



*****IMPORTANT*****

Following the result of the referendum, we would like to reassure the EMBARC network there will be no change in the short term. Funding for EMBARC is secure until 2020 and this will not change.

We will be working to ensure that close collaboration continues with our partners in Europe regardless of how the relationship evolves with Great Britain outside of the EU.

Our commitment to bronchiectasis research is stronger than ever!

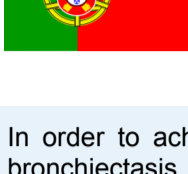
Welcome and Congratulations!



EMBARC would like to welcome our newest recruiters; Dr Thierry Weber from Belgium, Dr David Parr, Dr Nicholas Whithers and Dr David Derry all from England and Dr Adelina Amorim from Portugal!



The UK recruitment target for 2020 was 2000 participants, you are already over half way! Congratulations to all 53 UK centres who have recruited to date! With another 28 centres already set up, you are well on your way to an unimaginable recruitment record!



Also, many congratulations to three centres who all equally share the highest recruiter spot for this month; Dr Eleanor Gerada from Malta, Dr Muhammad Anwar from England and Dr Katerina Dimakou from Greece!

In order to achieve the most accurate representation of the bronchiectasis population across Europe, we are always looking to increase the number of participating centers. Areas of particular interest are Eastern Europe, Scandinavia and the Republic of Ireland.

If you know people working in these areas with an interest in bronchiectasis, we encourage you to share with them this opportunity to be part of the EMBARC network.



EMBARC publishes research priorities document for bronchiectasis



Now published online in the European Respiratory Journal, an EMBARC working group has published a list of 22 key recommendations for future research into bronchiectasis. This project involved a survey of more than 100 European and international experts in bronchiectasis care and a survey of more than 700 patients with bronchiectasis across Europe. The resulting document bring together priorities in areas such as treatment, microbiology, physiotherapy and basic science to create a "roadmap" for future development in the field. The document has been endorsed by the European Respiratory Society science council, the European Lung Foundation and by our international partners.

The document is open access and so everyone can read it [here](#).

See You in Hannover!

1st World Bronchiectasis Conference

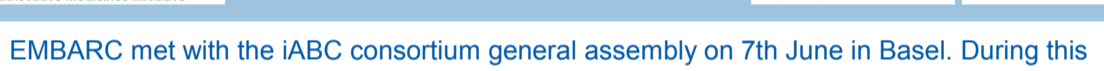
"Joining forces for a breakthrough in bronchiectasis"
July 07 – 09, 2016, Hannover, Germany



The EMBARC team are travelling to Hannover next month to help host the 1st world conference solely dedicated to bronchiectasis. With over 240 physicians, scientists, early-stage researchers and students registered to attend, we are looking forward to meeting with many of you and especially excited to see your data being presented to the EMBARC network.

For further information regarding the conference and session speakers please [visit](#)

IMI General Assembly 2016



EMBARC met with the iABC consortium general assembly on 7th June in Basel. During this time, the progress of the network and some data from the registry was presented, highlighting the hard work and commitment from all center's taking part in the study.

It is clear the Assembly are very happy with the progress of EMBARC and we are proud to still be ahead of schedule, exceeding our targets and milestones.

Some interesting data covered in the meeting;

- Over 60% of patients in the registry receive a long acting bronchodilator and almost as many are in receipt of an inhaled corticosteroid.
- Around 40% of the cohort receive/have received physiotherapy, however very few (<10%) receive/perform any other type of airway clearance.
- More that 30% of the registry population have a history of P. aeruginosa.

Helpful Advice and Guidance for Efficient eCRF entry

- When cases are returned with data queries, please remember to **SAVE** each page where edits have been made before resubmitting, otherwise the query will not resolve.
- Please collect all data and contact the study coordinator with any queries before submitting cases.
- Ensure all reference values (eg height, weight, spirometry etc) are entered using the correct units.
- 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.
- UK centres - Please remember to **SUBMIT** cases once all pages have been completed. Recruitment figures submitted to the Open Data Platform can only account for those which are submitted.
- The new CRF documents can now be downloaded from the website <https://www.bronchiectasis.eu/study-documents> along with the Patient Information Sheet and the Informed Consent Form.
- Coloured exclamations next to the submission date highlighted cases which require an annual review. Amber represents a 9 months warning, whereas red represents cases due or overdue.
- Nearly 1000 cases are still pending submission - please contact the study coordinator if you require assistance on submitting cases or if cases need to be deleted from your account.

ERS 2016
EUROPEAN RESPIRATORY SOCIETY
INTERNATIONAL CONGRESS 2016
LONDON united kingdom, 3-7 september
ERSCONGRESS.ORG

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16/03/2016	Approved
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16/12/2015	Approved
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New Publications from the EMBARC Network

- Research priorities in bronchiectasis: a consensus statement from the EMBARC Clinical Research Collaboration*
Aliberti S, Masefield S, Polverino E, De Soya A, Loebinger MR, Menendez R, Ringshausen FC, Vendrell M, Powell P, Chalmers JD; on behalf of the EMBARC Study Group.
<http://www.ncbi.nlm.nih.gov/pubmed/27288031>
- Non CF-bronchiectasis: Aetiologic approach, clinical, radiological, microbiological and functional profile in 277 patients.*
Dimakou K, Triantafyllidou C, Toubis M, Tsikritsaki K, Malagari K, Bakakos P
[http://www.resmedjournal.com/article/S0954-6111\(16\)30077-4/abstract](http://www.resmedjournal.com/article/S0954-6111(16)30077-4/abstract)
- Lung transplantation for non-cystic fibrosis bronchiectasis*
Rademacher J, Ringhausen FC, Suhling H, Fuje J, Marsch G, Warnecke G, Haverich A, Welte T, Gottlieb J
<http://www.ncbi.nlm.nih.gov/pubmed/27215505>
- Prevalence of nontuberculous mycobacterial pulmonary disease, Germany 2009-2014*
Ringhausen FC, Wagner D, deRoux A, Diel R, Hohmann D, Hickstein L, Welte T, Rademacher J
<http://www.ncbi.nlm.nih.gov/pubmed/27191473>
- Ciprofloxacin dry powder for inhalation in non-cystic fibrosis bronchiectasis*
De Soya A, Aksamit T
<http://www.tandfonline.com/doi/abs/10.1080/21678707.2016.1196129>
- Challenges in managing Pseudomonas aeruginosa in non-cystic fibrosis bronchiectasis*
Wilson R, Aksamit T, Aliberti S, Polverino E,
[http://www.resmedjournal.com/article/S0954-6111\(16\)30131-7/fulltext](http://www.resmedjournal.com/article/S0954-6111(16)30131-7/fulltext)
- Diagnostic challenges of bronchiectasis*
Guillermo Suarez-Cuartin, James D. Chalmers, Oriol Sibila
[http://www.resmedjournal.com/article/S0954-6111\(16\)30099-3/fulltext](http://www.resmedjournal.com/article/S0954-6111(16)30099-3/fulltext)

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.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

