

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 (financial, physical, human and informational) and best practice.

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

To incorporate Mental Health variables into the ECFS Registry.

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)

Maya Kirszenbaum (France)

Edwina Landau (Israel)

Jaqueline Noordhoek – European Parent Association

Nicoletta Popa (Italy)

Yvonne Prins (Adult with CF, Netherlands)

Ulrike Smrekar (Austria)

Doris Staab (Germany)

Marieke Verkleij (Netherlands)

Second Annual Report ECFS Mental Health Working Group April 2018

Co-ordinators
Professor Janice Abbott
Dr Trudy Havermans

Sadly, on 30th October 2017 we lost Professor Lutz Goldbeck at the age of 58. Lutz led the TIDES study in Germany and was a core member of the CFF and ECFS International Mental Health Guidelines committee. Lutz continued this work as a valued member of our ECFS Mental Health Working Group. It is part of his legacy that Mental Health screening has been introduced into CF Centres in Germany and these data are being recorded in the German registry.

Plan of work for Year 2.

- The two Subgroups to have monthly Telcos and continue to develop a network of CF Health Professionals who will act as 'Country Captains', assisting with the collection of Country-specific information.

Resources & Education Subgroup

- Develop the resource area on the ECFS website to provide easy access to resources to facilitate implementation of MH screening in many European languages.
- Continue the dissemination and implementation work aiming to attract more countries in Eastern Europe.
- Provide further opportunities for training.

Evaluation & Research Subgroup

- Administer the survey to CF Centres and analyse the data concerning the uptake of screening, treatment referrals, drivers, barriers and impact of the MH Guidelines.
- Develop surveys to evaluate the Mental Health Guidelines from the patient and caregiver perspective.

ECFS 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, people with CF and their caregivers. It holds:

- The depression screening tool (PHQ-9 in 31 languages) and the anxiety screening tool (GAD-7 in 29 languages).
- The Mental Health Guidelines, associated research papers and the step-by-step 'Guide to implementing depression and anxiety screening'. The 'guide' is currently available in six languages (Bulgarian, Danish, Dutch, French, English, Polish) with further language translations in progress.
- Mental Health screening information for patients / caregivers (currently in Bulgarian, Danish, Dutch, French, English, Polish).

Dissemination of the Guidelines across Europe

Active recruitment of 'Country Captains' and those to assist with dissemination, language translations, etc. has been successful, with 49 individuals involved in the Working Group's activities.

Representation of the 'wider' Working Group	
Australia	Cindy Branch-Smith Alice Morgen
Austria	Helmut Ellemunter Ulrike Smrekar
Belgium	Trudy Havermans
Bulgaria	Guergana Stoyanova
Croatia	Srdjan Banac Dorian Tjesic Drinkovic
Czech republic	Pavla Hodková Klara Benesova
Estonia	Urve Putnik Maire Vasar Tiina Kahre
France	Maya Kirszenbaum
Germany	Doris Staab
Greece	Argyri Petrocheilou
Hungary	Adrien Halász Judit Falus Szilvia Eitler
Ireland	Helen Gibbons Gary Killeen
Israel	Diana Kadosh Edwina Landau
Italy	Paola Catastini Nicoletta Popa
Netherlands	Jaqueline Noordhoek Yvonne Prins Marieke Verkleij
Poland	Urszula borawska Renata Zubrzycka
Portugal	Celeste Berreto
Russia	Yulia Gorinova Tatiana Sviridova Afonina Mariya Olga Poletajeva
Slovakia	Ludmila Bisova
Slovenia	Majda Ostir Valentina Stefanovo
Spain	Inez Perez Amparo Sole Karina Gonzalez
Sweden	Stina Jarvholm
Switzerland	Connstance Barazzone Julie Halimi Daniel Schechter
Ukraine	Kateryna Yavna
UK	Janice Abbott Sophie Cammidge
US (CFF representative)	Anna Georgiopoulos

Training and Networking Opportunities to date

'Meet the Experts' sessions at ECFS conferences:

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

Tomorrow lounge

1. Mental Health Screening (Basel, 2016).
2. Mental Health Guidelines: How to get started? Practical strategies and challenges (Seville, 2017).
3. Mental Health guidelines from East to West (and back). Local adaptation of the implementation of the guidelines (Belgrade, 2018).

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 (Belgrade, 2018).

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 and will be 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

The surveys for people with CF and their caregivers are almost developed. These will be piloted and amended as necessary to ensure understanding and ease of completion.

The English version will be translated into several languages (and subsequently piloted in that language) in an attempt to capture a more inclusive European sample.

Summary: Evaluation of MH Guidelines in CF Centres across Europe

The first step in the evaluation of the Mental Health Guidelines was a survey to CF Centres, which aimed to evaluate the dissemination and implementation of the guidelines two years following their publication. A short, 28-item, survey was developed and evaluated (a) who should be responsible for MH care, (b) the current awareness and agreement of the guidelines, (c) the provision of the recommended MH screening and follow-up care, (d) the successes of and barriers to screening and (e) further resource/training needs. Responses were received from 187 CF Centres across 29 European countries.

Responsibility for mental health

Ninety percent of respondents believed that MH care should be the responsibility of the psychologist, with a psychologist currently responsible for MH in 71% of centres. It was clear that many members of the CF team believed that they too share some of the responsibility.

Awareness/agreement of the guidelines

Sixty-two percent of respondents were aware of the MH Guidelines. Of these, 82% fully and 12% partially agreed with them. Reasons provided for partial or non-agreement were (a) that the guidelines were too rigid when some teams have the ability to perform a more comprehensive assessment and (b) a couple of respondents queried the sensitivity of the screening tools.

Current mental health care and outcomes

Fifty percent of centres had implemented MH screening. Seventy-five percent of those screening were using the recommended instruments (PHQ-8/9 and GAD-7), with others using additional measures to perform a more comprehensive assessment or administering other validated anxiety and depression scales (10 other scales were listed by participants). The percentage of patients and caregivers screened in the past year varied across centres (some centres were just starting) with a total estimate of 6000 patients and 2000 caregivers screened. A total of 551 treatment referrals for moderate/severe psychopathology and 84 urgent suicide ideation referrals were made. However, only 44% were always able to provide the recommended follow-up and one-third of those screening reported that they did not have a plan developed for suicide risk.

Benefits, barriers and further training needs

The main benefits of screening were 1) easier to initiate MH conversation (70%), 2) greater awareness of MH among the MDT (64%), patients (64%) and caregivers (49%) and 3) MH being destigmatised (51%). The main barriers included 1) insufficient staff time (69%) and 2) lack of qualified MH personnel (35%). Interestingly, the top training need was 'mental health training for the multidisciplinary team' (68%). Other resources required included funds to support a MH professional (62%), electronic tools for administration and scoring (54%) and access to a MH hotline for guidance (32%).

Plan of work for Year 3.

- Hold the Annual Mental Health Working Group meeting during the ECFS conference in Belgrade, June 2017.
- Consider the sustainability of the Working Group.
- Continue the dissemination and implementation work aiming to attract more countries in Eastern Europe.
- Develop further the resource area on the ECFS website to facilitate implementation of MH screening in many European languages.
- Provide further opportunities for training.
- Administer the surveys (analyse data & write report) to evaluate the Mental Health Guidelines from the patient and caregiver perspectives.