

Central Lancashire Online Knowledge (CLOK)

Title	Mental Health screening in cystic fibrosis centres across Europe
Type	Article
URL	https://clock.uclan.ac.uk/24161/
DOI	https://doi.org/10.1016/j.jcf.2018.09.003
Date	2019
Citation	Abbott, Janice, Havermans, T., Jarvholm, S., Landau, E., Prins, Y., Smrekar, U., Staab, D., Verity, L. and Verkleij, M. (2019) Mental Health screening in cystic fibrosis centres across Europe. Journal of Cystic Fibrosis, 18 (2). pp. 299-303. ISSN 1569-1993
Creators	Abbott, Janice, Havermans, T., Jarvholm, S., Landau, E., Prins, Y., Smrekar, U., Staab, D., Verity, L. and Verkleij, M.

It is advisable to refer to the publisher's version if you intend to cite from the work.
<https://doi.org/10.1016/j.jcf.2018.09.003>

For information about Research at UCLan please go to <http://www.uclan.ac.uk/research/>

All outputs in CLOK are protected by Intellectual Property Rights law, including Copyright law. Copyright, IPR and Moral Rights for the works on this site are retained by the individual authors and/or other copyright owners. Terms and conditions for use of this material are defined in the <http://clock.uclan.ac.uk/policies/>

Mental Health screening in cystic fibrosis centres across Europe

J. Abbott¹, T. Havermans², S. Jarvholm³, E. Landau⁴, Y. Prins⁵, U. Smrekar⁶, D. Staab⁷,

L. Verity¹, M. Verkleij⁸ on behalf of the ECFS Mental Health Working Group.

¹University of Central Lancashire, UK, ²UZ Leuven, Belgium, ³Sahlgrenska Academy, Sweden, ⁴Schneider Children's Medical Center of Israel, ⁵Yvonne Prins Coaching en Begeleiding, Netherlands, ⁶Medical University of Innsbruck, Austria, ⁷Charite University, Berlin, ⁸Amsterdam UMC University Medical Centers.

Corresponding Author

Janice Abbott: jabbott@uclan.ac.uk

Word Count: 2994

Keywords: Depression, Anxiety, Psychopathology, Suicide ideation, Implementation, Multidisciplinary care.

Abstract

Objectives: The Cystic Fibrosis (CF) International Mental Health Guidelines Committee published consensus statements for screening and treating depression and anxiety in individuals with CF and their caregivers. This work aimed to evaluate the dissemination and implementation of the guidelines in Europe two years following their publication.

Methods: A 28-item survey was developed by the multidisciplinary ECFS Mental Health Working Group and emailed to approximately 300 CF centres across Europe. The survey evaluated (a) who should be responsible for mental health (MH) care, (b) the current awareness and agreement of the guidelines, (c) the provision of recommended MH screening and follow-up care, and (d) successes, barriers and required resources/training needs.

Results: Responses were received from 187 centres (28 countries represented). There was consensus that a psychologist should be responsible for MH care, although members of the multidisciplinary team (MDT) believed they should also share this responsibility. Sixty-two percent of respondents were aware of the guidelines; 82% percent fully, and 12% partially, agreed with them. Fifty percent (94 centres) had implemented screening. In the past year approximately 6000 patients and 2000 caregivers had been screened, with 80% of respondents using the recommended screening tools. Respondents reported 551 referrals for moderate/severe psychopathology and 84 urgent suicide ideation referrals.

Conclusions: The challenges of different healthcare systems and language barriers are being overcome with a greater awareness of the importance of mental health among the MDT. MH screening is feasible and gaining momentum in both Western and Eastern Europe.

1. Introduction

Elevated symptoms of depression or anxiety in people with cystic fibrosis have been associated with poor health outcomes^{1,2}, poor adherence³⁻⁴, poor quality of life⁵, more frequent hospitalizations and increased health care costs². The recent TIDES study (The International Depression and anxiety Epidemiological Study) screened 6,088 patients (age 12+) and 4,102 parents across nine countries⁶. Elevated symptoms of depression were found in 10% of adolescents, 19% of adults, 37% of mothers and 31% of fathers; elevated symptoms of anxiety were reported by 22% of adolescents, 32% of adults, 48% of mothers and 36% of fathers. Of 1,122 parent-teen dyads, if either parent screened positive, the adolescent was twice as likely to report elevated symptoms of depression or anxiety.

