Introduction: A Brazilian civil society organization, which aims to develop the cystic fibrosis (CF) ecosystem through actions that impact on the improvement of the quality of life of patients, families and others involved, annually develops the National Meeting for the Development of Associations of FC, whose purpose is to professionalize, equalize and develop the organizations that work on the theme in the country, as well as to stimulate joint action in the solution of national demands. Method: The present study is a qualitative descriptive research, with the involvement of the leaders of 82% of the CF care institutions in Brazil, participants of this Meeting. Results: In 2019, during the third edition of the Meeting, the creation of the Brazilian CF Alliance was signed, with the participation of 22 of the 27 existing CF associations in the country. After identifying latent demands, aligning participants and creating strategies, the organizations joined together for the implementation of national action plans, more than 4,600 patients in the country. Conclusion: It is concluded that the professionalization of these institutions, the alignment on how to act on topics such as HTA and other issues related to social participation, public policies and advocacy, as well as the importance of networking with organizations with the same theme, is fundamental. that, strengthened and united, can achieve more consistent results. It is also revealed that civil society organizations are key actors in the process of social participation, as they have the ability to receive and share information with the cutting edge, where they find patients and family members, who are the direct beneficiaries of this ecosystem.

Keywords: Cystic Fibrosis, Non-profit organizations, collaborative networks, third sector, health technology assessment