

Mental Health in Cystic Fibrosis Quality Improvement Change Package

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I. Background

A large body of research indicates that children and adults with chronic illnesses, as well as parent caregivers, are at increased risk for psychological difficulties. The International Depression Epidemiological Study (TIDES) found symptoms of depression in 10% of adolescents with Cystic Fibrosis (CF), 19% of adults with CF, and over 30% of their parent caregivers; the prevalence of symptoms of anxiety were even higher (Quittner, Thorax 2014). Anxiety and depression are significant morbidities in themselves, but take on even greater importance in CF because of their impact on disease self-management, and ultimately on the course of lung disease (Riekert 2007 and Fidika 2014). Individuals with CF who report elevated levels of depression evidence worse adherence to prescribed treatments, higher rates of missed or canceled appointments, increased health care utilization, and higher health care costs. Furthermore, depression is associated with worse health-related quality of life (HRQOL) and higher mortality (Barker 2016, Reikert 2007, Fidika 2014, Yohannes 2012, Smith 2010, Snell 2014, Schechter 2017).

Given these findings, the CF Foundation and the European CF Society formed an international committee to develop clinical care guidelines for preventing, screening and treating anxiety and depression in individuals with CF and parent caregivers. This committee, which consisted of experts in pulmonology, psychology, psychiatry, psychopharmacology, social work, health services research, an individual with CF and a parent caregiver, spent two years reviewing the literature to identify the best screening tools and the best intervention practices. The [Cystic Fibrosis Foundation and European Cystic Fibrosis Society Consensus Statements for Screening](#)

[and Treating Depression and Anxiety](#) published in *Thorax*, provides evidence- and consensus-based recommendations for preventative steps, screening tools, and treatment [algorithms](#) for anxiety and depression (Quittner, Thorax 2016). Specifically, these guidelines recommend annual screening of depression and anxiety for all individuals with CF, beginning at age 12, and all parents of children with CF from birth to age 17, as well as steps to diagnose and treat mental illness in those with a positive screen.

One approach that has proven useful in primary care and will likely be successful in CF is the use of a “collaborative care model”. [Collaborative Care](#) is an innovative way of treating depression and anxiety, involving multiple health professionals working together to address mental health problems in the context of the medical home. Over the past 15 years, more than 70 randomized controlled trials have established a robust evidence-base for this approach (Archer 2012 and Thota 2012). A Cochrane review found collaborative care is associated with significant improvement in depression and anxiety outcomes compared with usual care, and represents a useful addition to clinical pathways for adult patients with depression and anxiety (Archer 2012). Within the context of medical illness, integrated collaborative care can improve medical and mental health outcomes including reducing rates of hospitalizations and health care costs, and optimizing health care treatments (Cooley 2009, Gordon 2011, Katon *N Engl J Med* 2010 and Katon *Gen Hosp Psychiatry* 2010).

Collaborative care is not achieved by [inserting](#) a mental health provider into a medical office. In collaborative care programs, care is provided by a [multidisciplinary team](#) including: 1. a primary provider or medical specialist; 2. a mental health coordinator (MHC) based in the medical clinic and trained to provide care coordination, brief behavioral interventions, and to support the treatments such as medications initiated by the medical physician; and 3. a mental health consultant, typically a psychiatrist, who can advise the medical care treatment team with a focus on patients who present diagnostic challenges or who are not showing clinical improvements. The MHC can be a licensed psychologist or social worker on the team or a team member (e.g. Nurse Practitioner/Physician’s Assistant) who has received special training or certification in mental health, with use of [psychiatric consultation](#) for complex cases.