The International Mental Health Guidelines Committee (IMHGC) in Cystic Fibrosis (established and supported by the Cystic Fibrosis Foundation and the European Cystic Fibrosis Society) set up consensus statements for screening and treating depression and anxiety in individuals with CF and their caregivers. These statements are advocated in the published guidelines⁷. The guidelines were informed by feedback from the CF clinical, parent and patient communities in Europe and the US. They recommend annual anxiety and depression screening for adults and adolescents (12+ years), and at least one primary caregiver of children under 18 years. Those with elevated symptoms are recommended to receive a formal psychological assessment prior to receiving evidence-based psychological and/or psychopharmacological intervention. A survey of 1454 international CF health professionals (Europe 48.9%; US 44.8%), undertaken during the development of the guidelines, highlighted that Mental Health (MH) care delivery in CF was inadequate and highly variable across care centres and countries⁸. Seventy-two percent of respondents had no experience of MH screening and the majority did not have a colleague *trained* to manage mental health issues. Forty-eight

depression and anxiety screening measures were in use and 30% of respondents were unable/unsure if they could refer to MH clinicians in their hospital. Perceived barriers to MH screening included (a) lack of trained personnel to administer and score the measures, (b) time required and clinic flow disruption, and (c) problems with referrals and in-house capacity for interventions.

The ECFS Mental Health Working Group (MHWG) is working with the European CF community to disseminate the guidelines across Europe. To facilitate implementation of annual MH screening, the MHWG has provided resources on the ECFS website (<https://www.ecfs.eu/mental-health-working-group>), recruited 'country captains' to assist with dissemination via national networks and provided opportunities for training. The dissemination and implementation of these guidelines across Europe, their effectiveness as determined by clinical outcome and as perceived by patients and caregivers has yet to be evaluated. The first step in this evaluation process is a survey to CF Centres which aimed to evaluate the dissemination and implementation of the MH guidelines in Europe two years following their publication.

2. Methods

2.1 Survey development and distribution

A short, 28-item, survey (Online supplement 1) was developed by the multidisciplinary Research and Evaluation Sub-group of the ECFS Mental Health Working Group. The questionnaire 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, and (d) the successes of, and barriers to screening, and further resource/training needs. To aid completion and analyses of the questionnaire, forced choice

or free responses and the input of numerical/text data only fields were developed. The survey was piloted, via email link, to members of the MHWG not involved in its development. This led to improvements in the survey design prior to distribution to CF Centres. Amendments were made to the wording of items and response categories to enable their understanding by individuals whose first language was not English.

Multiple ECFS (ECFS member database, ECFS conference attendees) and Psychosocial List-serves were merged in an attempt to reach all CF Centres in Europe. To ensure the final list was concise, duplicated contact information was removed as well as identified contacts for whom the survey was not appropriate e.g. microbiologists and geneticists. The survey was administered using the web-based tool 'SurveyMonkey'⁹ and distributed on 6th October 2017 by email, via the ECFS portal, to 1,016 CF multidisciplinary team contacts across Europe, representing approximately 300 CF Centres (the accuracy of contact data in the List-serves is not guaranteed as many people use non-institutional email addresses). A single reminder was sent on the 25th October 2017. Additionally, the MHWG had established 'country captains' and they were asked to send the survey link to their specific national networks. The survey clearly requested only one response from a CF Centre.

2.2 Data analyses

The data were downloaded from SurveyMonkey to SPSS version 24 and cleaned appropriately (finding and eliminating errors in the dataset e.g. duplicate cases, impossible values). Multiple response frequencies and percentages of responses were determined. Comparisons of Eastern and Western European CF Centres were undertaken where sample numbers permitted¹⁰.

3. Results

3.1 Respondents and location

Responses were received from 187 CF Centres across 28 European countries, suggesting a response rate of approximately 62%. Two duplicates were detected (responses from the same centre). To standardise procedure and eliminate bias we accepted the first response to the survey in both instances. Table 1 provides the characteristics of CF Centres and the profession of those who completed the survey. The numbers of participants from each country are listed in online supplement 2.

3.2 Responsibility for Mental Health

Table 2 lists those with current responsibility for MH and provides the results to the question 'Who should be responsible for MH care?' (multiple response options permitted). Seventy-two percent of respondents reported that the psychologist was currently responsible for MH but when asked 'who should be responsible' this increased to 90%. However, it is clear that many members of the multidisciplinary team (MDT) believe that they too share some of the responsibility and it is noteworthy that whilst retaining overall responsibility, 86% of psychologists endorsed other team members too, suggesting that MH should be a 'team approach'.

