

Year of report: 2021/22	Detailing activities from 1 <sup>st</sup> May 2021 to 8 <sup>th</sup> May 2022
Name of Working Group: ECFS Exercise Working Group	Date of initial approval of working group: 2011
Coordinator name Dr Thomas Radtke Vice coordinator name Dr Don Urquhart	
<p>Long term aims of the working group (maximum 100 words) including estimated achievement date:</p> <ul style="list-style-type: none"> <li>• Provide forum (the working group) for sharing exercise knowledge amongst CF professionals <b><i>Ongoing – Virtual WG meeting January 2022 attended by XX people</i></b> <b><i>New ECFS WG Journal Club meeting every 2<sup>nd</sup> month began in February 2022</i></b></li> <li>• Curate technical standards and position statements for clinical practice in the fields of exercise and physical activity <b><i>3 x documents published 2014-2015</i></b> <b><i>New documents in progress (to be submitted for publication in 2022/23):</i></b> <b><i>Standardising the undertaking and reporting of commonly-performed exercise tests</i></b> <b><i>Update of 2014 physical activity position statement</i></b></li> <li>• Establishment of educational package to provide support for those undertaking exercise testing and exercise counselling in persons with CF <b><i>Ongoing – First exercise education modules completed Autumn 2021*</i></b> *Progress has been hindered by the timescale (&gt;6 months) to have educational material approved by the ECFS Education Working Group. Once layout and format agreed then a number of module leads are willing and ready to record, which will enable us to curate a comprehensive teaching resource.</li> <li>• Develop Exercise WG Journal Club <b><i>Meetings every 2nd month began in February 2022 (Ongoing)</i></b></li> <li>• Utilise Working Group as a Clinical Research Network for research theme of exercise in CF <b><i>Ongoing – 4 studies completed (latest aimed to be submitted for publication in late 2022)</i></b></li> </ul>	
<p>Outcomes already achieved (maximum 100 words):</p> <ul style="list-style-type: none"> <li>• <b>Knowledge sharing</b> - Biannual meetings great resource for CF exercise professionals since 2011</li> <li>• <b>Technical Standards/Position Statements:</b> <ul style="list-style-type: none"> <li>- Exercise Testing (<i>Respiration</i> 2015)</li> <li>- Physical Activity (<i>J Cyst Fibros</i> 2014)</li> <li>- Exercise Recommendations (<i>Cardiopulm Physiotherapy J</i> 2015)</li> <li>- NEW: Standardisation of commonly-performed exercise tests - <i>In progress (Aim to submit late 2022)</i></li> <li>- UPDATE: Physical activity - <i>In progress (Aim to submit early 2023)</i></li> </ul> </li> </ul>	

- **Education**

Previous Exercise short course (Liverpool 2019)

Online education package in development - First module completed Autumn 2021.

*(Awaiting ECFS Education Group agreement with regard to format to enable continued development of this resource – see previous comments).*

- **Research**

Completed studies:

Exercise capacity and CF genotype – *Ann Am Thorac Soc* 2018

Exercise capacity and mortality – *Am J Respir Crit Care Med* 2019

ACTIVATE-CF – *Am J Respir Crit Care Med* 2022

Glycaemic control sub-study of ACTIVATE-CF – *J Cyst Fibros* (*UNDER REVIEW*)

Oral presentation of work in WS14.03, 45<sup>th</sup> European Cystic Fibrosis Conference, Rotterdam, June 2022.

Exercise capacity and outcome in those with  $FEV_1 < 40\%$  predicted

*Study data still being analysed with view to submission for publication to Annals ATS in late 2022.*

*Additionally, submission for presentation at either NACFC 2022 or ECFS 2023.*

Report for this year (max 1000 words)

- **Short term goals for the year**

**Knowledge-sharing**

- ECFS Virtual Exercise Working Group Educational Meetings took place on June 2021 and January 2022

- ECFS Exercise Journal Club Meetings took place in February and April 2022

**June 2021 Virtual ECFS Exercise Working Group Meeting**

This was a full-day meeting attended by 45 delegates, from 12 countries across 3 continents via Zoom Platform.

The programme included updates on ECFS exercise WG projects, invited speakers and a Young Researcher Prize

session – see below for full details.



ECFS Conference 9-12 June 2021

Exercise Working Group Meeting: 8 June 2021

#### Programme

All times are CEST.

