

American College of Rheumatology Guidance Statements for Addressing Mental Health Concerns in Youth With Pediatric Rheumatologic Diseases

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Objective. Pediatric rheumatologic diseases (PRDs) are characterized by high rates of anxiety and depression known to impact health-related outcomes. We present guidance statements to assess and manage mental health concerns for youth with PRDs in pediatric rheumatology practice.

Methods. Development of the guidance statements was initiated in 2019 and concluded in November 2023. It included (1) the formation of a task force (including pediatric rheumatologists, pediatric behavioral health providers, patients, and parents) led by two licensed pediatric psychologists and two board-certified pediatric rheumatologists, (2) iterative drafting of statements and rating of evidence based on the Oxford Centre for Evidence-Based Medicine levels of evidence, (3) an open comment period followed by revision of statements, (4) a Delphi panel process to attain consensus on the statements, and (5) review by the American College of Rheumatology (ACR) Committee on Quality of Care and refinement of statements to an identified list of those with the strongest empiric evidence for endorsement by the ACR.

Results. The task force drafted 34 statements for addressing mental health concerns in pediatric rheumatology, including identification, management, and clinic environment/education considerations. After two rounds of Delphi panel voting by a random sample of 76 members of the Childhood Arthritis and Rheumatology Research Alliance, 31 statements attained at least 80% consensus. Eleven of those statements had high empirical support and endorsement and were thus selected as the final guidance statements, including recommendations for depression and anxiety screening in youth aged 12 years and older, management of identified symptoms, and education of patients about mental health.

Conclusion. It is a goal that these recommendations be used to empower pediatric rheumatology teams to consider how they may better address mental health concerns in their setting and help improve both mental health- and health-related outcomes for youth with rheumatologic diseases.

INTRODUCTION

Mental health concerns, such as anxiety and depression, are common in youth, including children and adolescents with

pediatric rheumatologic diseases (PRDs). Recent reviews suggest anxiety rates range from 7% to 64%^{1–4} and depression ranges from 6% to 59%.^{1–4} Mental health problems are associated with adverse health outcomes, poorer health-related quality

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SIGNIFICANCE & INNOVATIONS

- Mental health concerns, such as anxiety and depression, are common and associated with adverse outcomes in youth with pediatric rheumatologic diseases (PRDs) yet are under addressed.
- A multidisciplinary task force used consensus methodology to develop the first guidance statements for assessment and management of mental health concerns for youth with PRDs in pediatric rheumatology practice.
- The final 11 evidence-based consensus guidance statements include recommendations for depression and anxiety screening in youth aged ≥ 12 years, management of identified symptoms, and education of patients about mental health.

of life, poor treatment adherence, and increased health care utilization.^{5–7} Mental health problems in youth with PRDs are recognized as a public health issue,⁸ and rates have only increased in recent years. For example, the COVID-19 pandemic has had a unique impact on the mental health of youth with PRDs⁹ because of illness uncertainty, fears surrounding lack of access to medications, and social isolation. Clearly, pediatric mental health concerns can be expected to arise during a rheumatology visit.

To optimize patient outcomes, it is imperative to effectively screen and manage mental health concerns in the context of the patient's medical care. Although pediatric rheumatologists are subspecialists and not primary care physicians, patients often identify them as their closest and most trusted providers,¹⁰ and their teams can play an important role in identifying and addressing mental health concerns.¹¹ Within the pediatric rheumatology community, mental health has been recognized as an important gap in care^{11,12} as well as among patients and families.¹³ Additionally, the importance of mental health in pediatric rheumatology has led to its recognition as a high research priority^{14,15} by the Childhood Arthritis Research and Rheumatology Alliance (CARRA) and led to the development of a prioritized CARRA mental health research agenda.¹⁶ Advancing this effort, the feasibility and acceptability of mental health screening for youth with PRDs has been studied in multiple pediatric rheumatology clinics,^{17,18} which are increasingly implementing mental health screening and care models.^{19–24}

Despite these ongoing efforts, one barrier to optimal care is the lack of guidance for the pediatric rheumatology community to address mental health concerns in the context of the medical

visit.¹² Therefore, we sought to establish guidance for pediatric rheumatologists and supporting care providers to address mental health concerns for their patients. Tailored recommendations for mental health screening and management are critically needed. Although guidance exists for managing pediatric mental health in primary care^{25,26} and for youth with cystic fibrosis²⁷ and diabetes,^{28,29} specific guidance for youth with PRDs is not currently available. Importantly, children with PRDs have particular mental health needs related to their disease (eg, pain and fatigue contributing to poor mental health and depression as part of neuropsychiatric lupus). Further, mental health symptoms may impact their health- and disease-related outcomes.^{5–7} This aligns with the Mental Health Roadmap Project by the American Board of Pediatrics,²⁹ which prioritizes optimizing mental health for pediatric patients living with chronic illness by adapting and tailoring strategies for subspecialty settings.

