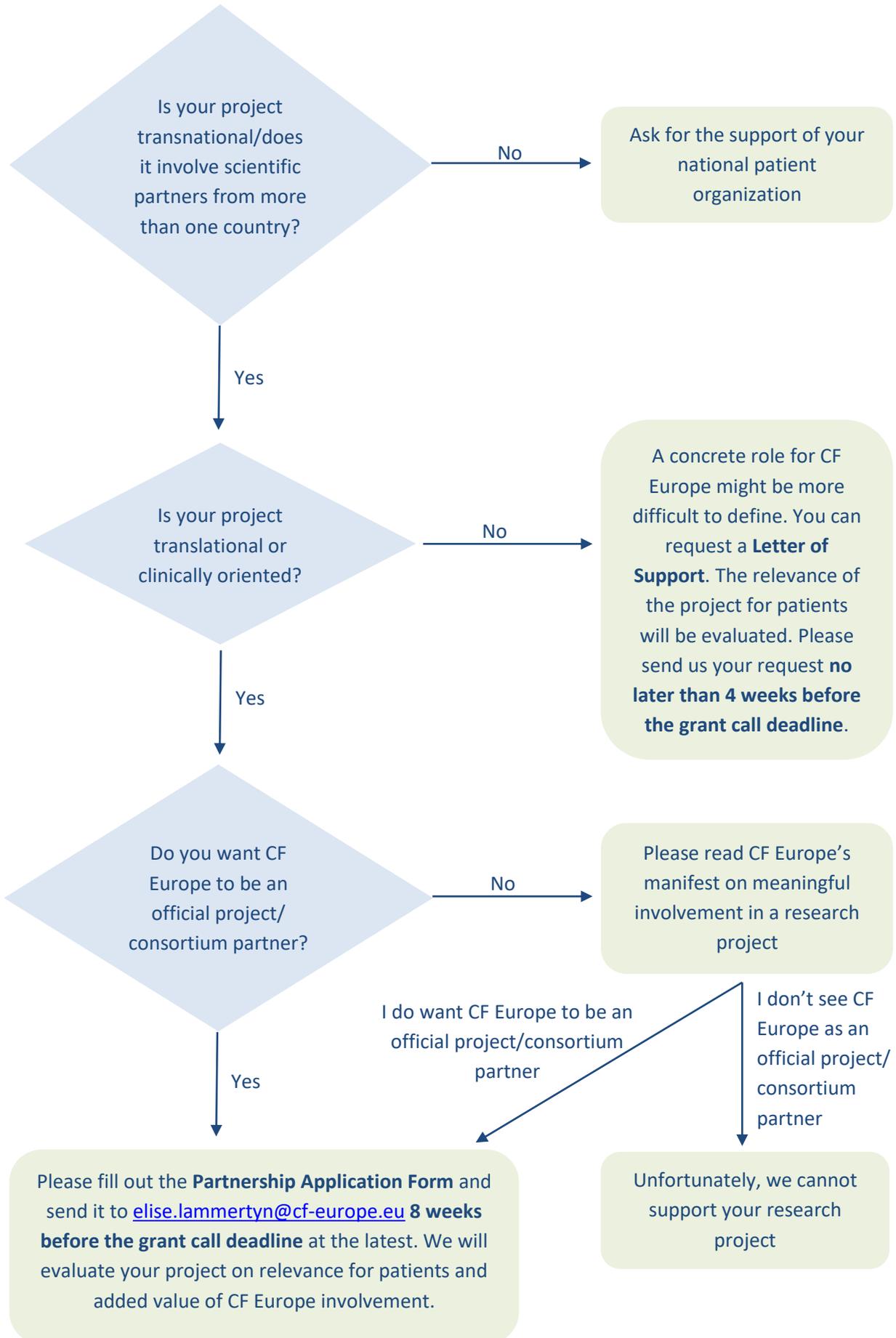




FLOWCHART FOR ASKING SUPPORT OR INVOLVEMENT OF CF EUROPE FOR YOUR SCIENTIFIC PROJECT





CF Europe's manifest on meaningful involvement in a research project

Stimulating patient-centered CF research is one of CF Europe's main goals, next to representing and defending the interests of people with CF in Europe and influencing for better CF care and equal access to medicines. In order to do so, CF Europe is willing and able to act as a full partner in international scientific projects.

As federation of national CF associations throughout Europe, we represent about 40 000 people with CF, and their families, in Europe. We are in close contact with our members and therefore have a clear view on the patients' interests and needs. We have the network to reach out to them when participants in studies are needed, and are experienced in disseminating scientific results to people with CF and their families, and to the wider public. Close cooperation with the patient community is a key success factor for research projects. Therefore, we want to play a key role in ensuring that research outcomes have a maximal impact on patient lives.

CF Europe wants to be involved in research projects, but in order to make a real difference in the lives of people with CF it is essential that the following conditions are met:

- to contribute to a project in a meaningful way, CF Europe needs to:
 - o be involved in the project from the design of the project and throughout the entire project
 - o be seen as a full partner
 - o play a role in advising on the patients' interests in the different aspects of the project
 - o receive the necessary resources to be able to contribute meaningfully to the project.
- In projects that are translational or clinically oriented, the ECFS Clinical Trials Network (CTN) may have an important advisory function. The aim of the ECFS-CTN is to increase the quality and quantity of CF clinical research by realizing efficient and high quality clinical trials. Therefore, we consider involvement of the CTN in the research consortium as a major advantage.
- CFE has a group of expert-members who evaluate the proposals we receive via the Partnership Application Form. They discuss and give advice on what collaborations to invest in, based on relevance of the project for the patients and added value of CF Europe involvement. This means we need to receive proposals well in advance for them to be able to study and discuss it. **We don't require a fully finalized research proposal** to evaluate your project, especially not for two-stage applications. We are open to co-designing the proposal based on your scientific needs and our recommendations for optimal patient-centered research.

Over the years, CF Europe has gathered ample expertise in CF research and continuously works on making it more patient-centered. We have been/are involved in multiple Horizon 2020-funded consortia such as MyCyFAPP, HIT-CF Europe and OligoGPivotalCF. Furthermore, CF Europe established the Patient Organizations Research Group (PORG). This working group consists of representatives from national CF patient organizations that are actively involved in research and in research funding. Together, they work on defining patients' priorities in research and setting out a strategy to promote research looking into these priorities. The PORG actively collaborates with the ECFS-CTN and Registry, and organizes initiatives like the European CF Young Investigator's Meeting and the ECFS Basic Science Pre-Conference Meeting.