10.00 – 10.15 Welcome (Tom Radtke & Don Urquhart)

10.15 – 10.45 Update on current research activities (Moderator Don Urquhart)

- Update New Exercise Testing Paper (Zoe Saynor)
- Update Physical Activity Paper (Craig Williams)
- Update Mortality II Study (Tom Radtke)

10.45 – 11.30 Update on current educational activities (Moderator Tom Radtke)

- First insights into educational activities (Craig Williams)
- Define next steps and topics on educational activities (All)

11.30 – 11.45 Break

11.45 – 13.05 Invited Presentations (Moderator Helge Hebestreit/Erik Hulzebos)

- **Topic I:** Engaging people with CF in exercise during the pandemic (Lisa Morrison: 15 min plus 5)
- **Topic II:** Pro/Con Debate: Exercise versus Chest Physiotherapy for Airway Clearance in CF (Nathan Ward/Brenda Button: 2x15min plus 10)
- **Topic III:** Exercise in the world of CFTR Modulators (Casey Derella: 15 min plus 5)

13.05 – 13.45 Break

13.45 – 14.30 Short presentations\* (Jury: Brenda Button/Mathieu Gruet/Larry Lands)

- **Topic I:** Exercise versus airway clearance techniques for people with cystic fibrosis; a Cochrane systematic review (Katie Patterson: 10min plus 5)
- **Topic II:** Exercise Testing and Training in Cystic Fibrosis Clinics in the United Kingdom: A Decade On (Owen Tomlinson: 10min plus 5)
- **Topic III:** Compositional Analysis of Physical Activity, Sedentary Time and Sleep and Associated Health Outcomes in Children and Adults with Cystic Fibrosis (Mayara S Bianchini: 10min plus 5)

14.30 – 15.00 Plans for the future/Any other business (Tom Radtke & Don Urquhart)

\* The best presentation is selected by a jury (Brenda Button, Mathieu Gruet, Larry Lands) and the "winner" receives a prize.

The feedback was extremely positive after the meeting.

#### January 2022 Virtual ECFS Exercise Working Group Meeting

This was a half-day meeting attended by 35 delegates, from 9 countries across 3 continents using the Zoom Platform.

The programme included updates on ECFS exercise WG projects, as well as keynote speakers summarising important exercise research that has recently been or is soon-to-be published.



Exercise Working Group

ECFS Exercise Working Group Online Meeting  
21 January 2022

**Time of meeting**  
11:00-13:30 CET  
10:00-12:30 GMT (UK)  
07:00-09:30 in Eastern USA  
22:00-00:30 in Australia

**Programme**

**Welcome**

11:00-11:05 Introduction Dr Thomas Radtke, Zurich (CH)  
Dr Don Urquhart, Edinburgh (UK)

**Session I Update on working group projects (10min plus 5)**

11:05-11:20 Overview of available exercise tests  
- Best practice statement - Dr Zoe Seynor, Portsmouth (UK)

11:25-11:40 Physical activity measurement in CF  
- Update of 2015 Position statement - Prof. Kelly Mackintosh, Swansea (UK)  
Prof. Melitta McNarry, Swansea (UK)  
Prof. Craig Williams, Exeter (UK)

11:45-11:50 Does cardiopulmonary exercise testing  
provide short-term prognostic information  
in advanced cystic fibrosis lung disease?  
- Progress report - Dr Thomas Radtke, Zurich (CH)

11:50-11:55 Online Journal Club  
- Introduction to new format - Dr. Owen Tomlinson, Exeter (UK)

12:05-12:20 Exercise working group education modules  
- Progress report - Prof. Craig Williams, Exeter (UK)

**Session II Invited lectures – Challenges and lessons learned from two large randomised, controlled  
exercise intervention trials (20min plus 5)**

12:30-12:55 ACTIVATE-CF Prof. H. Hebestreit, Wurzburg (DE)

13:00 -13:25 INSPIRE-CF Sean Ledger, Queensland (AUS)

13:25-13:30 Wrap-up Dr Thomas Radtke, Zurich (CH)

Again, the feedback suggested that the meeting and its format had been well-received.

**June 2022 ECFS Exercise Working Group Meeting**

This is a full-day meeting planned prior to the commencement of the 45<sup>th</sup> ECFS conference in Rotterdam. In excess of 50 attendees are expected.