The pediatric rheumatology community and CARRA are uniquely poised to address development of this guidance. Pediatric rheumatology providers in CARRA serve the majority of youth impacted with PRDs,^{30,31} and the CARRA Mental Health Workgroup has driven much of the research supporting development of these statements. Although the availability of mental health professionals in pediatric rheumatology settings is improving because of focused advocacy, we acknowledge that mental health supports are currently lacking for many pediatric rheumatology clinics. However, this guidance was developed with a collaborative approach for interdisciplinary partnership in mind. For example, pediatric rheumatology practices may consider partnerships with primary care providers and mental health professionals in the community for managing mental health concerns. It is our intention that these guidance statements empower pediatric rheumatologists and their teams to leverage available resources in their setting to better address mental health concerns and improve care for their patients. Although some youth with PRDs may receive care in settings outside of pediatric rheumatology clinics, such as in adult rheumatology settings, this guidance focuses on the pediatric rheumatology setting.

The following guidance is intended to provide the pediatric rheumatology community with a standardized approach to addressing mental health in the context of medical care. These guidance statements are designed with a collaborative approach in which pediatric rheumatologists work cooperatively with mental health providers to improve access to high-quality mental health care for youth with PRDs. For the purpose of these guidance statements, PRDs refer to chronic inflammatory conditions and

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other chronic systemic diseases treated by pediatric rheumatologists that include (but are not restricted to): juvenile dermatomyositis, juvenile idiopathic arthritis, childhood-onset lupus, childhood vasculitis disorders, and autoinflammatory disorders. Because some pediatric rheumatologists may treat amplified musculoskeletal pain syndrome/fibromyalgia, they may choose to apply the guidance for these patients as well.

PATIENTS AND METHODS

Initial planning and task force formation. This project was considered not human subject research by the Research Ethics Board at the Hospital for Sick Children. A timeline of project activities is shown in Supplementary Table 1. Development of the guidance statements was initiated in 2019 by the Mental Health Workgroup at the Annual Scientific Meeting for CARRA, the largest United States–based research network of pediatric rheumatologists and researchers. Workgroup attendees were divided into six teams, each made up of pediatric rheumatologists, behavioral health providers (psychologists, psychiatrists, social workers, and a psychotherapist), patients, and caregivers, to draft statements related to a priori content areas based on the modified World Health Organization Principles for Screening Programmes.³² These areas included (1) who to screen; (2) how to screen (eg, tools, frequency, and rules for interpretation); (3) what to screen for; (4) referral plans (eg, support, stratified care, and follow-up); (5) ensuring confidentiality and respect for autonomy; and (6) promoting mental health awareness, education, prevention, equity, and access. We drafted statement outlines followed by presentation and discussion with the larger workgroup.

Following the CARRA meeting from May to September 2019, the Mental Health Workgroup leaders (NRC, AMK, and TBR) assembled a Mental Health Task Force panel, led by two pediatric psychologists (NRC and AND) and two pediatric rheumatologists (AMK and TBR), all with mental health expertise in chronic disease and pediatric rheumatology care. Open calls to solicit interested members occurred during monthly CARRA Mental Health Workgroup conference calls. Additional members were also directly invited by the leadership to ensure a diverse CARRA membership representation including pediatric rheumatologists, a variety of pediatric behavioral health providers, patients, and parents. All invited task force members approached agreed to participate. The final 26-member task force included pediatric rheumatologists, pediatric behavioral health providers, and patients and parents of children with PRDs from the United States and Canada (see Supplementary Table 1).

The task force divided into two subgroups, one focused on screening and another on management/education. Each subgroup was led by a project leader/pediatric psychologist (NRC and AND) with two pediatric rheumatologists (AMK and TBR) serving in mentorship/support roles. Team members with different types of training/expertise (eg, pediatric rheumatologists,

behavioral health providers, parents, and patients) were distributed evenly between the two subgroups.