3.3 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 agreement were (a) that the guidelines were felt to be too rigid when some teams have the ability to perform a more comprehensive assessment (7%), (b) some clinicians were uncomfortable screening parent caregivers (4%) and (c) the sensitivity of the screening tools were questioned (1%).

3.4 Current Mental health care and outcomes

Fifty percent of centres (n=94, approximate total patients = 16,000) had implemented MH screening, with half of those able to integrate screening into their work schedule. Eighty percent of those screening were using the recommended instruments; the PHQ-8/9 and GAD-7 (5% reported using additional measures to perform a more comprehensive assessment). Twenty percent were administering other anxiety and depression scales, with nine other validated scales reported by participants (listed in online supplement 3).

The percentage of patients and caregivers screened in the past year varied across centres. Of those screening, forty-eight percent of paediatric centres and 43% of adult centres reported screening over 50% of patients in their clinic (with 32% of paediatric centres and 25% of adult centres screening more than 75%). Forty-six percent of paediatric centres had also screened more than 50% of caregivers. Some centres were just starting to screen with 22% of paediatric centres and 30% of adult centres screening <25% of their patients in the past year. A total estimate of 6000 patients and 2000 caregivers were screened. The number of referred cases were obtained from 56% of centres who were screening, with 551 treatment referrals for moderate/severe psychopathology and 84 urgent suicide ideation referrals reported. The ability to provide follow-up referrals/treatment is highlighted in Figure 1. Of note, 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.

3.5 Benefits, barriers and further training needs

Table 3 (values in parenthesis are from the pre-guidelines survey⁸) lists the benefits and barriers to MH screening and the further training needs. The main benefits of screening were

1) easier to initiate MH conversation, 2) greater awareness of MH among the MDT, patients and caregivers and 3) MH being destigmatised. The main barriers included 1) insufficient staff time and 2) lack of qualified MH personnel. Interestingly, the top training need was 'Mental Health training for the CF team'. Other resources required included funds to support a MH professional, electronic tools for administration and scoring, access to a MH hotline for guidance (peer support / guidance from someone who has implemented the guidelines).

3.6 Comparison of East and Western European Countries

There were 14 Western and 14 Eastern European countries represented in the survey data with 150 and 35 CF Centres responding respectively. Nine Eastern European countries (14 CF Centres) and 12 Western European countries (80 CF Centres) were screening. Comparisons of guidelines awareness, agreement and current MH care delivery are presented in Figure 2. There was no consistent pattern/difference observed between Eastern and Western European countries (overall, neither group fared better or worse than the other) concerning attitudes, screening implementation, suicide risk planning and follow-up referrals. Though, proportionally, respondents from Eastern Europe were more aware of the guidelines ($X^2 = 14.51$, $p < 0.01$), whilst those from Western Europe were more able to screen ($X^2 = 15.72$, $p < 0.01$) and provide referral pathways within their team ($X^2 = 13.98$, $p < 0.01$).

4. Discussion

The benefits of MH screening are evident with greater awareness of the importance of MH among the CF team. Health professionals report being able to initiate MH conversations more easily with patients and caregivers. As expected, the current responsibility for MH rests mainly with the psychologist, but a notable finding was that members of the CF team believed

that they too share this responsibility. Indeed, the majority of psychologists were supportive of a 'team approach' to MH. This demands opportunities for MH training for the entire multidisciplinary team. These data are specific to European countries where psychologists are employed to provide a range of psychological expertise in the management of chronic conditions. Over the last few years CF Centres in the US have expanded MH care. This has been sustained almost solely by social workers. More recently, the Cystic Fibrosis Foundation has funded Mental Health Coordinators to join the interdisciplinary CF team. Those appointed come from the disciplines of social work, psychology, counselling and psychiatry.

The vast majority of those who were aware of the guidelines agreed with them. Of those who had reservations, the main reason for partial agreement was due to the uncertainty around screening caregivers. Some clinicians were uncomfortable screening parent caregivers when they are 'not the patient'. There were difficulties concerning the ethics and logistics of caregiver depression and anxiety data storage; whether or not it should be enclosed within the child's medical notes. Additionally, for some centres, suitable treatment referrals have proved problematic. These issues require consideration and may need to be addressed at country or centre level. Over 90% of those aware of the guidelines fully agreed with (at least) screening people with CF for depression and anxiety annually using the PHQ-8/9 and GAD-7. Others were already implementing an annual comprehensive psychological screen, and this is the ideal where resources allow. Only one respondent was not in favour of any type of MH screening.