Meeting programme follows:

ECFS Exercise Working Group Meeting (Hybrid)  
8 June 2022

Programme

Welcome

11:00-11:05	Introduction	Dr Thomas Radtke (CH) Dr Don Urquhart (UK)
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Session I

Update on working group projects (10min plus 5)		
11:05-11:20	Exercise tests – best practice statement	Dr Zoe Saynor (UK)
11:20-11:35	Update Physical activity position statement	Mayara S Bianchim (UK)
11:35-11:50	Update "Mortality II" project	Dr Thomas Radtke (CH)
11:50-12:05	Educational activities	Prof Craig Williams (UK)

Break (10min)

Session II

Exercise testing and training prescription (10min plus 5)		
12:15-12:30	Case 1	Dr Erik Hulzebos (NL)
12:35-12:50	Case 2	Lisa Morrison (UK)
12:50-13:05	News on A-Step test	Prof Brenda Button (AUS)

Break (10min)

Session III

Invited lectures (20min plus 10)		
13:15-13:45	Overview of the current physical activity landscape: insights into analysis strategies and metrics (online)	Prof Melitta McNarry (UK)
13:45-14:15	Impact of habitual physical activity patterns on clinical outcomes in CYPwCF: Insights from Project Fizzyo	Prof Eleanor Main (UK)

Break (5min)

14:15-14:30	Wrap-up and communication of session II winner	Dr Thomas Radtke (CH) Dr Don Urquhart (UK)
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**ECFS CF and Exercise Journal Club**

Meetings have taken place as below:

**Wednesday 2<sup>nd</sup> February 2022**

**Presenter:** Máire Curran (PhD Candidate, Limerick, Ireland)

**Paper:** "Accuracy of the ActivPal and Fitbit Charge 2 in measuring step count in cystic fibrosis"

*This session had 25 attendees.*

**Wednesday 6<sup>th</sup> April 2022**

**Presenter:** Barlo Hillen (PhD Candidate, Mainz, Germany)

**Paper:** "Feasibility and implementation of a personalized, web-based exercise intervention for people with cystic fibrosis for 1 year"

*This session had 27 attendees.*

Four more ECFS Exercise Working Group 'CF and exercise' journal club sessions are planned for 2022.

**- Technical Standards/Position Statements:**

The group are actively working on two standardisation documents:

i. ONGOING WORK ON A NEW TECHNICAL STANDARD:

Overview of modes of exercise testing in Cystic Fibrosis:

Applying research and consensus to help advise and standardise clinical practice

Leads – Zoe Saynor, Don Urquhart and Thomas Radtke

Co-authors – Helge Hebestreit, Mathieu Gruet, Melitta McNarry, Lisa Morrison, Marlies Wagner, Abbey Sawyer

This document is close to completion with hopes to finalise with an in-person meeting alongside ECFS 2022.

The project an anticipated submission date of Autumn 2022, with the plan being to submit for consideration with Journal of Cystic Fibrosis.

ii. UPDATE OF PREVIOUS POSITION STATEMENT:

Physical activity in Cystic Fibrosis: A Systematic Review

Leads – Craig Williams and Kelly McIntosh

Co-authors – Mayara Silveira Bianchim, Melitta McNarry, Helge Hebestreit, Brenda Button, Tiffany Dwyer, James Shelley, Judy Bradley, Elpis Hatziagorou.

The 2014 Physical activity position statement is to be updated.

This will be a combination of an up-to-date review of the evidence along with expert recommendations.

The systematic review has been registered "Physical Activity Assessment in Cystic Fibrosis: A Systematic Review" to the PROSPERO register and that the record will be published on the website, the registration number is: CRD42022292165.

Data searches and screening is underway, with data extraction at the end of the May.

There have been several group meetings for this project with more planned over the summer.

A completion date of late 2022/early 2023 is anticipated.

**- Education**

The group are planning a comprehensive online exercise teaching and training resource comprising of a series of themed presentations with embedded questions and answers.

In brief, this would cover the following modules:

- Exercise Physiology

- Exercise Testing

- Physical Activity
- Exercise Counselling and Advice
- Preparation for Exercise
- Exercise and specific situations

A series of talks would be available for each of the above headings, providing an online knowledge network that links CF health professionals and provides a comprehensive modular curriculum devoted to the field of exercise in CF. The education workstream is being co-ordinated by Professor Craig Williams, Exeter, UK.

The first talks have been prepared and are awaiting feedback from the ECFS Education Group. Once style and format are agreed, there is a ready-made group of speakers who have self-assigned themselves to talks, such that the education base can be created.

***A more complete draft curriculum is available should further details be required (attached).***

## **- Research**

### **Recently-completed studies:**

1. Does cardiopulmonary exercise testing provide short-term prognostic information in advanced cystic fibrosis lung disease?