Guidance statement development and refinement.

During the development and refinement phases, the task force subgroups met between October 2019 and March 2021 (Supplementary Table 1). Of note, there was a pause in broader task force activity during the period of April 2020 to October 2020 secondary to the COVID-19 pandemic. Therefore, flexibility to work with team members in various formats (eg, phone/video conferencing or email) was afforded, and all members participated in the majority of informal/formal meetings (>75% participation).

A summary of development and refinements of the guidance statements is shown in Supplementary Table 2. Task force members agreed to use a guidance statement development process via (1) an iterative refinement phase within the task force, (2) an open comment period to solicit additional feedback from the broader CARRA membership, and (3) a modified Delphi consensus process³³ with asynchronous anonymous voting among a random sampling of CARRA members.

Drafting of statements by the task force. Task force members began to refine the statements in October 2019 drawing from a review of the pediatric rheumatology and broader pediatric (eg, primary care^{25,26} and pediatric chronic illness)^{27–29} literature. The task force conducted a scoping literature review related to assessing and managing mental health concerns in pediatric populations. Of note, the review revealed most available literature was focused on adolescent patients (ie, those aged ≥ 12 years).^{34,35} Considering this evidence, the groups modified the guidance statements. The level of evidence for each statement was rated according to the Oxford Centre for Evidence-Based Medicine.³⁶ Grades from 1 to 5 were assigned to each statement (with lower numbers indicating greater evidence: 1 = systemic review of randomized trials, 2 = randomized trial, 3 = nonrandomized controlled study, 4 = case series or studies, and 5 = mechanism-based reasoning). The task force reviewed/commented on ratings assigned by task force leaders using asynchronous methods. If there were discrepancies, these items were discussed with the broader task force until consensus was achieved.

In October 2019, the task force formally voted on the refined statements (see Supplementary Table 1). Members were asked to indicate whether they agreed or disagreed with statements and could provide commentary on statements. Statements were then revised based on this feedback and were reorganized to include a clinic environment education section (see Supplementary Table 2).

Open comment period. After the draft statements were approved by task force members, the statements were shared with

the broader CARRA membership for an open review period between May and June 2021 (Supplementary Table 1). The statements were posted on the CARRA website, and information about the open comment period was emailed to the entire CARRA membership. Feedback was obtained from 21 pediatric rheumatologist respondents, with the option of providing anonymous feedback. General comments indicated that the statements were well received, but limited availability of resources may be a barrier. For a complete description of changes, see Supplementary Table 2.

Delphi panel consensus process. A total of 34 revised statements were then evaluated by a random sampling of the CARRA rheumatology membership (January to March 2022) using a modified Delphi method.^{33,37} Approximately 25% of CARRA member pediatric rheumatologists (total n = 100: 80 attending pediatric rheumatologists and 20 pediatric rheumatology fellows) were randomly invited (through an online tool by

an administrative member of the CARRA organization external to our task force and team) to participate together with all active CARRA member behavioral health experts (n = 11) and parents/patients surveyed by CARRA (n = 12; 2 of whom were both behavioral health experts and parents). Those agreeing to participate in the Delphi panel were asked to submit asynchronous consensus ratings for each statement by email.

Participants rated their agreement on statements using a numeric scoring system from 1 to 9 with the following anchors: 1 “inappropriate,” 5 “uncertain,” and 9 “appropriate.” Achievement of consensus was defined a priori as at least 80% of participants rating the statement in the appropriate range (ratings of 7–9). Items that failed to achieve consensus in the first round were reviewed, and an additional round of voting was conducted for those items. After the first round of voting, the task force leaders identified several important areas that failed to achieve consensus (see Supplementary Table 2).

Table 1. Mental health guidance statements for patients in established pediatric rheumatology care endorsed by the American College of Rheumatology*