Thirty-eight percent of responding centres were not aware of the guidelines. An aim of the ECFS MH Working Group is to disseminate the guidelines across Europe and this endeavour is ongoing. This is being addressed by the active recruitment of 'Country Captains' to help

with language translations of resource materials. A positive, inadvertent consequence of the survey has been an introduction to the guidelines for those who were previously unaware of their existence.

Eighty percent of those screening were using the recommended screening tools (of these, 5% were using the GAD-7 and PHQ-8/9 as part of a more wide-ranging assessment). However, 20% were still using other screening tools. Nine other depression or anxiety validated measures were reported but this is a significant improvement from pre-guideline reports when 48 different screening tools were being used in clinical practice⁸. The most employed non-recommended tool was the Hospital Anxiety and Depression Scale (HADS, n=9). This is not surprising as it was the main tool administered in the TIDES study, but was shown to underestimate depression and anxiety in CF⁶. Indeed, recent work indicates that there is much more psychopathology in people with CF and their parent caregivers than was estimated by the TIDES study¹¹. In comparison with formal face-to face psychological assessment, the GAD-7 and PHQ-8/9 were able to identify all those with the most severe psychopathology and all those who endorsed the suicide ideation screening item. For those reporting less severe difficulties on screening, agreement with formal assessment was less accurate. Typically, this was because people underestimated/underreported their symptoms at screening (with patients and caregivers requiring treatment referrals following psychological assessment)¹¹.

Screening cannot replace clinical judgement but is a first step in MH care. The standardisation of screening tools is imperative and the PHQ-8/9 and GAD-7 are also the screening instruments of choice by national professional bodies¹²⁻¹⁸ as the items map onto current diagnostic criteria (DSM-5¹⁹) and are available in many languages. In Western European

countries where psychologists have been embedded in the CF team for many years it is typical for more comprehensive psychological assessments to occur. This is the ideal, but many countries and centres do not have this amenity. Following guideline recommendations, in particular, administering the standardised tools allows the data from those countries where resources are limited to contribute to larger research datasets (potentially including registry data).

Respondents reported screening approximately 6000 patients and 2000 caregivers. Clearly, these are underestimates of MH guideline implementation as the data is only based on those responding to survey, but they highlight rapid commitment to the recommendations provided in the guidelines and demonstrate the feasibility of overcoming local barriers. The percentage of respondents able to provide preventative strategies was low (61%) in comparison with the ability to provide referrals within the team (78%). This may reflect a focus on 'curative health care' in most health care systems, hence the availability of referral pathways but less attention on prevention. Even so, the ability to always provide follow-up referrals is currently less than optimal, with many centres unable to provide appropriate follow-up care or have a protocol for those presenting with suicide ideation. Prior to the commencement of screening, suitable resources need to be in place to ensure appropriate referrals. Where there is no plan/follow-up protocol for suicide risk, this requires immediate attention. Indeed, regardless of whether there is a formal screening program in place or dedicated MH professions, CF centres may encounter an individual expressing hopelessness and suicidal ideation, and should be familiar with local pathways for further evaluation.

Non-responder bias may have influenced the results of this survey. As a self-selecting group, it is possible that respondents were more interested and engaged in MH care. Additionally,

the questionnaire was distributed in English and this may have been a barrier to completion for non-native English speakers. To avoid the risk of being over-prescriptive (respondents were from 28 different countries/cultures with very different health systems), some questions were not operationally defined and this may have resulted in respondents interpreting questions in their own way. However, the questionnaire was developed by, and piloted on, individuals from 13 different countries who have implemented screening and no operational issues were raised. Neither did respondents query the meaning of any questions in the comment boxes provided in the survey.

The differential distribution of responses from across Europe is notable, with Eastern European participants in particular, underrepresented in the data. However, even though numbers for Eastern Europe are small for survey data, proportionally, there was no consistent pattern/difference observed between Eastern and Western European countries concerning attitudes and screening implementation. There does not appear to be the large chasm between East and West that might have been expected. This may be as a result of exposure to the guidelines given the MHWG's efforts in engaging 'Country captains' to network in their country (24 have been recruited from Eastern Europe), translating the required resources into many languages and providing easy access, via the ECFS website, to the screening tools (translated into 30 languages). A continued focus on Eastern countries is essential, particularly as a recent Eastern European survey of 16 countries highlighted that CF Care is variable across Eastern Europe and only 8 countries reported that clinical psychologists were part of the CF team. A complete multidisciplinary team was only reported in only 2 countries²⁰.