Leads – Thomas Radtke, Helge Hebestreit

Study sites in Australia, Austria, Canada, France, Germany, Greece, Israel, Serbia, Spain, Switzerland, UK, USA

This is a study assessing the prognostic value of exercise parameters in subjects with CF with FEV<sub>1</sub><40% predicted. Data entry is now complete.

A total of 180 separate data records so far including 44 cases where an adverse event has occurred including 11 deaths and 33 who have undergone lung transplantation.

Data analysis is underway with a plan for submission of these data for publication in late 2022.

### **Studies in planning:**

1. Exploration of physical activity and airway clearance therapy behaviours following initiation of elexacaftor/tezacaftor/ivacaftor in people with CF in Europe

This is a proposed study to be conducted by patient survey. There is provisional support for this being co-ordinated by the ECFS (Christine Dubois – *Personal communication*). The aim of the study will be to explore whether highly-effective modulator therapy has been an enabler of exercise ability in people with CF, and also whether starting Kaftrio has enabled a reduction in airway clearance physiotherapy. We will look to identify potential project leads for this initiative at the forthcoming (June 2022) Exercise Working Group meeting.

### **Establishment of junior researcher award:**

The group are mindful of the need for succession planning within the field of exercise and CF.

It is necessary to nurture the younger members of the group, to involve them in research and presentation, to enthuse them and to offer mentorship from senior group members. The inaugural junior researcher award was awarded to the best presentation given by an author aged <35 years on an exercise and CF-related topic at the 2021 ECFS virtual exercise group meeting. A high quality selection of abstracts were submitted with 3 of those being selected for presentation.

The first 'Junior researcher Award' was won by Dr Myara Bianchim for a presentation entitled:

“Compositional Analysis of Physical Activity, Sedentary Time and Sleep and Associated Health Outcomes in Children and Adults with Cystic Fibrosis” - The prize was registration for the ECFS 2022 conference.

- **Current number of members**

The exercise working group has 60 current members  
These have been provided as an Excel spreadsheet of:

- Member
- Institution
- ECFS membership status\*

*\*Up to date as far as last ECFS-provided membership data (Emily Bateman – 2021)*

- **Measures taken to encourage ECFS membership**

The working group highlights the benefits of ECFS membership when communicating with members. Our newly-developed logo (see below) makes it very clear that the Exercise Working Group is a sub-group of the ECFS.



- **Outcomes/achievements (e.g. meetings, activities, website development, awards, publications etc).**

- **Meetings**

- ECFS Exercise Working Group Meeting [Virtual] 8<sup>th</sup> June 2021
- ECFS Exercise Working Group Meeting [Virtual] 21<sup>st</sup> January 2022
- ECFS Exercise Working Group Meeting [Rotterdam] 8<sup>th</sup> June 2022

*Agendas as listed above*

- **Developments**

The instigation of the ECFS CF and Exercise Journal Club in 2021/22 has been a good new development. This initiative is being led by one of the Early Career Researchers (Dr Owen Tomlinson, Exeter, UK), which is great for the sustainability of our group.

- **Presentations**

Radtke T, Kriemler S, Stein L, Karila C, **Urquhart DS**, Orenstein DM, Lands L, Schindler C, Eber E, Haile S, Hebestreit H, ACTIVATE-CF Study Working Group.  
Cystic fibrosis related diabetes is not associated with maximal aerobic exercise capacity in cystic fibrosis: a cross-sectional analysis of an international multicentre trial (ACTIVATE-CF).  
WS 14.03, 45<sup>th</sup> European Cystic Fibrosis Conference – Rotterdam, June 2022.

- **Publications**

Original articles:

Hebestreit H, Kriemler S, Schindler C, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands L, Schaeff J, Radtke T, ACTIVATE-CF Study Working Group.

Effects of a partially supervised conditioning program in cystic fibrosis: an international multicenter randomized controlled trial (ACTIVATE-CF).

*Am J Respir Crit Care Med* 2022; **205**:330-339. doi: 10.1164/rccm.202106-1419OC.



The following has been submitted to *J Cyst Fibros* and is presently under review:

Radtke T, Kriemler S, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands LC, Schindler C, Eber E, Haile SR, Hebestreit H, on behalf of the ACTIVATE-CF Study Working Group\*.

Cystic fibrosis related diabetes is not associated with maximal aerobic exercise capacity in cystic fibrosis: a cross-sectional analysis of an international multicentre trial [ACTIVATE-CF].

*J Cyst Fibros* 2022; **Under Review**.

