

What is a Community Advisory Board (CAB)?

Patient Community Advisory Boards (CABs) are groups established, operated and maintained by patient advocates and expert patients to discuss the latest developments, challenges and issues related to medical treatments and procedures under development in your disease area. CABs, with anywhere from seven to sixteen advocates, are involved in scientific as well as policy-related issues (ie, access), and they provide expert advice to all stakeholders involved in the research, development and service provision of biomedical treatments.

Does there need to be a CAB in my disease area?

For most of history, medical science has evolved with little to no input from the people being studied. CABs change that, and help to design, carry out and communicate on studies that are more rational and inclusive from a patient's point of view, and by doing so, a bond of trust is formed.

What exactly do CABs give input on?

On a wide variety of topics that they in fact are the experts on: patient outreach, education, feedback on the study and its design, criteria for participation, informed consent forms and processes, compassionate use programmes, retention, and reporting on results...

Why now?

More and more, patients and the patient perspective are seen as a way to make clinical studies more impactful and just, possibly quicker, certainly more efficient.

Who are CAB members?

CAB members are people living with the specific condition, a close family member or carer, and/or a member of a patient organisation that works with the disease. If you are able to work in English to a decent extent, if your group adheres to the [Code of Practice for the Relations between Patients' Organisations and the Healthcare Industry](#), if you are interested in science and interested in expanding it, if you can dedicate at least four hours per week to the CAB and its activities, and have a stable internet connection, you will be very welcome!

What if a CAB does not exist for my disease area?

Working with the European Network of your disease, you can begin the journey! EURORDIS can help in distinct ways to help you get a CAB going.

I don't understand the science very well. How can I learn?

There are various ways of learning, at the pace you need. EURORDIS can offer specific training at a CAB meeting. There are also the [EURORDIS Summer School materials](#) online that can be accessed for free. And [EUPATI](#) has their clinical training course online in 8 languages, which EURORDIS contributed to greatly. However you need to be educated, EURORDIS can help.

My patient group is small with limited resources. Can I really do this?

Get in touch with EURORDIS and let's see how to make this work for your Network! Rob.camp@eurordis.org