Compared with the pre-guidelines survey⁸, barriers of limited staff time (struggling to incorporate screening into workloads) lack of qualified personnel to provide screening,

referrals or interventions still remain, but to a lesser extent. It is also notable that in the pre-guidelines survey more than 20% of respondents reported that 'no one on their team had responsibility for MH', this has decreased to 11%. The demand for training remains high with training for the whole MDT a priority. Requests for training in behavioural interventions and prescribing psychotropic medication have also increased post-guidelines.

The ECFS Mental Health Working Group is engaged in facilitating MH screening to improve the health outcomes of patients and caregivers.²¹ The working group will build on the successes and attempt to address the difficulties raised by CF teams in implementing MH screening. The MHWG will continue to disseminate the guidelines by (a) translating the patient and clinician information into many more languages, (b) engage more 'country captains' who are able to network in their country and language, (c) deliver training courses to fulfil the requested training needs. There is much work to do but we have overcome the challenges of different healthcare systems and language barriers, so that two-years post-publication of the guidelines, MH screening is both feasible, acceptable and gaining momentum across Europe.

Acknowledgements

We would like to acknowledge the support from the European Cystic Fibrosis Society, and in particular, thank Christine Dubois and David Debisschop for their administrative and technical assistance.

Conflict of Interest Statement

The authors have no conflicts to disclose

References

1. Ploessl C, Pettit RS, Donaldson J. Prevalence of depression and antidepressant therapy use in a pediatric cystic fibrosis population. *Ann Pharmacother* 2014;48:488–93. <https://doi.org/10.1177/1060028013514846>.
2. Snell C, Fernandes S, Bujoreanu IS, Garcia G. Depression, illness severity, and healthcare utilization in cystic fibrosis. *Pediatr pulmonol* 2014;49(12):1177-1181.
3. Hilliard ME, Eakin MN, Borrelli B, Green A, Riekert KA. Medication beliefs mediate between depressive symptoms and medication adherence in cystic fibrosis. *Health psychology* 2015;34:496-504.
4. Smith BA, Modi AC, Quittner AL, Wood BL. Depressive symptoms in children with cystic fibrosis and parents and its effects on adherence to airway clearance. *Pediatr pulmonol* 2010;45:756-763.
5. Riekert KA, Bartlett SJ, Boyle MP, Krishnan JA, Rand CS. The association between depression, lung function, and health-related quality of life among adults with cystic fibrosis. *Chest* 2007;132:231-237.
6. Quittner AL, Goldbeck L, Abbott J, Duff A, Lambrecht P, Solé A, et al. Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study across nine countries. *Thorax* 2014;69:1090-1097. <https://doi.org/10.1136/thoraxjnl-2014-205983>.
7. Quittner AL, Abbott J, Georgiopoulos AM, Goldbeck L, Smith B, Hempstead SE, et al. International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety. *Thorax* 2016;71:26–34. <https://doi.org/10.1136/thoraxjnl-2015-207488>

8. Abbott J, Elborn JS, Georgiopoulos AM, Goldbeck L, Marshall BC, Sabadosa KA, et al. Cystic Fibrosis Foundation and European Cystic Fibrosis Society Survey of cystic fibrosis mental health care delivery. *Journal of cystic fibrosis* 2015;14:533-9
9. SurveyMonkey, The simple way to create surveys [Online] Available from: <https://www.surveymonkey.com/>
10. Hogg RV, Tanis E, Zimmerman D. Probability and statistical inference 9th Edition. Pearson Education Limited. 2015.
11. Verkleij M, de Winter D, Hurley MA, Abbott J. Implementing the International Committee on Mental Health in Cystic Fibrosis Guidelines: Screening accuracy and referral-treatment pathways. *J Cyst Fibros* 2018; <https://doi.org/10.1016/j.jcf.2018.02.005>
12. Zuckerbrot RA, Cheung A, Jensen PS, Stein REK, Laraque D, and GLAD-PC STEERING GROUP. Guidelines for Adolescent Depression in Primary Care (GLAD-PC): Part I. Practice Preparation, Identification, Assessment, and Initial Management. *Pediatrics*. 2018;141(3):e20174081
13. National Collaborating Center for Mental Health. The NICE guideline on the management and treatment of depression in adults (updated edition). Leicester, UK:
14. British Psychological Society, 2010. National Collaborating Center for Mental Health. Depression in adults with a chronic health problem: treatment and management. Leicester, UK: National Institute for Health and Clinical Excellence, 2009.
15. Andersen B, DeRubeis R, Berman B, Gruman J, Champion VL, Massie MJ, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: An American Society of Clinical Oncology guideline adaptation. *J Clin Oncol* 2014;32:1605–19.