The Mental Health guidelines are analogous to other CF Foundation clinical care guidelines for screening and treatment of medical complications of CF such as vitamin D deficiency and CF related diabetes in that they invoke the need for care centers to develop processes to screen and expertise to care for the condition. The CF Foundation established MHC awards to help promote collaborative care by providing funding for a MHC to join a CF care team. Over time, and with the support of the CF Foundation, centers have trained personnel, adopted care algorithms, and engaged other subspecialists to help provide care for these other

complications. Similarly, as centers work towards implementing the Mental Health Guidelines, the CF Foundation is providing practical support and setting a clear expectation that anxiety and depression screening is equivalent in importance to other routine medical tests. To this end, the CF Foundation has formed a national steering committee, The CF Foundation Mental Health Advisory Committee to oversee and support implementation of the mental health guidelines and continue to identify best practices for screening, education and training of members of CF multidisciplinary staff, and use of evidence-based psychological and medical treatments. Members of this committee can be contacted via email at mentalhealth@cff.org. The recommendations brought forth in this document are supported by the CF Foundation Mental Health Advisory Committee.

II. Introduction

This document is designed to facilitate the implementation of the anxiety and depression guideline recommendations utilizing Quality Improvement (QI) principles as well as Collaborative Care methodology from the Advancing Integrated Mental Health Solutions Center ([AIMS Center](#)). The use of a quality improvement infrastructure will aid in achieving measurable improvements in both mental health and CF outcomes. A QI change package is a set of ideas and practical road map for teams to apply QI methods to increase the effectiveness of healthcare processes and outcomes. This change package provides a summary of the mental health guidelines, specific tools, strategies, and how to apply this to quality improvement work. The booklet [Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition](#) is a helpful reference to familiarize the CF Care Team with the QI process.

While developing an implementation plan using QI principles, the team will also need to consider methods to attain sustainability of screening and caring for the mental health needs of patients and caregivers. By reviewing sustainability opportunities, the team will [add value](#) to the work conducted, and develop a long term plan to maintain Collaborative Care within CF Centers. The AIMS Center has created a [Financial Modeling Workbook](#) in collaboration with the Institute for Family Health and the American Psychiatric Association. This workbook will help centers to identify opportunities for revenue as well as evaluating expenses and sustainability.

This is intended to be a comprehensive document to provide resources for centers who are either new to QI processes or those who have a more advanced infrastructure for QI. Therefore, an assessment of the care center's position within this continuum as well as utilization of this change package will elevate the CF team to the next level. Not all resources referenced in this document will be utilized by all teams; each team will have flexibility to access materials related to experiences and expertise.

III. Establishing your mental health team

The CF Care Center should establish a core team, including a patient or caregiver, in order to identify who will assist in the development of the mental health program within the care center as well as to clarify specific roles and responsibilities. This team should initially meet regularly using the meeting skills and rotating roles found in the [Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition](#). Most teams will need to [hire](#) a new clinician to serve as the Mental Health Coordinator (MHC); other Care Centers will be able to provide additional hours and support for an existing staff member to expand his/her role. The MHC should lead the development and oversee the success of the mental health program. This individual would ideally be a licensed mental health professional (LISW/LCSW, psychologist, etc.) or trained/credentialed NP/PA specifically designated as the case manager for mental health activities. Responsibilities of the MHC will need to be delineated. These activities typically include development and implementation of strategies for prevention, screening, and tracking; establishing a referral database; coordinating treatment; providing [education for staff](#), the institution and community practitioners; and facilitating information flow between team clinicians and mental health providers in and outside of the CF Center/institution. The MHC can be involved in providing direct interventions to treat anxiety/depression, promote adherence, etc., and/or coordinate these services with another mental health provider. To further clarify the Mental Health Coordinator role, a [sample job description](#) is available from AIMS as well as a training video titled [Collaborative Care Manager Role](#) .

As with all team development and QI processes, it will be important to include at least one patient and/or family member to be part of your mental health QI lead team. Once the mental health team is identified, current practice can be assessed using the [Team Member Self-Assessment](#) from AIMS. This document identifies strengths and weaknesses of the care center, how this will impact mental health care and how the MHC and mental health team can address these strengths and weaknesses. Additionally, team members can complete the [Task Summary Worksheet](#) to assess for duplication and opportunities for team members to develop role identification within the team, tasks to complete, and identify gaps in care and training requirements for team members.