Identification of mental health concerns	LOE grade 1–5	Level of consensus
1. Screening for anxiety, depression, and suicidal ideation (SI) should occur annually, at a minimum, for individuals aged 12 years and up ^a , and more frequently as deemed necessary.	1	84%
2. Patients who demonstrate evidence of clinically significant symptoms of anxiety, depression, or SI at a prior screening should be reassessed at subsequent visits.	2	95%
3. Screening measures should be developmentally appropriate, patient-reported psychometrically validated measures, when possible.	2	92%
4. Additional screenings should occur more frequently during periods of increased disease activity, psychosocial changes, and periods of transition (e.g., a move, starting a new school).	2	86%
5. Screening for anxiety, depression, and suicidal ideation (SI) should occur as soon as is feasible following the initial rheumatology clinic visit or onset of a new rheumatologic diagnosis.	2	80%
6. Screening for SI should occur at least annually using a clinically validated tool with an item to assess for SI, in a setting where there are resources in place to address positive screens.	2	80%
7. Minoritized groups ^b are often less likely to be diagnosed and referred for mental health treatment. Providers should understand and assess for inequities in evaluation and access to mental health resources, especially in minoritized groups, when implementing mental health screening.	3	89%
Collaborative management of mental health concerns	LOE grade 1–5	Level of consensus
8. For patients who demonstrate moderate to severe symptoms (with or without SI), an: An urgent assessment by a mental health specialist is preferred to advise on evidence-based treatments, including possible options for medication management to be used in conjunction with psychological intervention.	1	100%
9. For patients who demonstrate mild symptoms ^c (and no SI), recommend that the patient follow-up with a primary care provider to help monitor symptoms.	3	81%
Clinic environment/education	LOE grade 1–5	Level of consensus
10. Ongoing discussions and education about mental health should occur (e.g., annually), including discussion of warning signs and symptoms of mental health disorders. Information should be given in a manner consistent with the patient's developmental stage and socio-cultural background.	3	84%
11. To facilitate discussion about mental health, patients who have been given a new diagnosis should be offered resources (e.g., fact sheets, brochures, websites, peer support) that address common mental health concerns in rheumatologic/chronic disease.	3	80%

* LOE, level of evidence; SI, suicidal ideation.

^a Screening is recommended for ongoing patients of pediatric rheumatology providers ages 12 years through young adulthood given the most empirical support currently available for mental health screening of individuals at this age with validated tools.

^b This statement is in reference to research showing that despite high rates of mental health concerns, African American people with lupus are less likely to be diagnosed with mental health conditions or receive appropriate treatments (36). Limited access to effective diagnosis and treatments may apply to other minoritized populations impacted by cSLE.

^c Mild symptoms are determined by clinical cut-offs on validated anxiety and depression screening measures (for more details, see Table 2. Pediatric Anxiety and Depression Screening Measures.

Table 2. Pediatric anxiety and depression screening measures*

Measure	Description	Age range, y	Time to complete, min	Validated cutoffs (yes/no)	Freely available (yes/no)	Available languages
Anxiety symptom measures						
Generalized Anxiety Disorder-7 (GAD-7) ⁵⁹	7-item scale. Raw scores 5–9 = mild, 10–14 = moderate, and 15–21 = severe	≥12	<2	Yes	Yes	>50 translations, including Arabic, Chinese, English, French, Hindi, and Spanish
Beck Youth Inventories-Anxiety Inventory (BAI-Y)	20-item scale. Raw scores are converted to standardized T-scores: <55 = average, 55.0–59.9 = mildly elevated, 60.0–69.9 = moderately elevated, and ≥70 = extremely elevated	7–18	5	No	No	Danish, English, French, and Polish
Screen for Childhood Anxiety Related Emotional Disorders (SCARED)	41-item scale. Raw scores ≥25 indicate clinically significant anxiety	8–18	10	Yes	Yes	Arabic, Chinese, Czech, English, Finnish, French, German, Hebrew, Italian, Spanish, Tamil, and Thai
State-Trait Anxiety Inventory for children (STAIC)	40-item scale. Raw scores 39–40 and above are clinically significant	9–12	10	Yes	No	Arabic, Cambodian, Chinese, Croatian, Czech, Danish, English, Filipino, Finnish, French, German, Greek, Hungarian, Italian, Korean, Malay, Norwegian, Persian, Polish, Portuguese, Romanian, Russian, Slovak, Spanish, Swedish, Thai, and Turkish
Patient-Reported Outcomes Information Measurement System (PROMIS)	8-item scale. Raw scores are converted to standardized T-scores: <50 = normal, 50.0–54.9 = mild, 55.0–64.9 = moderate, and ≥65 = severe	8–17	5	No	Yes	Arabic, Bengali, Chinese, Czech, Dutch, English, French, German, Gujarati, Hindi, Hungarian, Italian, Japanese, Kannada, Korean, Malayalam, Marathi, Polish, Portuguese, Punjabi, Russian, Spanish, Tamil, Telugu, and Ukrainian
Depressive symptom measures						
Patient Health Questionnaire-9 (PHQ-9)	9-item scale. Raw scores 5–9 = mild, 10–14 = moderate, 15–19 = moderately severe, and 20–27 = severe	≥12	5	Yes	Yes	>50 translations, including Arabic, Chinese, English, French, Hindi, and Spanish
Children's Depression Inventory (CDI)	28-item scale. Raw scores between 17 and 19 and above (depending on age/gender) indicate clinically elevated symptoms	7–17	5	Yes	No	English and Spanish
Mood and Feeling Questionnaire for children (MFQc)	Short (13-item) and long (33-item) versions are available. Raw scores ≥12 on the short form and ≥27 on the long form indicate clinically elevated symptoms	6–17	5–10	No	Yes	Arabic, English, Filipino, Finnish, German, Norwegian, Portuguese, and Spanish
Patient-Reported Outcomes Measurement Information System (PROMIS)	8-item scale. Raw scores are converted to standardized T-scores: <50 = normal, 50.0–54.9 = mild, 55.0–64.9 = moderate, and ≥65 = severe	8–17	5	No	Yes	Arabic, Bengali, Chinese, Czech, Dutch, French, German, Gujarati, Hebrew, Hindi, Hungarian, Italian, Japanese, Kannada, Korean, Malayalam, Marathi, Polish, Portuguese, Punjabi,

