

Pulmonary Exacerbation Working Group

Year of report: 2023

Date of initial approval of working group: 2019

Coordinator name: Robert Gray

Vice coordinator: Cliff Taggart/Damien Downey

Long term aims of the working group including estimated achievement date:

1. To facilitate multi-centre CF pulmonary exacerbation (PEX) research and formulate identification of these events to enable to improve the prediction, diagnosis and monitoring of PEX.
 2. To investigate the utility of biomarkers in the prediction and assessment of treatment response in PEX and develop these towards clinically useful tests.
 3. To explore if a precision medicine approach is feasible by utilising individual and registry patient data as well as assessing the potential of new technologies and biomarkers, such as near patient testing.
- Our approach is outlined in the sections below.

Outcomes already achieved:

2022-2023 represented an opportunity to re-establish the pulmonary exacerbation WG post-covid and post-modulators. Our major achievement this year was to hold a hybrid 1 day meeting dedicated to outlining unmet needs and future research planning for CF exacerbation. A summary of the action points from this meeting has been attached. We now have a clear strategy moving forward and would like to continue working on this area as a group. An exacerbation WG meeting will take place at the 2023 ECFS meeting and new membership of the group will be actively encouraged.

Report for 2022-2023

Summary: Renewal of the working group has allowed a strategic reboot of aims and objectives in the post-COVID, post-modulator era. We held a successful hybrid 1 day meeting on the 16th March 2023 in Edinburgh, Scotland. This was well attended in person and online and a wide range of subjects were enthusiastically discussed. The group has a renewed sense of purpose and have adjusted goals accordingly.

Short term goals for the year:

1. Continuing work on updated definition of exacerbation. Patient engagement through CF Europe and CF trust are key to this as well as closely liaising with groups active in exacerbation such as Project Breathe. A sub-group has been set up to take forward the task of arranging Delphi process led by Dr Malcolm Brodrie. This process will take around 9 months. Aim to have results ready for presentation at ECFS 2024.
2. Access European registry data. Data application has been submitted by group member Dr Virginia De Rose to cover pre- and post-pandemic period to assess changing rates of exacerbation and simple demographic profiles. Initial data extraction and analysis will take around 6 months, aiming to submit to ECFS 2024.
3. Prepare future perspectives in CF exacerbation article. Group favours preparation of this once further data from goals 1 and 2 available. Aim to have article ready to submit at 12 months.
4. Suggest exacerbation symposium for ECFS 2024 meeting. Aim to use this session to engage the CF community and increase interest and involvement in the development of exacerbation studies. Suggested aspects of this include clinical vignette polling session.

Current number of members: 15

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

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

Outcomes/achievements: So far this year data application to European CF registry and completion of one day meeting with associated action points and plan for work over the next 12 months.

Aims for the coming year :

The initial renewal period following COVID was one year. The group is now highly active and is engaging in multiple activities. Our short-term goals are listed above and are achievable. Our major aim for the coming year is to have data ready for presentation at ECFS 2024 and publication of a perspective article. Funding applications for further research activities will build on this.

Summary:

After a challenging few years, the Exacerbation WG is on track and work is already underway on our key aims and objectives including exacerbation definition and registry data access and analysis. The key driver of the group is improving the lives of people with CF and as a community we have seen a return of exacerbations in the CF population (including those on modulators) in the post-lockdown(s) period. Key future research questions have been formulated and we are now assessing the feasibility of performing studies that will assess key clinical and scientific questions once we have obtained key baseline information on exacerbation rates and demographics across Europe.

Breakdown of expenses:

8000 Euro Budget for 2022-2023

Edinburgh meeting room hire and catering and meeting dinner: 791 GBP Accommodation for Edinburgh Attendees: TBC (attendees made own claims to ECFS)

Budget amount requested for next year

Proposed budget 8000 Euro (includes open access publication fees not utilised in 2023-2023)