Mental health care teams should seek to recognize opportunities for collaboration and integration of mental health care within their current care model or be open to changes within their model if needed. MHCs should be fully integrated into the CF team and, in addition to having a firm understanding of the [Mental Health Guidelines](#) and effective mental health interventions, should also gain an understanding of CF care, including medications, treatment

recommendations and guidelines, comorbid conditions, and especially the problems of adherence and treatment [burden](#). They will need access to and familiarity with [Port CF](#), particularly the resource section which includes educational tools and information related to Mental Health and Quality Improvement. To obtain access to the CF Foundation's Data registry, Port CF, contact the center's registry coordinator within the care center.

In addition, MHCs should also review published literature on mental health in CF including the following articles, [Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study](#) , [Maintaining Mental Health and Function for the Long Run in CF](#) and [mental health resources](#) found on the [CF Foundation](#) website.

Just as the care center requires a readiness assessment, the institution's organizational structure and readiness for integrating mental health care should be assessed by completing the [Review Organizational Readiness Worksheet](#). This document provides an opportunity to review and identify resources and tools available within the institution and the larger community as well as potential barriers. For example, some pediatric programs have faced barriers to screening parent caregivers (see Section V for further comments on this). It is important for the MHC and CF Team Leaders to identify [key individuals](#) within the institution and facilitate collaborative relationships with the MHC in order to address the needs and gaps identified before, during and after the assessments.

IV. Tools to Know and Love

The following tools will help in screening and developing the program within the Care Center. All of these tools are found in the shared Mental Health Drop Box, which also contains additional materials and educational resources for review by the MHC. Access to the Drop Box can be achieved by emailing mentalhealth@cff.org. The Dropbox is routinely updated with materials vetted by the CF Foundation Mental Health Advisory Committee.

- Anxiety and depression screening tools:
 1. [PHQ-9 and GAD-7](#): These brief tools can be administered and scored in a short period of time, typically less than 5 minutes, ideally during a routine well visit in the CF Care Center. The tools are used for both initial screening and for ongoing monitoring as clinically indicated. It is necessary to determine if the Care Center will utilize paper format of the screening tools or electronic versions. If administered on paper, a process for having the data transferred or scanned into the electronic medical record is needed. The screening tools can also be accessed on electronic tablets, REDCap and most electronic medical records. Contact your institution's Information Technologies (IT) department for guidance on loading the screens into the EMR and administering them

electronically. Many electronic medical record (EMR) systems have the ability to build the PHQ-9 and GAD-7 into their systems to document the final score. With this functionality, the team can work with IT to develop reports on patients with specific scores which may require a clinical assessment, treatment and coordination of care. Additional information regarding QI and measurement tools can be found in The QI Start section of this document. Speak with your institution's health information management (medical record) and legal departments to discuss where and how to store parent/caregiver scores and recommended interventions. Refer to the Clinical Assessment and Treatment section for the [algorithm](#) related to the screening scores.

- Suicide assessment and safety plans:

While there will be few individuals with suicidal ideation or plans, prior to initiation of screening it will be imperative to review the current policy and protocol the care center and institution follows for individuals endorsing suicide on the PHQ-9. **If there is not a policy or procedure in place, it will be necessary to develop a clear, specific plan which identifies all team members who will ensure the safety of those at imminent risk and next steps while under the care of the CF Center team.** For example, will the identified patient or parent/caregiver be escorted to the Emergency Room for a thorough mental health evaluation? By whom? What community resources and crisis interventions, such as crisis hotlines or mobile crisis teams, are available? Included in the Mental Health Dropbox are the following additional tools:

1. [The Columbia Suicide Severity Rating Scale \(C-SSRS\)](#) is a tool designed to assess and prevent suicide. The questions assist in determining the risk of suicide as well as the severity and immediacy of suicide and with identifying support needed for the individual. There is a sample triage protocol for C-SSRS screening in the Mental Health Drop Box. Teams should modify the triage protocol based on community resources and services available. The C-SSRS should only be used by personnel that have been trained in its use. Online [training](#) is available and takes less than 30 minutes.
 2. Sample [adult](#) and [pediatric](#) safety plan templates and educational materials related to suicide are available to complete and print from the Dropbox including but not limited to [Facts For Families-Teen-Suicide](#), [National Suicide Prevention Lifeline](#), and [Boystown National Hotline](#).
- CFF Mental Health Screening [Tracking Log](#): Once the screening process is determined within the care center, there is a need to monitor the screening results. The Mental Health Dropbox has an Excel spreadsheet with instructions for use to assist the center to track and monitor screening results. The log will help to establish a variety of tasks including who will enter the data at the care center, such as screening scores and treatment

recommendations provided. The tracking log can also assist in discussing patients who screen positive during the pre-clinic huddle or team meetings. In addition, the log will assist with evaluating the efforts from a QI perspective within the center. The tracking log is designed to support measurement of intended mental health care processes such as the percentage of patients and caregivers screened in a year, who answered positively on question 9 of the PHQ-9, or who scored above the clinical cutoffs and it also allows tracking of the longitudinal trend for individual patients.

- There are numerous educational materials to share with patients and families in the Mental Health Dropbox. Psychoeducation is important for ongoing prevention, as well as an intervention for all levels of depression and anxiety severity. The Mental Health Advisory Committee has collected additional handouts and educational materials which include:
 1. A comprehensive resource of adolescent depression tools can be found in a toolkit that accompanies the [Guidelines for Adolescent Depression in Primary Care \(GLAD-PC\)](#).
 2. Additional educational materials and screening tools for other mental health issues, such as substance abuse, ADHD, oppositional-defiant disorder, and a variety of behavioral health problems are available at [Child and Adolescent Psychiatry for Primary Care website](#).
 3. For adolescent patients the [Academy of Child and Adolescent Psychiatry](#) has developed facts for families, which are concise handouts with up-to-date information on a variety of topics that affect children.
 4. For pediatric patients, the [Massachusetts General Hospital School Psychiatry Program](#) Mood and Anxiety Disorders Institute has developed resources aimed at parents, teachers, and clinicians for implementing school-based interventions for depression, anxiety, and other mental health disorders.
 5. For adult patients the [American Psychiatric Association](#) “Let's Talk Facts” brochures provide answers to commonly asked questions on mental health disorders and their treatments.
 6. In addition, comprehensive information can be found at the [National Institute of Mental Health](#) website.

If your care center is utilizing the patient portal within your EMR, some of these handouts can be added to the portal.

V. Determining Workflow

Now that you have established your core team and are familiar with the screening tools and educational materials, teams should develop a process for annual screening and follow up. A [Manual of Procedures and Toolkit for Implementation](#) is available as an online supplement to the mental health guidelines, and an implementation planning worksheet has been created based on this manual. Determining the current and future work flow needs can be identified with the core mental health team completing the [Mental Health Screening Implementation Planning Worksheet](#) in addition to the tools previously referenced. Understanding [clinic flow](#) is imperative prior completing the worksheet. Page 30 of the [Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition](#) has tools to further assist and define current processes. Included in the worksheet is help in determining your process for beginning screening, for example:

- **Who are you screening?** If you have a large Center, will you start by screening the patients seen by a particular physician first and then advance to the entire Center? For pediatric teams: Are you going to begin with adolescents and once the program is running smoothly add parents or begin screening both at the same time? Note that while the Mental Health Guidelines recommend screening of parent/ caregivers as well as patients, some pediatric providers may be uncomfortable with this, and there may also be institutional barriers to screening of parent caregivers and/ or the recording of their screening scores in the patient's medical record. How will your team address this? Can you identify key personnel/ administration to problem-solve this issue? There may be a short-term, temporary solution (for example, offer parent caregiver self-screening- see the self-screening packet in the Dropbox) while a better long-term solution is developed.
- **When will you screen?** Ideally, it is preferable to screen at a well-visit, as stress may be increased during inpatient stays. However, some teams reported screening at the end of an inpatient medical admission where they had access to more resources, which increased their comfort. They then refined the process prior to screening in the CF center during a well visit.
- **Who will administer the tools?** It is important that whoever is going to be responsible for the screening is comfortable with introducing the rationale for screening and can answer questions that the individual or family may have, including who is going to have access to the screening information and how it is going to be used.
- **How much time will the MHC need with patients?** While this is difficult to estimate, it is safe to assume that at a minimum 10 minutes would be needed for the individual to complete the screening tools and for staff to score the tools and share the results (ex. are symptoms minimal, mild, moderate, or severe). If the process includes a more in-depth assessment at the time of a positive screen, the time needed by the MHC will increase. It is critical to help your team understand that investing time in mental health