(Continued)

Table 2. (Cont'd)

Measure	Description	Age range, y	Time to complete, min	Validated cutoffs (yes/no)	Freely available (yes/no)	Available languages
The Center for Epidemiological Studies Depression Scale for children (CES-DC)	20-item scale. Raw scores ≥ 15 indicate significant depression	6–17	5	Yes	Yes	Russian, Spanish, Tamil, Telugu, Ukrainian, and Urdu English
Mental health and behavior screening Patient Symptom Checklist 17 items (PSC-17) ^{60,61}	17-item scale; raw scores ≥ 15 indicate possible behavioral health disorder; subscores for certain groups of questions indicate internalizing, externalizing, and attention problems	4–17	<5	Yes	Yes	English, Spanish, Chinese, Vietnamese, Indonesian, and Norwegian
Child Behavioral Checklist (CBCL)	113-item scale scored using computer software. Scores >97 th percentile indicate clinically significant symptoms	6–18	10	Yes	No	>50 translations, including Arabic, Chinese, English, French, Hindi, and Spanish
Behavior Assessment System for Children (BASC)	Child form (ages 8–11 years): 137 items. Adolescent form (ages 12–21 years): 189 items. Standardized T-scores are generated via computerized software, with $T > 70$ indicating clinically significant symptoms	8–21	30	Yes	No	English, Spanish, and French

* This table has been adapted from Treemarcki et al.⁴ Many considerations (eg, age of patients or prior screening practices in a given setting) may drive selection of specific tools, but one example we suggest is the use of the Patient Health Questionnaire-9 and the Generalized Anxiety Disorder-7 for screening for depression and anxiety, respectively.

The team presented preliminary results and elicited additional feedback on items related to these areas from the broader CARRA Mental Health Workgroup (September 2022). Clarification related to these items was incorporated into a follow-up email to the original panel asking them to vote on the selected items (see Supplementary Table 1). The original panel members then voted again on these statements during December 2022 and January 2023.

RESULTS

Delphi panel results. Of the 123 CARRA members invited to participate in the Delphi panel, 77 accepted and 76 (62%) participated in the first round of voting. The response rate may have been directly or indirectly affected by the COVID-19 pandemic. Among the 76 participants, respondents were 48 attending pediatric rheumatologists, 13 pediatric rheumatology fellows, 9 behavioral health professionals, 8 parents/caregivers (2 were both parents and behavioral health professionals), and 4 patients with PRDs. In the second round of panel voting on four selected items that did not initially reach consensus, 57 (75%) members responded. More than 90% of those respondents provided voting.

After two rounds of voting, 31 of the 34 statements achieved consensus. Of these, 11 recommendations with a higher level of empirical support (evidence grades 1–3) were moved forward for American College of Rheumatology (ACR) endorsement as final guidance statements (Table 1) upon review by the ACR Quality of Care Committee. The full set of 31 statements achieving consensus are shown in Supplementary Table 3.

