



ECFS and CF Europe's European Twinning Expansion project

Terms of Reference

Establishment

The European Cystic Fibrosis Society (ECFS) mission is to improve survival and quality of life for people with CF. It strongly supports professional and educational activities that help improve CF care in every European country. The ECFS patient registry (ECFSR) output data show considerable discrepancy in clinical outcomes across Europe. To address this issue, in 2020, the ECFS Standards of Care group set up the Twinning Project which aims to develop a long-term **centre-to-centre partnership** where one CF centre guides, advises and helps another CF site to optimise the care for people with CF. Five pairs were matched together. Four pre-existing pairs with a history of ongoing partnership, were also supported. In 2023, the Twinning Expansion Project (TEP) was launched to promote and expand twinning activities as a joint project of the ECFS and CF Europe (CFE). The main objectives of the TEP, as the next stage of the original Twinning project, are not only to recruit new CF centres, but also to better understand and address the unmet needs of CF healthcare in the mentee regions.

Terms of Reference

DEFINITIONS

Mentor site: A well-established CF centre with state-of-the-art expertise in CF care. Mentor sites are selected amongst the ECFS-CTN sites as they have already been assessed by ECFS.

Mentee site: Any CF care-providing establishment which expresses an interest in participating in the Twinning Expansion project and is open to the guidance offered by the Mentor site. Sites must be from countries in Europe defined by the World Health Organisation (WHO) criteria.

Pair: Paired mentor and mentee sites. The pairing will be proposed by the Twinning Executive Board (TEB) based on the information provided in the application forms.

Patient Organisation (PO): An organisation which is patient-focused and represents the interests and needs of patients, their families and/or caregivers.

Twinning Executive Board (TEB): The body which oversees the course of the twinning between the mentor and mentee site and provides regular reports to the ECFS Board and CF Europe.

AIM AND DESCRIPTION OF THE PROJECT

The TEP is a three-year collaboration between CFE and ECFS building on the ECFS Twinning project launched in 2020 to improve patient care, aiming at better access to high quality, multidisciplinary CF care and optimal treatment.

The aim of the TEP is to address gaps in clinical outcome discrepancy across Europe by building a long-term collaborative partnership between Mentor and Mentee sites and address specific needs of the mentee site to optimise patients' clinical outcomes.

The TEP will also engage POs, who will play pivotal role in identifying and addressing unmet needs (e.g. adult care, trained healthcare professionals), facilitating communication, and identifying possible mentee sites. Well-resourced patient organisations with advanced advocacy, digital expertise and

capabilities will provide support to those patient organisations needing more support or training. As well as the twinned pairs building their partnership, the project also aims to support and facilitate networking between POs and CF centres participating in the project.

The TEP's points of action are:

1. Establish new CF centre mentor and CF centre mentee sites with the aim of facilitating collaborations and exchanges between the twinned pairs
2. Identify unmet needs in CF care in the mentee sites and formulate feasible goals
3. Connecting participating CF centres to ECFS learning resources and creating translations of these resources into relevant languages
4. Facilitate knowledge sharing and networking opportunities between CF centres and POs in different regions

It is expected of the new twinning pair that the mentor site will organise at least one visit to the mentee site within the first six months. The visit will include a CF physician and possibly a CF nurse and/or other CF team members. The aim of the visit is to establish a partnership, to get an overview of the mentee site, to discuss unmet needs and opportunities, and build on this to develop further twinning. The duration of the TEP for new sites is one year. After one year, a summary report will be prepared and submitted jointly by both sites and will serve as the basis for the continuation of the funding.

GRANT DURATION

The twinning pair will be initially funded for 12 months. Upon the review of the summary report, the grant and financial support can be renewed by one year. The pair has the option to submit summary reports every year and thus, to ask for yearly funding repeatedly. If approved by the ECFS Board, this will entitle the participants to get longer-term funding.

FUNDING SUPPORT

Up to Euro 2,000, in the first year of the project, is available for the costs of travel and accommodation for the purpose of site visits (both mentee and mentor sites). The expenses will be refunded via expense claim forms where original receipts/invoices need to be attached and submitted to the CFE Twining Coordinator. Other eligible costs beside travel and accommodation include onsite translator services if needed.

LANGUAGE

The application must be in English.

APPLICATION PROCEDURE

The mentor and mentee application forms (see separate documents) are to be filled out and sent back to this address: education@ecfs.eu by the deadline advertised.

The deadline to send the applications is: **31 January 2024 (23:59 CET)**

EVALUATION OF APPLICATIONS

A TEB will be appointed by the ECFS Standards of Care Group. The TEB will review the application forms and match pairs according to expertise needed and offered. The twinning pair proposals will be presented to the ECFS Board for final approval.



Twinning project



TIMELINE FOR THE EXPANSION CALL

- Call: 18 December 2023 to 31 January 2024
- Evaluation and selection: February 2024
- Results: February 2024
- Launch of a six-month project initialization: As from March 2024
- Summary report: by February 2025