issues as early as possible can have a marked impact on overall health. In order to have an informed estimate of the time needed, consider starting with 1-3 patients, and monitor the flow and timing of the visit.

- **When will you screen?** Will you use a one-year interval from initial screen or rescreen all patients at a certain time every year (for example screen everyone in the first quarter of the year, have a mental health month, or coordinate with another annual screen/medical test).
- **How will you track follow up?** Also included in the [Mental Health Screening Implementation Planning Worksheet](#) are key questions to help develop a process for documenting results. For example:
 - How will the treating clinician know screening was complete and the results?
 - How will you keep track of screening scores?
 - How will the information be fed back to the team?

The CFF Mental Health Screening Tracking Log is a preprogrammed Excel [tracking log](#) created to assist the care center and MHC in this function, and is explained below. At some institutions where the IT department has created documentation forms in the EMR, downloads offered from that may provide all the data necessary to ensure that all processes are adhered to.

VI. Educating Patients and Families

It is important to educate patients and families about why the care center is implementing screening for anxiety and depression. A variety of resources have been developed including letters for [adults with CF](#), [parent caregivers](#), PowerPoint presentations, and [newsletter](#) articles. Many centers have used the annual CF educational day as an opportunity to discuss and provide education regarding the guidelines and implementation. A center may choose to share the handout, [Depression, Anxiety and Cystic Fibrosis: What the Guidelines Mean For You](#) to help explain the basics of anxiety and depression and why the care team is asking to screen. This is also available in [Spanish](#). The team may also send a letter to families or place an article in the center newsletter. The key aim of educating your patients and families about screening, the importance of early identification and what we can do to prevent and treat anxiety and depression is to reduce the stigma that exists surrounding mental health.

The implementation of the mental health guidelines should be promoted in the same way as other clinical care processes (such as those supporting nutrition or lung health) that have been instituted to improve the overall health of patients. The team can discuss mental health screening scores being akin to other routine markers of health, such as FEV1 and BMI. The information provided by FEV1 and BMI values serve as a starting point for providers to ask

more questions to assess what, if any, additional education and treatments may be needed to improve these health markers. Anxiety and depression screening scores are comparable to these other markers and serve as a reflection of mental health, that are responded to with evidenced based interventions. The relationship with the patient and/or family is one of the most important tools. When these conversations are approached with patience, warmth, and understanding, teams can be more effective in reducing stigma and shame and give the attention that mental health needs in order to promote maximum health and well-being.

VII. Local Resources and Referral Pathways

Once the mental health screening plan is established, the next step is to determine the available resources within the institution and community for the treatment of moderate to severe depression and anxiety. This is an imperative step to complete prior to initiating screening and will likely take the most time to compile, organize and keep up to date. Even if there are opportunities for a mental health provider to treat patients and/or family within the care center, it will be necessary to identify community providers for families who travel a distance from the CF Center. To begin this process, contact the Psychology and Psychiatry Departments within the institution to ask for resource availability and a direct contact for psychiatry services and consultation. Additionally, consider connecting with the patient or caregiver's Primary Care Provider (PCP). The PCP may have established mental health pathways, or someone on staff, to provide access to community mental health providers. This also facilitates the link to Primary Care and improves coordination and less fractionation of care. Many professional websites, including national and state mental health organizations have a "[Find a Therapist](#)" search function within their websites.

