouris, Petros Bakakos  
[https://ac.els-cdn.com/S1043466617302387/1-s2.0-S1043466617302387-main.pdf?\\_tid=4447734c-a1d4-11e7-8f4c-0000aacb361&acdnat=1506332051\\_88eee7270080ccc2b70ba23d8763ca42](https://ac.els-cdn.com/S1043466617302387/1-s2.0-S1043466617302387-main.pdf?_tid=4447734c-a1d4-11e7-8f4c-0000aacb361&acdnat=1506332051_88eee7270080ccc2b70ba23d8763ca42)
- ◇ *Profile of the ProAxis active neutrophil elastase immunoassay for precision medicine in chronic respiratory disease.*  
Keir HR, Fong CJ, Dicker AJ, Chalmers JD.  
Expert Rev Mol Diagn. 2017 Oct; 17(10): 875–884. doi: 10.1080/14737159.2017.1374174. Epub 2017 Sep 7.  
<http://www.tandfonline.com/doi/abs/10.1080/14737159.2017.1374174?journalCode=ihero20>
- ◇ *Molecular epidemiology of Pseudomonas aeruginosa in an unsegregated bronchiectasis cohort sharing hospital facilities with a cystic fibrosis cohort.*  
Mitchellmore PJ, Randall J, Bull MJ, Moore KA, O'Neill PA, Paszkiewicz K, Mahenthalingam E, Scotton CJ, Sheldon CD, Withers NJ, Brown AR  
<http://dx.doi.org/10.1136/thoraxjnl-2016-209889>  
<http://thorax.bmj.com/content/early/2017/08/26/thoraxjnl-2016-209889.long>