Screening guidance statements. All statements pertaining to screening achieved consensus, and seven of these comprised the 11 final guidance statements (Table 1). These included recommendations for screening of adolescent patients in pediatric rheumatology care and using clinically validated and developmentally appropriate measures of anxiety, depressive symptoms, and suicidal ideation (SI). Initial screening should occur as soon as is feasible, and re-screening should occur at least annually, and more frequently when indicated owing to disease flare, distress, or a history of positive screens. Screening for SI should occur in a setting with resources to address positive SI screens. Assessment of inequities in mental health screening is important for helping to address barriers to care.

Nine additional screening recommendations achieved high levels of consensus but had less empirical support (Supplementary Table 3). A summary of mental health screening tools with literature support in pediatric rheumatology settings is provided in Table 2.

Collaborative management statements. Delphi panel members reached consensus after two rounds of voting in all

but one of the collaborative management guidance statements, and two of these comprised the 11 final guidance statements (Table 1). These two recommendations were that patients with moderate or severe symptoms need urgent assessment by a mental health specialist and patients with mild symptoms should follow up with their primary physician for monitoring. Eight additional statements reaching consensus, but with less empirical support, are detailed in Supplementary Table 3.

Clinic environment and education statements.

Delphi panel members reached consensus after two rounds of voting in all but two of the clinic environment/education statements, and two of these comprised the 11 guidance statements. These two recommendations were that patients with a new PRD diagnosis should be offered resources (eg, websites or peer support) that address common mental health concerns for youth with PRDs and that ongoing discussions and education about mental health should occur in a manner consistent with the patient's developmental stage and sociocultural background. A summary of resources providers may wish to consider referencing are provided in Table 3.

Additional perspectives from the pediatric rheumatology community.

We captured additional insights on addressing mental health concerns for patients with PRDs through comments submitted by the pediatric rheumatology community during the open comment period and from participants in the Delphi panel. Most comments came from pediatric rheumatologists and overall supported the importance of addressing mental health for pediatric rheumatology patients and the usefulness of providing clinicians with consensus-supported guidance statements. Additionally, however, some voiced concern about the lack of existing mental health support and resources for pediatric rheumatologists to effectively address mental health in practice. It was noted that mental health education for pediatric rheumatologists would be helpful to discuss mental health concerns and potential interventions. Several comments emphasized the potential for optimizing engagement of primary care physicians in mental health care as an approach for mitigating the lack of access to other mental health specialists, such as social workers, psychologists, and psychiatrists. Other comments highlighted the opportunity for pediatric rheumatology practices to use guidance statements to advocate for integration of these much-needed specialists into the medical team.

DISCUSSION

We present the results of a project to develop consensus-based guidance to empower pediatric rheumatologists to address a current gap in clinical care regarding the mental health of youth with PRDs. The 11 mental health guidance statements endorsed by the ACR are supported by substantial evidence

Table 3. Resources for addressing mental health for youth with PRDs*

Name and website	
For patients and families: educational resources from patient organizations	American Board of Pediatrics: https://www.roadmapforemotionalhealth.org/patients-and-families Arthritis Foundation: https://arthritis.ca/support-education/mental-health/supporting-your-child-s-mental-health/resources-to-promote-mental-health Cassie + Friends Foundation: https://cassieandfriends.ca/mentalhealth/ Cure JM Foundation: https://www.curejm.org/mental-health-resources/ https://www.curejm.org/mental-health-resources-for-parents-and-caregivers-of-newly-diagnosed-children/ https://www.curejm.org/emotional-and-mental-health-getting-help/
For clinicians: educational resources, toolkits, and training	American Board of Pediatrics Mental Health Roadmap Project: https://www.roadmapforemotionalhealth.org/ American Academy of Pediatrics Screening Tools: Pediatric Mental Health Minute Series: Screening Tools: Pediatric Mental Health Minute Series (aap.org) Effective Child Therapy: https://effectivechildtherapy.org/ Anxiety and Depression Association of America: https://adaa.org/professionals Ask Suicide-Screening Questions Toolkit: https://www.nimh.nih.gov/research/research-conducted-at-nimh/asq-toolkit-materials The Columbia Lighthouse Project: https://cssrs.columbia.edu/the-columbia-scale-c-srs/cssrs-for-communities-and-healthcare/#filter=.healthcare.english Cure JM Foundation/Children's Hospital of Colorado: Mosaic of Mental Health Trainings: https://www.youtube.com/watch?v=bPk33EkI93U https://www.youtube.com/watch?v=XS6GXmzMxEM&t=5s
For clinicians and researchers: opportunities for quality improvement and research in mental health for youth with PRDs	Cure JM Foundation grants: https://www.curejm.org/grants/ Cassie + Friends youth mental health strategy: https://cassieandfriends.ca/youthmentalhealthstrategy/ The REACH Institute: https://thereachinstitute.org/