16. U.S. Preventive Services Task Force. Screening and treatment for major depressive disorder in children and adolescents: U.S. Preventive Services Task Force recommendation statement. *Pediatrics* 2009;123:1223–8.
17. Geoffrey RS, Cynthia B, Graham AB III, Brown OW, Hardin A, Lessin HR, et al. 2014 recommendations for pediatric preventive health care. *Pediatrics* 2014;133:568–70.
18. Siu AL, and the US Preventive Services Task Force (USPSTF). Screening for Depression in AdultsUS Preventive Services Task Force Recommendation Statement. *JAMA*. 2016;315(4):380–387. doi:10.1001/jama.2015.18392
19. American Psychiatric Association, ed. Diagnostic and Statistical Manual of Mental Disorders (DSM-5). 5th edn. American Psychiatric Publishing, Incorporated, 2013.
20. Walicka-Serzysko K, Peckovac M, Noordhoek J, Sands D, Drevineket P. Insights into the cystic fibrosis care in Eastern Europe: Results of survey. *J Cyst Fibros* 2018; <https://doi.org/10.1016/j.jcf.2018.04.003>
21. The ECFS Mental Health Working Group Website: <https://www.ecfs.eu/mental-health-working-group>

Online supplement 1

Mental Health Survey to CF Centres

1. Please indicate your role on the CF team:

Adult Physician

Nurse

Paediatrician

Psychiatrist

Psychologist

Social Worker

Other (please specify):

2. Are you the Centre Director?

Yes

No

3. In which country do you live?

4. Is your centre:

Adults

Paediatrics

Both

5. Approximately how many patients attend your Centre?

Adults:

Paediatrics:

6. Do you currently have someone on your CF team whose primary role is to address mental health issues?

Adult Physician

Nurse

Paediatrician

Psychiatrist

Psychologist

Social Worker

No one holds this role

Other (please specify)

7. Are you aware of the CF Mental Health Guidelines?

Yes

No

Vaguely

8. If you are aware of the CF Mental Health Guidelines: Do you agree with the Guidelines?

Yes

Do not know

Some recommendations

No

9. Which professional/s do you think should be responsible for mental health screening? (Tick all that apply)

Adult Physician

Centre Director

Nurse

Paediatrician

Psychiatrist

Psychologist

Social Worker

No one

Other (please specify)

10. Is your clinic screening for mental health issues?

Yes

No (if no, please go to question 26)

11. Were you able to implement screening as part of your regular work schedule?

Yes

Yes, but not consistently

No (specify additional resources/training required)

12. Which screening tools for measuring anxiety and depression do you currently use? (Tick all that apply)

Patient Health Questionnaire – 2 (PHQ2)

Patient Health Questionnaire – 8 (PHQ8)

Patient Health Questionnaire – 9 (PHQ9)

Generalised Anxiety Disorder – 7 (GAD7)

Other (please specify)

13. What method do you use to screen patients? (Tick all that apply)

Computer

Paper

Tablet

Other (please specify)

14. Approximately what percentage of adult patients have you been able to screen in the last year?

<25%

25% - 49%

50% - 74%

75% +

Not Appropriate

15. Approximately what percentage paediatric (age 12+ years) patients have you been able to screen in the last year?

<25%

25% - 49%

50% - 74%

75% +

Not Appropriate

16. Approximately what percentage of caregivers have you been able to screen in the last year?

<25%

25% - 49%

50% - 74%

75% +

Not Appropriate

17. If you are using the PHQ8/9 or GAD7: Approximately how many required intervention because of moderate/severe levels of symptoms (above 10 points)? If you are not using these recommended screening tools or do not have this information, please go to question 19

Adults:

Caregivers:

Paediatrics (12+ years):

18. How many required immediate intervention because of indicated suicidality? If you are not using these recommended screening tools or do not have this information, please go to question 19.