**Abstracts:**

Radtke T, Kriemler S, Stein L, Karila C, Urquhart DS, Orenstein DM, Lands L, Schindler C, Eber E, Haile S, Hebestreit H, ACTIVATE-CF Study Working Group.

Cystic fibrosis related diabetes is not associated with maximal aerobic exercise capacity in cystic fibrosis: a cross-sectional analysis of an international multicentre trial (ACTIVATE-CF).

*J Cyst Fibros* 2022; **In press**.

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

The aims for the coming year are as follows:

- **Knowledge-sharing**  
Undertake face-to-face meeting at ECFS Rotterdam in June 2022  
Plan to continue 2 meetings per year thereafter  
a) Virtual -January 2023  
b) Face-to-face at ECFS June 2023  
ECFS CF and Exercise Journal Clubs (Virtual) every 2 months
- **Technical Standards/Position Statements:**  
Complete of technical standard – Standardisation of commonly-performed tests  
*Aim to ratify final version at ECFS 2022 and submit for publication thereafter*  
Complete Physical Activity position statement update  
*Planned submission date early 2023*
- **Education**  
Continue to build online knowledge network for exercise in CF.
- **Research**  
Submission of completed research project on exercise testing in advanced lung disease  
*Estimated date of submission – late 2022.*

Summary (maximum 100 words):

The ECFS Exercise Working Group celebrated its' 10 year anniversary in 2021.

The group has been a fertile ground for knowledge-sharing and developing collaborations.

**Group output:**

Published international technical standards and position statements on:

1) Exercise Testing (Respiration 2015, Eur Respir Rev 2019)

- 2) Physical activity (J Cyst Fibros 2015)
- 3) Exercise recommendations (Cardiopulm Physiotherapy J 2015)

**Investigator-initiated research:**

Exercise Capacity and CFTR genotype (published Ann Am Thorac Soc 2018)  
Exercise Capacity and Mortality (published Am J Respir Crit Care Med 2019)  
Exercise testing in advanced cystic fibrosis lung disease (study ongoing)  
Randomised, controlled trial of exercise intervention - ACTIVATE-CF (published Am J Resp Crit Care Med 2022)  
Glycaemic substudy from ACTIVATE-CF (under review at J Cyst Fibros, submitted April 2022)  
Mortality II study – Data being analysed (planned submission to Ann Am Thorac Soc, late 2022/early 2023)

**Education:**

Pre-course workshop on exercise testing at ECFS Liverpool (2019).  
Online modular education resource – *In development*.  
Regular Exercise Journal Club held virtually every 2 months.

**Ongoing:**

Current projects include guideline development, education and research.

We would value your ongoing support to complete these projects and to develop new ideas.

Breakdown of expenses (please include total amount received as well as expenditure and, if applicable, the outstanding balance (Euros)). Please refer to the WG TOR for examples of budget expenses:

- Total amount requested for 2021/22: €6000
- Expenditure:
  - Junior Researcher Award - €1000**  
Flights from within Europe and registration for ECFS 2022 for winner of best presentation at ECFS Exercise Working Group meeting in June 2021.
  - ECFS Exercise Working Group Meeting, Rotterdam:**
    - AV costs - €600**
    - Catering expenses - €600 approx.**

This should leave an outstanding balance of > €3000

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

Total requested = **€5000**

**Development of patient-facing pages for working group - €2000 approx.**

- Factsheets on working group projects
  - Factsheets on physical activity and exercise by people with CF for people with CF
- We will look to seek group members to work on these tasks as part of our face-to-face exercise WG meeting in June 2022.*

**Junior Researcher Award - €1000**

Flights from within Europe and registration for ECFS 2023 for winner of best early career researcher



presentation at ECFS Exercise Working Group virtual meeting in January 2023.

**ECFS Exercise Working Group Core Group Meeting €2000 approx.**

Plan for 1 day face-to-face meeting at airport hotel (e.g. Amsterdam, Frankfurt, London)

Proposed attendees would be: Thomas Radtke (Co-ordinator), Don Urquhart (Deputy Co-ordinator), Helge Hebestreit (Chair of group from 2011-2019), Zoe Saynor (Lead for ECFS exercise guideline updates)

Proposed agenda for meeting would include:

- Group peer review of received education videos
- Prioritisation exercise to guide direction of future projects
- Succession planning for DU/TR reaching end of 3-year term as group co-ordinators

Airport hotel would allow all to attend for 1-day meeting with 1 night of overnight accommodation

Cost - €500 per person approximately.