

## 2026 ECFS WORKING GROUP ANNUAL REPORT

Please use this template for your annual Working Group report.  
For more information, please read the following ECFS Working Group [Terms of Reference](#) document:

### Group Info & Background

Name of Working Group:



**Telehealth for Cystic Fibrosis Working Group (THCF)**

Date of initial approval of Working Group:  
**October 2023**

Names and emails of chair/coordinators:

Position	Name
Coordinator	Tamara Vagg
Steering Committee	Barry Plant
Steering Committee	Sarath Ranganathan

Long term aims of the Working Group (maximum 100 words) including estimated achievement date:

**Summary of proposed work:**

1. To understand current experiences of CF telehealth practices for all stakeholders in this space and benchmark against other lung diseases. This will be done through:
  - a. Stakeholder Questionnaires  
**Currently analysing data**
  - b. Literature Reviews  
**Data synthesis**
  - c. And Public Patient Involvement Activities (PPI)  
**Currently exploring financial reimbursement -literature + THCF survey**
2. To design frameworks for developing standards for future care of CF telehealth and guidance on implementation.  
**Ongoing – Technical documentation about to be launched.**

3. To develop educational materials that will support potential implementation of the practices. ***WP5 have completed first four part webinar series and a Telehealth syllabus has begun (in conjunction with the education committee).***

Outcomes already achieved (maximum 100 words):

Over the last 12 months (April 2025 – April 2026):

- Held second ECFS meeting.
- Established new WP6 – who have had several monthly meetings and launched a THCF wide survey.
- The 6 work packages continue to meet (see next section for numbers).
- Work continues in WP1, WP2, WP3.
- WP4 has soft launched its technical consideration document.
- WP5 has completed a 4-part webinar series (with speaker take home messages document) and are now starting a telehealth syllabus.
- “Digital Health” was added as a submission category for the ECFS Lisbon CF conference.
- Symposium proposal for ECFS 2026 was accepted.
- Four new members.

## Year Report

### Report for this year (max 1000 words):

- *short term goals for the year*
- *measures taken to encourage ECFS membership*
- *current number of members*
- *outcomes/achievements (e.g. meetings, activities, website development, awards, publications etc).*

#### **Short term goals for the year (6 months):**

- To continue research work activities across the 6 work packages.
  - WP1 = public patient involvement activities
  - WP2 = literature reviews
  - WP3 = stakeholder surveys
  - WP4 = technical documentation
  - WP5 = education
  - WP6 = telehealth innovations
- To hold third THCF meeting at the ECFS conference in June 2026.

#### **Current number of members:**

Groups	No.
Steering Group	3
Core Group	25
Reach-Out Group	31
<b>Total:</b>	<b>59</b>

A full list of group member names, expertise, and countries are provided at the end of this document.

**Measures taken to encourage ECFS Membership:**

At all group meetings, including ECFS conference meetings, membership is encouraged. This has also been encouraged in the “THCF 6 Month Update Newsletter” sent at the end of April 2026, October 2025, and April 2025 to both Core and Reach-Out Group Members.

**Outcomes/Achievements/Developments:**

**Meetings (as of April 30<sup>th</sup> 20256:** Since the group was established in October 2023:

WP	Achievements	Number of Meetings:
1	After Townhall meeting data – thematic analysis was performed. The most common themes were presented to the group at ECFS 2025. “Financial Reimbursement/Cost” was seen as a priority. Literature scoping exercises were conducted before generating a THCF wide survey.	19
2	This WP has 3 reviews. <ol style="list-style-type: none"> <li>1. A systematic which is registered on Prospero and is currently in the data synthesis phase.</li> <li>2. Practical review (scoping): currently finalising search strategy.</li> <li>3. Short communication: Currently scoping out publication criteria.</li> </ol>	20
3	Data collection is complete, data synthesis and analysis has begun. Group is currently reviewing data to start structuring a paper.	13
4	Have soft launched a technical considerations document and spider map.	8
5	Have completed their first 4 part webinar series, with a plan for another in autumn 2026. Currently developing a syllabus with the ECFS education committee.	9
6	Have already conducted scoping exercises and launched a survey with the THCF to understand current service gaps/challenges. Data has been summarised and the group is formulating this into question to be answered via a narrative review.	6

Aims for the coming year (please state year) (max 50 words):

- Year = 2026-2027
- To renew/extend THCF.
- To continue the work currently being carried out in all 6 WPs (see previous table).
- To hold third THCF meeting at the ECFS conference in June 2026.

Summary (maximum 100 words):

Over the last year, the THCF have continued to research the various components needed to develop best practice guidelines for CF telehealth. This has been done through the 6 WPs.

**The group has achieved many of its milestones including engaging with PwCF, performing novel literature reviews, developing educational and technical resources.** For this coming year, the group has many more aims, including reaching out to and collaborating with other ECFS groups, and generating CF telehealth guidelines. To continue this work, we would greatly appreciate your continued support over the coming year.

## Finances

Breakdown of expenses (please include total amount received as well as expenditure and, if applicable, the outstanding balance (Euros)):

### 2023-2024:

- Total amount received: €10,000 (group active only for 6 months – this amount might be halved €5,000)
- Expenses: ECFS June Meeting Catering € 201 (VAT incl.)

### 2024-2025:

- Total amount received: €10,000
- Purchase of admin software: €286.91
- Expenses:
  - ECFS June 2025 Meeting Catering € 201 (VAT incl.)
  - Hybrid Meeting: €1097,60
  - Catering: €240 (VAT excl.)

### 2025-2026:

- Total amount received: €10,000

- Purchase of admin software: €256.29
- Poster Advertisements: 61.50
- Expenses:
  - ECFS June 2026 Meeting Catering € 218.10 (VAT incl.)

Budget amount requested for next year (please give the amount in Euros and the year):

Total spend over the last 3 years = €2361.4

- We would like to request the full amount of €10,000.
- This will support the group in this year's Work Package tasks. Also, this fund will help support the work being carried out in the education work package. Finally, this amount will also support the group with future open-access publication fees.
- As we are coming to the end of our first "3 years", we also plan to apply to renew our WG, not only to complete the work currently being conducted – but also workshop pursue new CF telehealth areas which have emerged.

The deadline for submission to the ECFS Office is 1st May.

The report will then be presented to the board prior to the summer ECFS board meeting and then a decision will be made at the next board meeting for approval before being distributed.