Adults:

Caregivers:

Paediatrics (12+ years):

19. Have you been able to provide the recommended follow-up (according to the guidelines) in your Centre?

Yes

Sometimes

No

Do not know

20. Do you offer preventative strategies?

Yes (please describe in the text box)

No

21. Do you have referral pathways for Mental Health issues available to you within your clinic?

Yes

No

Do not know

22. Have you developed a plan for patients or caregivers who screen positive for suicide risk?

Yes

No

23. Have you referred outside your CF Centre? (But in your hospital)

Yes

Sometimes

No

Do not know

24. Have you referred outside your hospital?

Yes

Sometimes

No

Do not know

25. What benefits have you seen from implementing mental health screening at your CF Centre? (Tick all that apply)

Easier to initiate conversations with patients and caregivers about Mental Health issues

Greater awareness among caregivers of Mental Health issues

Greater awareness among health professionals of Mental Health issues

Mental Health being destigmatised

Other (please specify)

26. Have you experienced any barriers in implementing Mental Health screening at your CF Centre? (Tick all that apply)

Difficult logistics (e.g. how/where to store data)

Ethical dilemmas

Lack of interest from CF team

Lack of qualified personnel to provide screening

Lack of qualified personnel to provide referrals or interventions

Maintaining patient confidentiality/privacy

Patient burden (e.g. concern about patients' time)

Patient unwillingness/refusal to complete questionnaires

Space limitations

Other (please specify)

27. What type of assistance would be helpful in implementing an annual mental health screening program for all patients in your Centre? (tick all that apply)

Access to a list of local mental health resources and referrals

Access to electronic tools (e.g. tablets, computers) for administration and scoring

Access to mental health hotline for guidance

Additional funds to support a mental health professional

Training

Other comments:

28. Would you be interested in training in any of the following at the European CF Society (ECFS) conference? (Tick all that apply)

Behavioural interventions (e.g. Cognitive Behavioural Therapy)

Counselling or supportive therapy

Mental health screening

Mental health training for the CF team

Prescribing medications for depression or anxiety

Preventative education

Other comments:

Online Supplement 2.

List of Countries and number of responding centres

Austria (7)
Belgium (7)
Bulgaria (1)
Croatia (2)
Czech Republic (3)
Denmark (3)
France (21)
Germany (21)
Greece (3)
Hungary (2)
Ireland (3)
Israel (5)
Italy (8)
Macedonia (4)
Netherlands (14)
Norway (2)
Poland (5)
Portugal (4)
Russia (2)
Serbia (2)
Slovakia (2)
Slovenia (2)
Spain (12)
Sweden (4)
Switzerland (8)
Turkey (1)
United Kingdom (36)
Ukraine (1)
No Country Given (2)

187 responses from 28 different countries

Online Supplement 3.

Depression and Anxiety Scales employed other than those recommended (n)

Hospital Anxiety and Depression Scale (HADS)	9
Beck's Youth/Depression Inventory (BDI, BYI-D, BYI-A, BYI-S)	3
Hamilton Depression Scale (HAM-D)	1
State-trait Anxiety Inventory (STAI)	1
Centre for Epidemiologic Studies Depression Scale (CES-D)	1
Depression Anxiety Stress Scale (DASS)	1
Child Schedule for Affective Disorders and Schizophrenia (KiddieSads)	1
Paediatric Index of Emotional Distress (PI-ED)	1
Revised Children's Anxiety and Depression Scale (RCADS)	1

Table 1. Characteristics of CF Centres and Respondents

Type of Centre	% (n)
Adult	18.7 (35)
Paediatric	26.2 (49)
Both	52.4 (98)
Not disclosed	2.7 (5)
Profession of Respondent	% (n)
Psychologist	33.7 (63)
Paediatrician	29.4 (55)
Adult Physician	11.2 (21)
Nurse	10.7 (20)
Social Worker	3.7 (7)
Psychiatrist	1.1 (2)
Other profession*	10.2 (19)

*Other profession e.g. Dietitian, Physiotherapist, Research Co-ordinator.