When identifying institutional or community mental health providers, it is important for the MHC to determine the need to provide information and education specific to CF. This education can provide patients and families with confidence and reassurance to pursue psychotherapy. Patients and families are often relieved they do not have to provide basic information regarding CF and that they can direct their attention and focus on therapy services. There are many tools within the Mental Health Dropbox including Power Point presentations with [written](#) and [audio](#) scripts to teach community mental health providers about CF. The MHC should connect directly with the mental health provider prior to referring patients to discuss [infection control guidelines](#) and practices, and to provide CF education. This can be accomplished by establishing meetings with each provider or by organizing a regional educational session targeted to mental health providers.

While completing referrals, it will be important to consider insurance coverage and preferred

provider status of mental health clinicians. Preferred providers can be identified by calling the patient/caregiver’s insurance plan or by reviewing the insurance plan’s website. When referring to mental health providers outside of the care center it will be helpful to establish a formal pathway for ongoing collaboration to discuss treatment recommendations and plans. [CF Foundation Compass](#) case managers can assist in contacting insurance companies to determine insurance coverage for mental health services. The case managers can be reached at 844-COMPASS (266-7277).

VIII. Clinical Assessment and Treatment

Treatment should always be based on a clinical assessment and formal diagnosis by an experienced behavioral health provider. It is imperative this provider conduct a thorough clinical assessment prior to initiating treatment or completing a referral for ongoing treatment. This assessment should include presence, duration and severity of mental health symptoms, prior mental health history, risk factors, prior treatment for anxiety/depression, their response to treatment, and any other underlying mental health conditions or substance misuse. Additionally, the clinician should take into consideration the patient and family’s mental health history, as well as their physical condition as related to CF. Disease severity as well as comorbid chronic health conditions such as, CF Related Diabetes and transplant status, have the ability to affect mental health care.

All interventions are based on severity of the symptoms (Refer to Table 1). Per the [mental health guidelines](#) psychotherapy is recommended as the first-line intervention for those who require treatment except in cases of severe depression where prompt treatment with a combination of medication and psychotherapy is recommended as the initial strategy. When treatment is indicated for anxiety/depression, treatment plans should be developed and implemented in collaboration with patients and parents, the multidisciplinary CF team, and any other providers involved (e.g. primary care or mental health providers).

Table 1

PHQ-9 and GAD-7 Severity Score and Treatments Recommendations		
Provisional Diagnosis	PHQ-9 and GAD-7 Score	First Line Treatment Recommendation
No/Minimal Symptoms of Depression or Anxiety	0-4	Rescreen next year

Mild Depression or Anxiety	5-9	Supportive interventions Education
Moderate Depression	10-14	Evidenced Based Psychotherapy (Including CBT and IPT)
Severe Depression	≥ 15	Combined antidepressant and evidenced based psychotherapy treatment
Moderate & Severe Anxiety	≥ 10	Exposure-based CBT

CBT = Cognitive Behavioral Therapy

IPT= Interpersonal Therapy

Treatment Modalities

Supportive interventions are recommended in the guidelines as the first step for mild depression or anxiety. Cognitive Behavioral Therapy (CBT) is a form of psychotherapy that has an extensive evidence base for use in pediatric and adult patients with depression and anxiety, as well as in some chronically ill populations. A variety of [trainings](#) have been delivered at the North American CF Conference. Interpersonal psychotherapy (IPT) is also recommended as a first-line intervention for depression of at least moderate severity. Educational handouts for patients and families are available in the Drop Box, including topics such as what is [psychotherapy](#), the types of therapies and [relaxation techniques](#).

When [medication](#) is indicated Selective Serotonin Reuptake Inhibitors (SSRIs) are the mental health guideline committee’s recommended first line treatment. [SSRIs are recommended](#) by virtually all national and international guidelines as first-line choices to treat depression and anxiety in both adolescents and adults. Training in [psychopharmacology](#) and [special issues in prescribing](#) have been delivered at the [North American CF Conference Short Course: Depression and Anxiety Treatment in CF: Therapy, Medications and Preventative Strategies Oct. 2016](#). Of note, weight gain is an important side effect of SSRI’s (some greater than others) and this may provide adjunctive benefit in patients with CF who are facing nutritional challenges.

