

TEMPLATE FOR ECFS SPECIAL INTEREST GROUP REPORTS

Please use this template for your annual Special Interest Group report. Please use black ink, Calibri font size 11. For more information, please read the following ECFS special interest group [Terms of Reference document](#):

Year of report: 2024/2025

Name of Special Interest Group:
ECFS Psychosocial Special Interest Group

Date of initial approval of Special Interest Group:

Name and email of coordinator, vice coordinator and assistant (if applicable)

Coordinator name **Urszula Borawska – Kowalczyk**

Vice coordinator name **Dagmar Brocke**

Assistant name **Annet Bongen**

Long term aims of the Special Interest Group (maximum 100 words) including estimated achievement date:

The aim of EPSIG is to provide education and support for CF psychosocial professionals and teams by sharing good practice, research, and information in a friendly and supportive environment. Understanding and addressing psychosocial factors is important in helping people with CF and their relatives achieve the best possible health outcomes. In part, the psychosocial role is to deliver a psychological and social work service to the MDT.

It is also essential to cooperate with other ECFS special interest groups and the Mental Health Working Group to collaborate in activities aimed at improving the care of patients with CF and their families. In addition, EPSIG participates in tasks conducted by the ECFS Education Group and actively co-creates psychosocial content for the Educational Platform.

Outcomes already achieved (maximum 100 words):

The described goals are systematically achieved by sharing the experience of group members and organizing meetings, workshops, and courses.

The main activity of the group takes place during the annual ECFS conferences, during which members organize and actively participate in such activities as Pre-conference ECFS Psychosocial Special Interest Group Meetings, Pre-conference Short Courses, and Interactive sessions "Tomorrow lounge".

In addition to the activities during the annual conference, EPSIG co-organized the ECFS Lunchtime webinar series.

The EPSIG Committee meets regularly online monthly to organize the EPSIG pre-conference meeting and course, discuss the group's goals, and plan future activities.

Report for this year (max 1000 words)

- short term aims and objectives for the year
- current number of members
- measures taken to encourage ECFS membership
- outcomes/achievements (e.g. meetings, activities, website development, awards, publications etc).

The EPSIG Committee update.

The current EPSIG committee consists of four psychologists and four social workers:: Urszula Borawska-Kowalczyk, Clinical Psychologist, PL, Annet Bongen, Medical Social Worker, Dagmar Brocke, Clinical Social Worker, NL; Stina Järvholm, Clinical Psychologist, SE; Katie Smith, Social Worker, UK; Sue Braun, Clinical Psychologist, BE; Jacqueline Boekhoff, Social Worker, NL and Steve Jones, Clinical Psychologist, UK. The EPSIG comprises approximately 70 psychosocial professional members.

- Urszula Borawska-Kowalczyk, Annet Bongen, and Dagmar Brocke have completed their tenure as a coordinators on the EPSIG and will step down from the EPSIG committee after the ECFS conference in Milan.
- Sue Braun, Clinical Psychologist and Jacqueline Boekhoff, Social Worker will be carrying on as the new EPSIG coordinators.

The EPSIG committee has organized the following activities during the European Cystic Fibrosis Conference in Glasgow:

- EPSIG pre-conference meeting “Well-being, important topic for patients and professionals” on the 5th of June 2024
- Pre-Conference Short Course Co-creating personalized treatment plan, how to live your best life by Steve Jones, Sheffield, UK on 4th of June 2024, in collaboration with the MHWG
- Interactive session “Tomorrow lounge” titled Psychological considerations in relation to. Cystic Fibrosis Screen Positive, Inconclusive Diagnosis (CFSPID)

The activities provided valuable opportunities for participants to enhance their competencies, engage in knowledge exchange, and extend professional networks. All sessions were well-attended and received positive evaluations, with participants emphasizing their educational value and high standard of organization.

The EPSIG and MH WG organized a series of three lunchtime webinars for the CF MDT, focusing on a wide range of mental health and psychosocial aspects. The goal was to demonstrate the collaboration of various specialists in developing best practices within the MDT framework. Furthermore, the online format enabled the involvement of clinicians from diverse regions, with participants registering from multiple countries. The topics covered in the webinars included:

- Is Telehealth taking over regular face to face consultations?– 27th of November 2024 (151 registrations)
- Perspectives from different ages: generation to generation – 12th of February 2025 (150 registrations)
- Substance abuse and risk-taking behaviour – 9th of April 2025 (149 registrations)

The pre-conference course, as well as all CF Lunchtime Webinars, have been recorded and are available on the Education Platform for active ECFS members interested in psychosocial content.

The EPSIG Committee actively encourages members to renew their ECFS membership by sending reminders to the full contact list at the beginning of the year, during the ECFS conference registration period, and in all email communications related to EPSIG membership. Additionally, during EPSIG meetings and activities, participants are reminded and strongly encouraged to maintain active ECFS membership. This year, we observed a significant increase in the proportion of EPSIG members who are also active ECFS members.

However, despite the availability of a reduced membership rate for Allied Health Professionals, we have received feedback indicating that some members, especially from less prosperous countries, face challenges in obtaining funds or renewing their ECFS membership from their resources every year.

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

The EPSIG committee is organizing the following activities during the 48th European Cystic Fibrosis Conference in Milan:

- **EPSIG pre-conference meeting** “The Brain: Life, Breath and Beyond” on the 4th of June 2025.
- **Pre-Conference Short Course** – The Challenges of Managing the Neuropsychiatric and Psychological Effects of Modulators: Practical and Clinical Implications. Facilitator: dr Beth Smith *on the 3th of June 2025*, in collaboration with the MHWG
- **Interactive session “Tomorrow lounge”** titled I’ve got a gut feeling this is going to be important: the brain-gut axis in CF care.

The CF lunchtime webinar series organized jointly with MH WG is planned to be continued next year.

Summary (maximum 100 words):

Most of the goals and plans set for 2024 have been successfully achieved. The EPSIG activities held during the ECFS conference in Glasgow were well-attended and well-received by participants. The Committee meets online monthly, facilitating the organization of EPSIG tasks and the attainment of group objectives.

EPSIG's primary regular activities, including pre-conference meeting, course, and interactive session, will continue during the 48th ECFS Conference in Milan. EPSIG will also maintain its collaboration with other ECFS Groups, resulting in joint initiatives such as courses and webinars, as well as participation in ECFS projects like the Education Platform. The EPSIG Committee will actively encourage members to renew their ECFS membership.

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

EPSIG requested for 3000€ of ECFS Support in 2024.

Pre-conference short course: Instructor’s fee, travel, and one night of accommodation – €500; catering – €450, moderators’ registration 150€, (half of the total expenses, with the other half covered by the MH WG),

Pre-conference EPSIG meeting: catering 2000€, speakers’ registration 75€

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

According to the Special Interest Group Terms of Reference, we are applying for 3000 euros.

Estimated costs:

EPSIG pre conference meeting – catering 2000€



Pre-conference short course EPSIG costs: catering, Instructor's fee, travel and accommodation 1 night 1000 € (EPSIG covers half of the course costs, while the MGWG covers the other half).

Catering costs are estimated and will be adjusted directly to the number of registrations

The deadline for submission to the ECFS Office is 1st May.

Please email the report and the excel spreadsheet of your members to: jess.matthews@ecfs.eu

The report will then be presented to the board prior to the summer ECFS board meeting and then a decision will be made at the next board meeting for approval before being distributed.