

EMBARC CRC Steering committee Job description

EMBARC (European Multicentre Bronchiectasis Audit and Research collaboration) is the European Bronchiectasis network, a group of doctors, nurses, physiotherapists, surgeons, other health professionals and patients working to improve the treatment of bronchiectasis around Europe and around the world. Central to the mission of EMBARC is the creation of the European Bronchiectasis registry, a database of patient information that will be used to stimulate research and improve the treatment of patients.

The function of the steering committee is to define what activities EMBARC should undertake to achieve its mission and to monitor the conduct of the EMBARC registry.

Detailed knowledge of the EMBARC project is not required in order to be a member of the steering committee as a full briefing and information regarding the registry and the role will be provided by the EMBARC chairs prior to participation in steering committee meetings.

EMBARC steering committee members have the following roles in collaboration with EMBARC staff:

- Represent EMBARC values and convey its strategic decisions and goals to the outside world.
- Attend EMBARC steering committee meetings twice a year. Meetings generally take place in spring in an external location that is easily accessible by train or air and in autumn during the ERS Congress. Attendance is strongly encouraged as the steering committee directs the general activities of EMBARC and makes all strategic decisions. If a member is unable to attend a meeting physically, attendance through teleconference can be accepted.
- Members may be required to attend additional meetings by teleconference (3-4 times per year)
- When necessary, approve minutes, final texts of official documents or communication material.
- In addition, EMBARC steering committee members may be asked to take part in working groups related to specific projects.

The patient representative(s) to the EMBARC steering committee will have the following specific and additional roles in collaboration with the European Lung Foundation (ELF) and the EMBARC chairs:

- To ensure that EMBARC activities always reflect the opinions and priorities of patients with bronchiectasis
- To give a patients' perspective on EMBARC decisions and activities, for example in relation to protection of patients personal data and design of research studies
- To aid in disseminating information from the EMBARC project to patients with bronchiectasis in collaboration with the ELF and the other EMBARC members
- To interact with the other members of the patient advisory group and keep them informed of the activities of the EMBARC project

In short, the role has been created to ensure that patients have a strong voice in all decisions being made by the European bronchiectasis network.

The participation of patients in EMBARC meetings will be supported by the EMBARC chairs and by the ELF. EMBARC will adhere to ELF guidelines for the involvement of patients in ERS projects and will ensure that patients are fully involved and find the experience rewarding and impactful.

EMBARC being a not-for-profit organization, this is a voluntary position and no salary or honorarium is paid to the patient representative or any other member of the EMBARC steering committee. The duration of the mandate will be agreed between the patient representative and ELF. Travel expenses for meeting attendance will be covered by EMBARC as detailed in the EMBARC and ERS Travel Expense Policy (available on request)

Personal Requirements:*Mandatory:*

- A patient or carer with experience of bronchiectasis not related to cystic fibrosis
- Ability to communicate confidently in English
- Keen interest in furthering medical research and education
- Available to attend and travel to meetings in Europe
- Able to input to discussions and review documents by e-mail on an ongoing basis as required
- Able to devote time for the duties outlined
- Good team worker

Desirable:

- Previous experience in medical research
- Previous experience of public speaking and/or committee work
- Completion of the European Patient Ambassador Programme (EPAP; www.EPAPonline.eu)