Table 2. Responsibility for Mental Health (multiple responses permitted)

Currently responsible for Mental Health (n=170)		Should be responsible for Mental Health (n=187)	
	%(n)		%(n)
Psychologist	71.8 (122)	Psychologist	89.6 (162)
Social Worker	5.3 (9)	Social Worker	34.2 (64)
Adult Physician	0.6 (1)	Adult Physician	29.4 (55)
Paediatrician	4.1 (7)	Paediatrician	29.4 (55)
Psychiatrist	3.6 (6)	Psychiatrist	27.3 (51)
Nurse	0.0 (0)	Nurse	35.8 (67)
Centre Director	0.0 (0)	Centre Director	7.5 (14)
Don't know	0.6 (1)	Don't know	0.5 (1)
No one holds this role	11.2 (19)	No one	0.5 (1)
Joint psychologist & Social Worker	2.9 (5)		

Table 3. Benefits, barriers and further training needs (multiple responses permitted)

<i>Benefits of Screening</i>	<i>% of those screening (n=94)</i>
Easier to initiate conversations with patients/caregivers about MH	70.2
Greater awareness of MH issues among health professionals	63.8
Greater awareness of MH issues among patients	63.8
Greater awareness of MH issues among caregivers	48.9
Mental Health being destigmatised	51.0
<i>Barriers to Screening</i>	<i>% of all respondents (n=187)</i>
Limited staff time	69.9 (75.8)
Lack of qualified personnel to provide screening	34.6 (60.6)
Lack of qualified personnel to provide referrals or interventions	31.6 (56.0)
Patient unwillingness or refusal to complete questionnaires	22.6 (21.6)
Patient burden (e.g. concern about patient time and availability)	21.8 (29.5)
Difficult logistics (e.g. how and where to store data)	19.6 (31.0)
<i>Further training needs</i>	<i>% of all respondents (n=187)</i>
Mental Health training for CF team	68.0
Preventative education	56.0
Mental Health screening	55.2 (53.0)
Counselling or supportive therapy	49.6 (52.5)
Behavioural interventions (e.g. CBT)	40.0 (31.4)
Prescribing medications for anxiety or depression	24.8 (17.6)

Pre-guideline European survey data in parenthesis⁸

Figure 1. Ability to provide recommended follow up.

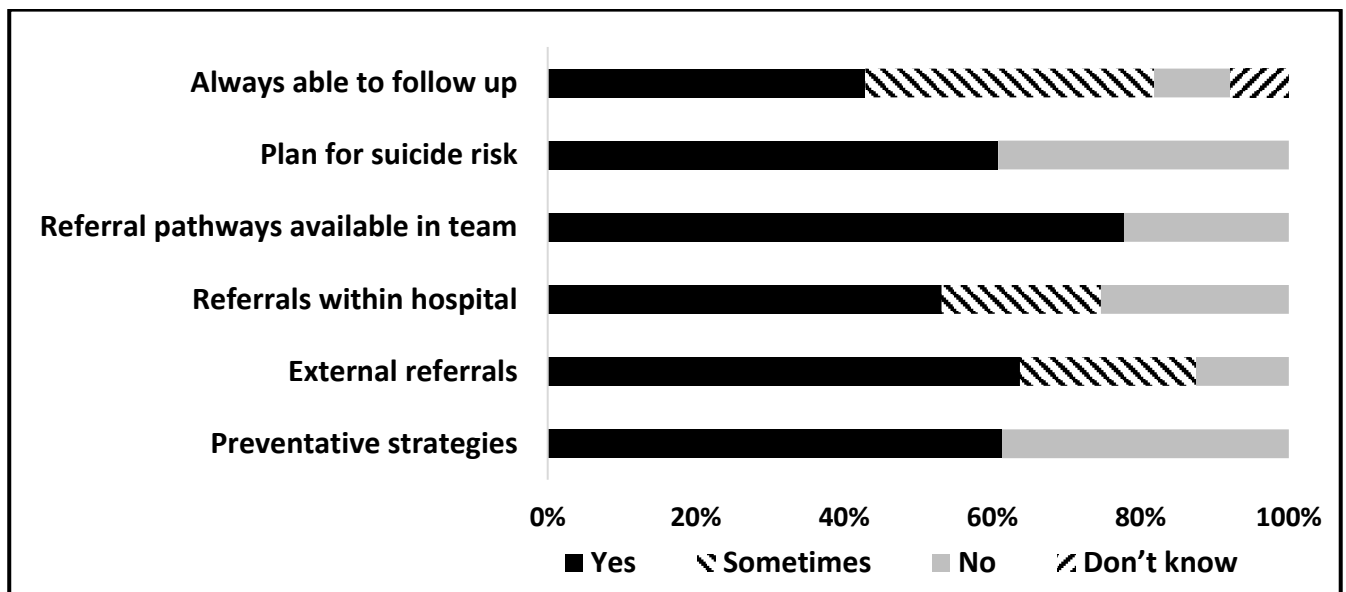


Figure 2. Guideline awareness and implementation in CF Centres: Eastern and Western Europe