* JM, juvenile myositis; PRD, pediatric rheumatologic disease.

and supported by the North American pediatric rheumatology community. Drawing on the growing literature on mental health in pediatric rheumatology, along with evidence from pediatric chronic disease and general pediatrics, this guidance is anticipated to advance and align increasing efforts to address mental health concerns for youth with PRDs in the pediatric rheumatology setting.

All the mental health *screening* statements, focused on depression, anxiety, and SI in youth aged 12 years and older, achieved consensus in the first voting round. Seven of these statements were also endorsed by the ACR. Given the large evidence base for these recommendations, there is likely more comfort with screening recommendations. Furthermore, mental health screening emerged as a high-priority item in the CARRA Mental Health Workgroup Prioritized Research Agenda,¹⁶ and there was high support for these practices among the respondents representing the pediatric rheumatology community. It is notable that several screening statements achieving high levels of consensus, but with less empirical support (and therefore not endorsed by the ACR), pertained to an important role of pediatric rheumatologists in interpreting mental health concerns in the

context of disease (eg, neuropsychiatric manifestations, medication adherence, and side effects). This highlights a need for further research on the relationship between mental health disorders and disease factors/outcomes, which was identified as one of the highest-priority topics in the research agenda developed by the CARRA Mental Health Workgroup.¹⁶

All adolescents and young adults receiving ongoing care from a pediatric rheumatology team would likely benefit from universal mental health screening and assessment of contributing socioenvironmental factors. This is important to promote equity in access to care,³⁸ which is reflected in the endorsed statements. Because mental health screening is recommended to be completed universally in pediatric primary care and other specialty clinic settings, we believe that adoption of this approach in the pediatric rheumatology setting is important and reasonable. However, when resources are limited, pediatric rheumatology clinics may choose to start with particular patient populations (eg, adolescent patients with lupus). Several sites within the pediatric rheumatology community have had success using the Generalized Anxiety Disorder 7-item scale and the Patient Health Questionnaire 9-item scale as short self-report tools for routine

assessment of anxiety and depression, although the specific screening tools used may vary based on existing processes underway in pediatric rheumatology practices. Brief clinically validated tools available for use in pediatric rheumatology settings are listed in Table 2.^{4,39,40} Of note, although our current recommendations are focused on screening youth aged 12 years and older, some validated measures are normed for use with younger children.

Encouragingly, mental health screening has gained momentum in pediatric rheumatology, as recent multicenter studies have shown feasibility and acceptability of mental health screening in rheumatology clinics,^{17,18} and several efforts are focused on using quality improvement and implementation science to implement screening within pediatric rheumatology clinics.^{20,21,23} For pediatric rheumatology clinicians wishing to implement mental health screening, the American Board of Pediatrics Mental Health Roadmap Project has developed educational resources and toolkits for integrating mental health care into pediatric subspecialty practices (Table 3; <https://www.roadmapforemotionalhealth.org>). Additionally, integration and automation of screening processes within electronic health records may also allow for reliable and minimally burdensome execution, as recently demonstrated in a pediatric rheumatology setting.⁴¹

Most of the collaborative management guidance statements achieved consensus. Two of these ACR-endorsed statements address interdisciplinary management of mental health symptoms in youth with PRDs through the involvement of mental health specialists. The other management statements reaching consensus reflected additional principles of shared care (patient-provider) and interdisciplinary care (eg, team communication), handling of SI, and taking a proactive approach to mental health. We recognize that the feasibility of implementing these guidance statements may be limited at specific institutions/sites depending on the level of resources/support for mental health care and from primary care providers. However, it is important to recognize that these management recommendations allow for tailored levels of care based on mental health symptomology as illustrated by the psychosocial preventive health model,⁴² which has been adapted for pediatric rheumatology.⁴ In this model, tiered support is offered based on levels of need. Because most patients will have mild or moderate symptoms, they may benefit from low-intensity proactive support with psychoeducation and, if needed, brief counseling or psychotherapy. These supports, particularly psychoeducation and brief counseling, can be provided by a variety of providers, including social workers,^{20,22} child life specialists, and community/school counselors or psychologists. Additionally, a recent study showed the value of partnering with adolescent medicine specialists to evaluate and manage mental health problems in adolescents with lupus.⁴³ Because only a small percentage of patients may need urgent and/or intensive intervention, a stratified approach to care can maximize the use of limited resources by reserving higher levels of care (eg, with

a psychologist or psychiatrist) for children with more severe mental health problems.⁴⁴

