

	Telehealth for Cystic Fibrosis Working Group (THCF)																		
Year of Report: May 2024 (*6 months after initial approval)																			
Name of Working Group: Telehealth for Cystic Fibrosis	Date of initial approval of working group: October 2023																		
<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 15%;">Position</th> <th style="width: 20%;">Name</th> <th style="width: 25%;">Email</th> <th style="width: 40%;">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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<p>Long term aims of the working group</p> <hr/>																			
<p>Summary of proposed work:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> a. Stakeholder Questionnaires Ongoing, work package established with aim to deploy questionnaires by end of year. b. Literature Reviews Ongoing, work package established with aim to complete data gathering by end of year. c. And Public Patient Involvement Activities (PPI) Ongoing, work package established with aim to begin activities this year. 2. To design frameworks for developing standards for future care of CF telehealth and guidance on implementation. Ongoing – to begin in year 2. 3. To develop educational materials that will support potential implementation of the practices. Ongoing – to begin in year 2. 																			

Outcomes already achieved:

Over the last 6 months the group have focused primarily in getting established and understanding the plan of action ahead. During this time THCF have:

- Held two online meetings with all Core members before establishing 3 work packages. The 3 work packages have had a subsequent 10 meetings total.
- Agreed upon a group logo (on first page, top left of document),
- Setup the THCF webpage on the ECFS website,
- Workshopped and agreed upon a definition for Telehealth.
- First working group meeting at the ECFS conference scheduled for June 2024

Report for this year:

- *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 establishing the group.
- To create Work Packages (WPs) to begin data and information gathering:
 - WP1 = Public patient involvement activities
 - WP2 = literature reviews
 - WP3 = stakeholder surveys
- To hold first THCF meeting at the ECFS conference in June 2024.

Current number of members:

Groups	No.
Co-Ordinator + Steering Committee	3
Core Group	23
Reach-Out Group	25
Total:	51

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 the meetings held with the Core Group Members, membership was encouraged as an agenda item. This has also been encouraged in the “THCF 6 Month Update Newsletter” sent at the end of April 2024 to both Core and Reach-Out Group Members (see attached). This message will also be repeated in each update newsletter going forward.

Outcomes/Achievements:

Meetings: Since October the Core group have met twice before splintering into three work packages.

- Work Package 1 is focused on developing a Public Patient Involvement Panel to support the overall work of the group (have met four times).
- Work Package 2 focuses on an extended literature review to capture information beyond what is available in the current systematic reviews (have met three).
- Work Package 3 focuses on developing a survey to capture as much insights as possible from all stakeholders, including a list of active telehealth CF centres (have met three).

Developments: Over the last 6 months the group have worked towards building an identity. This was done by:

- Creating a THCF webpage on the ECFS website: <https://www.ecfs.eu/telehealth>
- Developing a logo (visible on the website and below):



Within the digital health space, definitions often evolve over time in a *bloat-burst* manner. Whereby the definition grows to match the pace of developing technologies and their capabilities before separating into new definitions. This particularly evident with Telehealth, which is often used synonymously with Telemedicine, Virtual Monitoring, and many others. One of the first tasks undertaken by the working group so far was to develop a definition for telehealth to aid in guiding and understanding future works carried out by the group. THCF define Telehealth as:

“Telehealth provides safe and accessible care/education through remote consultations between a patient/caregiver and healthcare professional using communication technology (e.g. videoconferencing, smartphone). It can be further enhanced using remote patient monitoring technologies coupled with safe and meaningful digital data transfer and storage.”

This definition is also available on the THCF ECFS webpage.

There have been no formal presentations on behalf of THCF yet. Several members have introduced THCF as part of their own presentations at local conferences for both scientific and patient/public audiences.

Aims for the coming:

- Year = 2024-2025
- To continue establishing the group.
- To continue the work currently being carried out in WP1, WP2, WP3.
 - WP1 = Public patient involvement activities
 - WP2 = literature reviews
 - WP3 = stakeholder surveys
- To hold first THCF meeting at the ECFS conference in June 2024.

Summary:

The THCF Working Group received initial approval in October 2023. Over the last 6 months there have been a number of meetings all with the ambition of establishing the Working Group, defining what is meant by telehealth, and initiating work packages to support the groups aims. The work completed in the last 6 months are supportive to the groups aims and objectives and demonstrates the enthusiasm and aspirations of the group. Over the next 6 months the group will begin generating tangible data to support our overall aims of developing a framework for best practices for telehealth within CF care and would greatly appreciate your ongoing support over the coming year.

Breakdown of expenses

- 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.)

Budget amount requested for next year:

- 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. Finally this amount will also support the group with open-access publication fees.