Goals of Treatment

The goal of treatment is to insure 100% of individuals who scored >10 on the PHQ-9 and/or GAD-7 are informed of treatment options and treatment plans are co-created. Any individual who agrees to treatment should receive follow-up from the MHC to ensure all patients who

agree to treatment, actually receive treatment.

The PHQ-9 and GAD-7 should be used to monitor treatment response with a goal of symptoms returning to a normal range and improved functioning. If anxiety or depressive symptoms continue, or functioning remains impaired, a stepped care approach should be used and alternative interventions offered until symptoms are within normal range. If symptoms are not improving, referral for additional specialty consultation may be indicated.

IX. Institution of Mental Health Screening and Care as a QI Activity

The commitment and active engagement of all team members is required in order to have successful and sustainable change. A core mental health QI team should be established with representatives from the multidisciplinary care team. As mentioned previously, the voices of patients and families are invaluable, so make sure that at least one patient or family representative joins the core team. The secret to success is that ‘it takes a village’ and the entire team should be involved for the process to be successful.

The first step in preparing the core team is to make sure everyone receives baseline knowledge about depression and anxiety, its prevalence in CF and its effect on disease management and health outcomes. The handout [Depression, Anxiety and Cystic Fibrosis: Guide for CF Clinicians](#) can be used together with results of the [TIDES Study](#) and the [published consensus statements](#). Having this baseline knowledge will help the team have a shared belief that screening for depression and anxiety is important for the health and wellbeing of patients and families.

The team will need to develop a plan that includes identifying which person will conduct the screens, score them, respond to positive screens and enter the data into the charting system. The knowledge and skills needed to effectively carve out these roles should be clearly outlined so new roles can be assigned to the appropriate team member. As the core team has full ownership of this process they will be better able to support each other through the process and in turn, successfully implement screening.

The QI Start

CF teams with knowledge about quality improvement principles are familiar with the language of QI. Teams needing additional information should review the [Action Guide for Accelerating Improvement in Cystic Fibrosis Care, 2nd Edition](#).

Your team has decided on mental health as your theme for improvement. The [global aim statement](#) suggested for this initiative is:

We aim to improve the rate of screening at our care center. The process begins with offering annual screening for anxiety and depression to all eligible patients and ends with appropriate treatment referral and follow-up if indicated.

The next step is to develop a [specific aim](#) that will provide a clear focus and a plan to measure this aim. Using the “model for improvement,” Plan-Do-Study-Act (PDSA), it is necessary to ask the following three questions before starting on the improvement journey

1. What are we trying to accomplish?
2. How will we know that a change is an improvement?
3. What changes can we make that will result in an improvement?

This is also a good time to establish protocols and processes to determine the most efficient way to screen at the care center (Plan). The team will then test the new protocols and processes. (Do). This will be done one clinic, one patient at a time. The team should reflect and evaluate (Study) the success of the process and collect and implement ideas to make the process run more smoothly at the next clinic (Act). For example, if your team decides to screen as soon as an individual is placed in an exam room, start with one clinic session and assess the implementation of this process at the end of the session. What worked? What didn't? How could the process be improved? This set of actions and evaluations should continue until an acceptable and successful process is in place.

Evaluate your progress

To know if the change implemented is an improvement, data must be collected. When the aim statement is written, determine what will be measured to evaluate if the change idea is meeting the stated aim. The best way to track how well you are doing is through the use of [run charts](#) that show changes in the proportion of patients receiving intended screening or referral over time.

As noted above, the key to managing change is measurement. The CFF's Mental Health Advisory Committee has developed an Excel spreadsheet to facilitate recording of which patients and parents have been screened, and record responses to individuals who screen positive for anxiety and depression. From this data, run charts (or process control charts, see below) can be generated to visualize the progress and achieved the goals of universal screening for mental health disorders and appropriate treatment or referral for those who show evidence of anxiety or depression, and the progress over time.

