

	<p align="center"><b>Telehealth for Cystic Fibrosis Working Group (THCF)</b></p>																
<p align="center"><b>Year of Report:</b> May 2025 (*18 months after initial approval)</p>																	
<p align="center"><b>Name of Working Group:</b> Telehealth for Cystic Fibrosis</p>	<p align="center"><b>Date of initial approval of working group:</b> October 2023</p>																
<table border="1"> <thead> <tr> <th>Position</th> <th>Name</th> <th>Email</th> <th>ECFS Membership No.</th> </tr> </thead> <tbody> <tr> <td>Coordinator</td> <td>Tamara Vagg</td> <td></td> <td></td> </tr> <tr> <td>Steering Committee</td> <td>Barry Plant</td> <td></td> <td></td> </tr> <tr> <td>Steering Committee</td> <td>Sarath Ranganathan</td> <td></td> <td></td> </tr> </tbody> </table>		Position	Name	Email	ECFS Membership No.	Coordinator	Tamara Vagg			Steering Committee	Barry Plant			Steering Committee	Sarath Ranganathan		
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Coordinator	Tamara Vagg																
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<p align="center">Long term aims of the working group (maximum 100 words) including estimated achievement date:</p> <hr/>																	
<p><b>Summary of proposed work:</b></p> <ol style="list-style-type: none"> <li>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:             <ol style="list-style-type: none"> <li>Stakeholder Questionnaires <b>Currently collecting data.</b></li> <li>Literature Reviews <b>Review Registered and currently reviewing manuscripts.</b></li> <li>And Public Patient Involvement Activities (PPI) <b>4 townhall meetings have been held with PwCF and their family/caregivers.</b></li> </ol> </li> <li>To design frameworks for developing standards for future care of CF telehealth and guidance on implementation. <b>Ongoing – to begin in year 2/3.</b></li> <li>To develop educational materials that will support potential implementation of the practices. <b>WP5 has now been established and have met twice.</b></li> </ol>																	

### Outcomes already achieved (maximum 100 words):

Over the last 12 months (April 2024 – April 2025):

- Held our first ECFS meeting.
- Held an online group update meeting.
- The 3 work packages continue to meet (see next section for numbers).
- Work Package 1: has held 4 townhall meetings with patients and caregivers with another 2 anticipated for this year.
- Work Package 2: Has registered and began a systematic review. Click here for Prospero link.
- Work Package 3: Have three currently active surveys collecting data. More details on ECFS webpage here.
- We have now established two new Work Packages: 4 (technical documents), 5 (education).

### 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 5 work packages.
  - WP1 = Public patient involvement activities
  - WP2 = literature reviews
  - WP3 = stakeholder surveys
  - WP4 = technical documentation
  - WP5 = education
- To hold second THCF meeting at the ECFS conference in June 2025.

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

Groups	No.
Steering Group	3
Core Group	25
Reach-Out Group	28
<b>Total:</b>	<b>56</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 2024, October 2024, and April 2025 to both Core and Reach-Out Group Members (see attached).

**Outcomes/Achievements/Developments:**

**Meetings:** Since the group was established in October 2023:

WP	Achievements	Number of Meetings:
1	Have held townhall meetings with the CF community in Ireland, UK, Belgium, Netherlands, and France.	10
2	Have registered a systematic review in <a href="#">PROSPERO 2025</a> <a href="#">CRD42025561953</a> and have begun the review process. A second potential mini-review is also being explored.	10
3	Developed 3 surveys which are currently actively collecting data.	8
4	Have established this year (Feb 2025) have already begun meeting to discuss aims and objectives.	2
5	Have established this year (Feb 2025) have already begun meeting to discuss aims and objectives.	2

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

- Year = 2025-2026
- To continue the work currently being carried out in all WPs
  - WP1 = Public patient involvement activities
  - WP2 = literature reviews
  - WP3 = stakeholder surveys
  - WP4 = technical documentation
  - WP5 = education/training
- To hold second THCF meeting at the ECFS conference in June 2025.

Summary (maximum 100 words):

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Over the last year, the THCF have begun researching the various components needed to develop best practice guidelines for CF telehealth, this has been done through the 5 WPs. The group has achieved many of its milestones including engaging with PwCF to learn more, developing and releasing stakeholder surveys, and registering and beginning a systematic review. For this coming year, the group has many more aims and objectives which we confidently aspire to achieve, particularly through the new WPs established in 2025 (4 & 5). To continue this work, we would greatly appreciate your continued support over the coming year.

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

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**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.)

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

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- We would like to request the full amount of €10,000.
- This will support the group in this years Work Package tasks. These tasks include PPI activities, literature reviews, and survey development which will also require support from third party sources for translating documents to various languages, database management support. 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 open-access publication fees.



Please provide us with a list of all current members (name, professional title,  
email address and ECFS membership number):

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