Although statements related to the management of those with mild symptoms did not achieve consensus during the first voting round, there may be a role for using additional supports, including a multidisciplinary team in pediatric rheumatology-based interventions to address mild symptoms and potentially prevent worsening via a proactive approach. This was indeed identified as one of the highest-priority topics in the CARRA mental health research agenda¹⁶ and was identified by the international task force for development of treat-to-target guidelines for childhood-onset lupus.⁴⁵ Importantly, there is an ongoing study of promising approaches with interventions such as cognitive behavioral therapy tailored to youth with lupus and milder mental health symptoms,^{46,47} and there has been success of similar collaborative efforts to enhance mental health supports in other subspecialty settings.^{48,49} Additionally, implementation science methods⁵⁰ may also allow for training other providers within the rheumatology team (eg, social workers, nurses, or medical assistants) to address mild or moderate mental health symptoms. As research on mental health management in the context of pediatric rheumatology settings continues to emerge, the statements pertaining to mild symptoms will warrant revisiting and future consideration.

Among the final selected recommendations, the two pertaining to the pediatric rheumatology clinic environment and education address discussion about mental health with the patient, both soon after PRD diagnosis and in an ongoing manner, to promote awareness and education about common mental health challenges for youth with PRDs. Of course, particularly in the case of minors, parent engagement and support are critical. Mental health education of youth with PRDs and their families can be facilitated by leveraging online resources, including resources that targeted to newly diagnosed youth (Table 3). Recent efforts in pediatric rheumatology are also aiming to increase mental health literacy and skills for clinicians supporting care of patients with PRDs through rheumatology-specific workshops.^{51,52} Additionally, resources for clinicians available from the American Board of Pediatrics Mental Health Roadmap Project (Table 3) include tools to support mental health assessment and management.

There are limitations to the application of these guidance statements. First, the screening recommendations do not address concerns for patients younger than age 12 years. Second, our work focused on the opinions of CARRA members, the majority of whom are pediatric rheumatologists. Furthermore, our respondents were largely from North America, and findings may not be applicable to other geographic regions. However, these guidance statements are aligned with ongoing international efforts striving to address mental health for youth with PRDs. These include the international task force for the development of treat-to-target guidelines for childhood-onset lupus⁴⁵ and the Psychological Impact Scientific Working Group for the Myositis

International Health & Research Collaborative Alliance.⁵³ Additionally, the 2010 British Society of Paediatric and Adolescent Rheumatology Standards of Care for youth with juvenile idiopathic arthritis specify that every patient should have access to a pediatric clinical psychologist as part of the core multidisciplinary team.⁵⁴ There may also be special considerations for addressing mental health care during (often shortened) rheumatology telemedicine visits whereby the patient may not have adequate privacy. However, strategies to adapt mental health practices for telemedicine have been provided by other subspecialties^{55–58} such as psychiatry. For example, mental health screeners may be completed using secure patient portals. Patients may also be informed in advance that a private space is needed for their appointment.

Finally, it must be recognized that there are widely varying levels of resources available across pediatric rheumatology practices to address mental health concerns. We recognize that these resource differences cannot be solved by creating guidance alone, and it is crucial for the pediatric rheumatology community to advocate for access to mental health services for patients.³⁵ In conclusion, the finalized mental health guidance statements are supported by substantial evidence and supported by the North American pediatric rheumatology community. This guidance provides a standardized, evidence-based approach for addressing mental health concerns for youth with PRDs receiving care in pediatric rheumatology practices. These guidance statements provide a framework to consider local steps needed for improving mental health intervention for our patients and can be used to advocate for resources to enable collaborative interdisciplinary care of youth with PRDs. Although this guidance is intended to evolve as new evidence becomes available, it may be used now to help improve both mental health and health-related outcomes for youth impacted by rheumatologic conditions.

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AUTHOR CONTRIBUTIONS

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