

Aims and objectives of the Working Group:

To develop a multidisciplinary network of clinicians and researchers to facilitate and support the dissemination and implementation of the Mental Health Guidelines¹.

To monitor the implementation of Mental Health Screening and identify the range of clinical practice and treatment referral pathways across Europe.

To identify *driving and restraining themes* that CF teams encounter when implementing the guidelines to inform resource issues and best practice.

To determine patient / parent and clinician-reported effectiveness / impact of Mental Health Screening.

To promote excellence in Mental Health research across the European CF Community.

'Core' Working Group:

Janice Abbott (UK)
Urszula Borawska (Poland)
Sophie Cammidge (UK)
Helmut Ellemunter (Austria)
Anna Georgiopoulos (US)
Trudy Havermans (Belgium)
Pavla Hodkova (Czech Republic)
Stina Järholm (Sweden)
Diana Kadosh (Israel)
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Nicoleta Papa (Italy)
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Ulirke Smrekar (Austria)
Doris Staab (Germany)
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ECFS Administrative & Website support

Christine Dubois
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¹Quittner AL, Abbott J, Georgiopoulos AM, et al. The International Committee on Mental Health: Cystic Fibrosis Foundation and European CF Society consensus statements for screening and treating depression and anxiety. *Thorax* doi:10.1136/thoraxjnl-2015-207488

Third Annual Report – April 2019 ECFS Mental Health Working Group

Co-ordinators

**Professor Janice Abbott
Dr Trudy Havermans**

The Mental Health Working Group (MHWG) has completed the majority of aims and objective over the initial three-year term of the working group. It is proposed to extend the work of the group for a further three years. Janice Abbott and Trudy Havermans will step down as Co-Leads and Eddie Landau and Marieke Verkleij will take on the leadership of the group for the next phase.

Summary of the completed plan of work during Year 3

- The Annual Mental Health Working Group meeting was held during the ECFS conference in Belgrade, June 2018.
- The ECFS MH website is continually updated to provide a bank of resources for clinicians to facilitate implementation of MH screening. Translations in many European languages are now available.
- Further opportunities have been provided for training in Mental Health.
- The dissemination and implementation of the MH Screening Guidelines in countries in Eastern Europe. Active recruitment of 'Country Captains' and those who assist with dissemination and language translations continues to grow, with more than 50 individuals involved in the MHWG's activities.
- The survey evaluating the MH Guidelines in CF Centres across Europe has been published in *JCF (Journal of Cystic Fibrosis 2019;18:299-303)*. The lay summary published in *CF Research News* has been posted on the ECFS MH website.
- A questionnaire to evaluate the effectiveness of the MH Guidelines from the perspective of people with CF and their caregivers has been developed and piloted. It is being administered with the help of CF Europe. The results will be posted on the MH website.

ECFS Mental Health Website

The ECFS Mental Health Working Group Website is updated regularly.

(<https://www.ecfs.eu/mentalhealth>)

The website provides a resource for CF Health Professionals, patients & caregivers. It holds:

- The depression screening tool (PHQ-9 in 31 languages)
- The anxiety screening tool (GAD-7 in 29 languages).
- The Mental Health Guidelines.
- The step-by-step 'Guide for CF clinicians.
- Information for parents & caregivers
- Associated research papers.

The 'step-by-step Guide for CF clinicians' and the 'Information for parents & caregivers' is available in several language translations (others are in progress).

- Bulgarian
- Czech
- Danish
- Dutch (Belgium)
- Dutch (The Netherlands)
- English
- French
- Greek
- Latvian
- Polish
- Russian
- Serbian
- Slovakian
- Ukrainian

Training and Networking Opportunities during the first three years

'Meet the Experts' sessions at ECFS conferences:

- Implementing the Mental Health Guideline (Basel, 2016).
- Psychopharmacological treatments for mental health problems in CF (Seville, 2017).

Tomorrow lounge at ECFS conferences:

- Mental Health Screening (Basel, 2016).
- Mental Health Guidelines: How to get started? Practical strategies and challenges (Seville, 2017).
- Mental Health guidelines from East to West (and back). Local adaptation of the implementation of the guidelines (Belgrade, 2018).
- Mental Health in my hospital: How to start screening and how to move on (Liverpool, 2019)

Evidenced-based Therapy Course

A one-day course to introduce the basics of Cognitive Behaviour Therapy and Interpersonal Therapy for members of the CF team was held in Belgrade, 2018. This introductory course was delivered by an expert in CBT, Dr Alexandra Klein Rafaeli (Israel). Very positive feedback was received from participants and therefore the course will run again in Liverpool, 2019. It is aimed at any health professionals who wants to know more about the most common psychological therapy.

Networking

A database / network of Health Professionals who have expressed an interest in mental health, and Patient Associations (European countries and Australia) has been developed, is regularly updated and sent to all those on the list.

Evaluation of the MH Guidelines from the perspectives of people with CF and their caregivers

Health professionals have reported that MH screening has been successfully implemented in many CF Centres. From these data, we now have some understanding of the benefits and barriers of mental health screening. To complete this picture, we are interested in the importance that patients and caregivers put on mental health, their preferences and experiences of screening and any follow-up care.

CF Europe will assist in the administration of a questionnaire. The English version is being translated into other languages for clinic administration in an attempt to capture a more inclusive European sample.

The results of the survey that seeks the views of people with CF and their caregivers will be posted on the MH Website later in 2019.