In addition to measuring what was done, consider measuring how it was done. Improvement can be achieved by addressing either component; however, the greatest impact for QI is when both are addressed at the same time. As part of your QI measurements consider obtaining patient's or caregiver's perspective on screening and mental health care in your center. This can be accomplished using [patient satisfaction surveys](#) or focus-group discussions. The intent is to improve satisfaction with the mental health care experience within the center by identification of opportunities for process improvements and implementing process changes in your PDSA cycles.

Advanced QI Techniques

Central to the change package is a driver diagram; this will serve as the improvement roadmap. The [key driver diagram](#) displays the overall aims (for example: to screen all eligible patients for anxiety and depression and provide assessment and treatment as indicated), key drivers (conditions needed to be in place to achieve the goals) and the tools/interventions to help get there. The diagram is the core of what your center is trying to accomplish. As an example, on the [driver diagram](#) if the aim to have 100% of patients who screen positive to be referred for treatment, a data owner will need to track the patients who screened positive and who was referred.

Teams should review their data on a regular basis to assess progress, trends and needed process changes. [P-charts](#) are useful as the team starts plotting simple data over time. For example, if you want to measure the success of implementing the process of screening during clinic, the run chart may help in that evaluation. Once there are 12-15 data points the addition of a median line will turn the graph into a Run Chart. The simple line graph and [run chart](#) are useful for short term improvement monitoring.

For long term outcome monitoring, [XmR charts](#) can be used to assess data trends. This can be done by using the CFF Mental Health Screening [Tracking Log](#). Review the measurement charts for runs (one or more points on the same side of the median), shifts (a run of 8 or more data points) and trends (7 consecutive directional data points) to identify:

- **Special Cause Variation:** variation caused by special circumstances not inherent to the system. If positive replicate and standardize, if negative strive to eliminate.
- **Common Cause Variation:** variation caused by chance or by random variation in the system. Teams should strive to reduce variation.

As data is reviewed, note what changes have resulted in improvements and seek to standardize those changes. Those that have not resulted in positive change should be reassessed and a new

test of change implemented. Depending on the outcome measure being assessed, time may be needed until there is enough data to assess; this is generally 15-20 data points. Remember to review data to assess improvements in both your process and outcomes.

X. Conclusions

The data is compelling: anxiety and depression in individuals with CF and their caregivers is common, with potential long-term negative ramifications if not addressed and treated. Following the CF Foundation Mental Health Guidelines, screening for anxiety and depression with treatment as indicated, is essential in addressing the mental well-being of individuals with CF and their caregivers. Additionally, this affords an opportunity for open discussions, to eliminate stigma related to mental health and finally an opportunity to provide psychoeducation and support. Using Collaborative Care, CF care teams will be able to address mental health needs in conjunction with CF health care needs. CF medical care is complex with a tremendous treatment burden. CF care teams have a unique opportunity to fully assess and treat patients and families to insure they have all their physical and psychological needs met for ensuring improved quality of life for everyone involved.

QI principles can help facilitate implementation of the mental health guidelines and provide tools to measure your progress and evaluate outcomes. This document can assist centers in evaluating their own program prior to and during implementation and identify barriers to implementation. Each program will have individual barriers to address; however, this document addresses common challenges.

Addressing mental well-being is an opportunity for growth within each care center by caring for the entire patient with CF, not just their disease or manifestations of CF related to digestive or lung health. Additionally, by addressing mental health there is an opportunity to impact adherence, longevity and quality of life for those with CF, as stated during the 2015 NACFC plenary, "[There is no health without mental health](#)".

As programs are developed across the country, resources will also be developed. We encourage teams to share resources with the Mental Health Advisory Committee using the email address mentalhealth@cff.org. This email address can also be used for any questions, concerns or consultation needed by Mental Health Coordinators or CF Teams. The Mental Health Advisory Committee is committed to assisting all care centers in implementation of the guidelines and addressing barriers or concerns.

XI. References

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