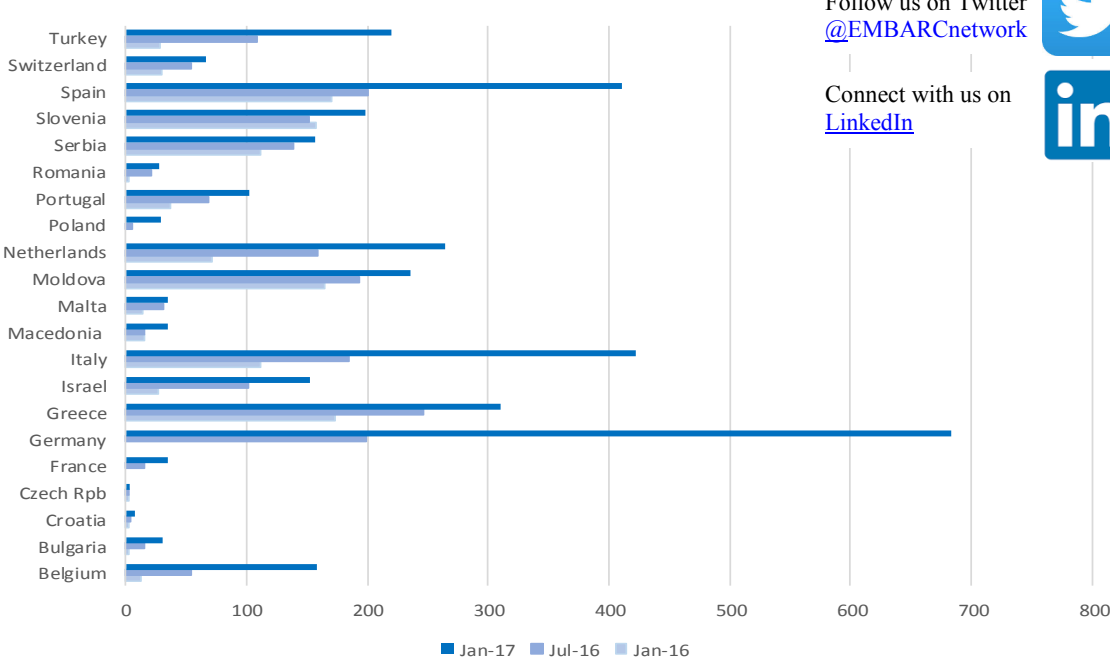




Recruitment Progress



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New Year — New Targets Reached!

EMBARC has had a fantastic start to the new year as recruitment passes 6000 patients already!

The above graph shows a nice representation of just how well you are all doing with recruitment - keep up the great work!

We would like to congratulate our German partner group, PROGNOSIS on their continued hard work. Recruitment to the German National bronchiectasis registry has nearly reached 700 patients and continues to grow rapidly adding to the success of collaborative work with the EMBARC network.



January has also welcomed data from a number of new research teams across Belgium, England, Italy, Romania and Spain. Following on from more networking events we have also received interest from researchers as far as Tunisia, Peru and Sri Lanka, and hope to collaborate with these groups in the near future.



Registration is now open!

EMBARC, along with IRENE, IRIDE and SIP have come together to organize the 2nd World Bronchiectasis Conference, 6-8th July in Milan. Visit www.world-bronchiectasis-conference.org for details on abstract submission and registration fees.

The website also gives details on how to enter the Rising Stars programme to which there are three spaces for young researchers to have their work presented in front of an audience of International bronchiectasis specialists.



***** IMPORTANT CRF HELP *****

* 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. If the patient has died/has been discharged please enter the reason and proceed to update any new information which has been documented since the previous data capture. This will be the last data submission for this patient.

* 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.

If no height/weight/spirometry values have been updated, please select "NA" beside each data point.

If no MRC score has been recalculated, please enter the previous years' score.

**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.

* 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.

N.B Respiratory Treatments "OTHER"

In the event a patient is prescribed a respiratory medication which is not in the eCRF, please select the type(s) of medication treatment with the drug as "other" and record in the Additional Information section the name of the "other" drug(s).

This should only be done for respiratory medication and only for those not recorded in the drop down menu.

⇒ Short Acting inhalers eg Salbutamol (Ventolin) and Ipratropium (Atrovent) are **not** required.

⇒ Please only record relevant information in the Additional Information section.

New Publications from the EMBARC Network

- ◇ *Bronchiectasis and Aspergillus: how are they linked?*
De Soyza A, Aliberti S.
<https://www.ncbi.nlm.nih.gov/pubmed/27794529>
- ◇ *Etiology of Bronchiectasis in a Cohort of 2047 Patients. An Analysis of the Spanish Historical Bronchiectasis Registry.*
Oliveira C, Padilla A, Martínez-García MÁ, de la Rosa D, Girón RM, Vendrell M, Máiz L, Borderías L, Polverino E, Martínez-Moragón E, Rajas O, Casas F, Cordovilla R, de Gracia J.
<https://www.ncbi.nlm.nih.gov/pubmed/28118936>
- ◇ *Bronchiectasis Rheumatoid overlap syndrome (BROS) is an independent risk factor for mortality in patients with bronchiectasis: A multicentre cohort study*
De Soyza A, McDonnell MJ, Goeminne PC, Aliberti S, Lonni S, Davison J, Dupont LJ, Fardon TC, Rutherford RM, Hill AT, Chalmers JD.
<http://www.sciencedirect.com/science/article/pii/S0012369217300090>
- ◇ *Comparing accelerometer, pedometer and a questionnaire for measuring physical activity in bronchiectasis: a validity and feasibility study*
O'Neill B, McDonough SM, Wilson JJ, Bradbury I, Hayes K, Kirk A, Kent L, Cosgrove D, Bradley JM, Tully MA.
<http://respiratory-research.biomedcentral.com/articles/10.1186/s12931-016-0497-2>
- ◇ *Sugar coating bronchiectasis*
Loebinger M
<http://thorax.bmj.com/content/early/2017/01/09/thoraxjnl-2016-209274.long>
- ◇ *Investigating the Etiology of Bronchiectasis: You Do Not Find What You Do Not Look For.*
Amati F, Franceschi E, Gramegna A, Chalmers JD, Aliberti S
<https://www.karger.com/Article/FullText/455880>
- ◇ *Microbial Dysbiosis in Bronchiectasis and Cystic Fibrosis*
Dicker AJ, Chalmers JD.
<http://www.sciencedirect.com/science/article/pii/S0300289616303465>
- ◇ *Additional important research priorities for bronchiectasis in China*
Aliberti S, Dhar R, Aksamit TR, Morgan L, Chalmers JD.
<http://erj.ersjournals.com/content/49/1/1602317.long>

If you have not already done so - please do not forget to submit your signed Data Sharing Agreement to the EMBARC team. Without this we cannot pay you for your hard work!!

It is the responsibility of each centre 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.i.crichton@dundee.ac.uk

Please do not send invoices directly to the finance department.