

CF Exacerbation Working Group

Year of report: 2021-2022

Name of Working Group:
Pulmonary Exacerbation

Date of initial approval of working group:
2019

Contact details of coordinator, vice coordinator and assistant (if applicable) including ECFS membership numbers:

Coordinator name Robert Gray

Vice coordinator name Cliff Taggart/Damien Downey

Long term aims of the working group (maximum 100 words) including estimated achievement date:

Due the changing nature of CF both during the global pandemic and since the introduction of CFTR modulators to large numbers of people with CF in Europe and North America the original aims of the exacerbation group require recalibration.

Our approach is outlined in our report for this year (below).

Outcomes already achieved (maximum 100 words):

The group had the first official meeting as a funded working group in June of 2019 at the ECFS annual conference followed by a satellite meeting at the North American CF meeting in Nashville in October of 2019. Plans for 2020-22 have been impacted significantly by COVID19 both in terms of our inability to meet in person, and the diversion of many people's activities to COVID response work and the roll out of new CFTR therapies.

Report for this year (max 1000 words)

Aside regular zoom catch-up meetings for the group coordinators we have not had a formal meeting of the whole group in the past year. Online meeting fatigue and uncertainty about the effects of COVID, new CFTR modulators and lockdowns on CF have made planning difficult.

There is renewed enthusiasm in the group members to reconnect in person at Rotterdam and recharge our programme. The landscape of CF exacerbation has changed and continuing to do what we were doing pre-pandemic is unlikely to lead to increased benefit for the CF community. In short, we need to re-think what CF exacerbation means in the changed clinical landscape of CF.

Our goals for the coming year are:

1. An assessment of changing rates of CF exacerbation at a disease registry level but also with the collection of granular data (where available) from individual centres.

2. A wide-ranging consultative exercise of clinicians and people with CF to assess the perceived importance of exacerbation in CF
3. A frank assessment of how relevant previous studies of exacerbation including definitions, biomarkers and treatments are to the entire CF patient group, including those with no access to modulator therapy at a national level, those with genetic mutations not covered by present modulators and those taking modulators.

Timeline for goals:

1. 0-6 months from June 2022: Access registry data at UK, Ireland and European levels and compared to local datasets where available initially Scotland/Belfast/Dublin for adults, Newcastle/Scotland for paediatrics. Follow up meeting at NACF in Philadelphia to confirm progress.
2. 0-9 months from June 2022: Design and conduct online questionnaire/survey of CF clinicians and patients.
3. 0-12 months: Review of present publications, data from aims 1 and 2 and conduct a 1 day in-person seminar of the working group in February 2023 to outline a vision for CF exacerbation management in the “modern CF era”.

Current number of members: 14

Measures taken to encourage ECFS membership: all members of the exacerbation group are expected to be members of the ECFS

Outcomes/achievements: In progress

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

2022-2023: Recalibration of working group as outlined above.

Summary (maximum 100 words):

The global pandemic has been no doubt challenging for many ECFS working groups. We also acknowledge as a group that the face of CF exacerbation is evolving, and a recalibration of our aims is required. The group remains enthusiastic and will meet in person in Rotterdam 2022 to re-establish our vision for CF exacerbation assessment and management going forward.

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:

Expenditure so far: minimal, room costs for in person meetings at 2019 ECFS Liverpool and 2019 NACF in Nashville.

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

Approx 10,000 Euro to enable 1 day seminar and admin costs to cover additional support in administering survey. 1000 EURO funding for room at NACF in Philadelphia 2022.