Public Comments

The 2022 American College of Rheumatology (ACR) Guideline for Physical, Psychosocial, Mind-body, and Nutritional Interventions for RA: An Integrative Approach to Treatment *call for public comment was posted on the ACR website December 7, 2021. The announcement was emailed to the Practice Guidelines Subcommittee, Quality of Care Committee, and ACR Board of Directors, and was included in multiple ACR publications and on ACR social media platforms. Twenty-two (22) responses were received via the online form. The public comment period closed on January 7, 2022.*

RESPONSES RECEIVED ONLINE:

- Name: Fuki Hriuchi
- > Institution:
- > Position:
- > **Disclosure (optional):** Nothing to disclose

Comment:

Hello. I am a RA patient in Japan (30 years RA history), used to work for Wyeth (Rheumatorex, Embrel, Minomycin developer) in Drug Safety Compliance Dept. Now I am working for electronics sector so completely free of IO

P 11 #297 15. Should patients with RA use adaptive equipment? #300

Suggestion; Inserting "Table Chair with neck-support" RA patients often suffer neck problem. I switched my table chair from wood to gaming chair with neck support. In Japan National Insurance cover

16. Should patients with RA use environmental adaptations?

Suggestion; Inserting "Covered by insurance"

In Japan over 40 years old RA patients can receive "Long-term caring Insurance program" an receive home reform at discount rate. I did my house at age 40 with my bathroom(handle and grip aid), kitchen door handle, toilet slope. Also Handicapped welfare Law support is capable for apply who recognized Class 2 or above to reform kitchen equipment usability for wheelchair. If you look up for paper review for Japanese RA patients, I will work out.

P14 #403 24. Should patients with RA receive massage therapy?;

Suggestion; inserting #490 "Long term outcomes Lymphedema, Venous infarction QOL."

Due to multiple long-term drug use/ cardio failure, legs of RA patients often swollen. I often receive massage therapy (not acupuncture but along the trigger spot line method called "Tsubo Shiatsu" 25 minutes; oil massage wet with squaran oil with aroma essence oil 120 minutes). It improves swollen leg fatigue.

Public Comments

- Name: Akemi Torin
- > Institution:
- > Position:
- > **Disclosure (optional):** Yes, I wish to disclose information

Comment:

7 1. Should patients with RA use a formally defined diet? 158 P - Patients with RA

I believe the Pt immediately needs to refer to functional medicine and dietitian. Without the adequate tests, which diet strategy would work optimally might be not determined.

Genomic weakness like MTHFR or COMT.

I had nutrigenomic analysis approach and worked great.

That approach takes time so the immediate access to those professionals is the key.

167 2. Should patients with RA use a commercially available dietary supplement?

168 P - Patients with RA

169 I - Dietary supplement (vitamin D, probiotics, fish oil/omega-3 fatty acids, antioxidants [selenium, zinc,

170 vitamin A, vitamin C, vitamin E], turmeric, glucosamine, γ-linolenic acid, borage seed oil, evening

171 primrose oil, black currant seed oil, selenium, Boswellia, ginger, probiotics)

Again, it depends on Pts. So adequate tests over time and follow up is inevitable.

- Name: Dana DiRenzo
- Institution: University of Pennsylvania
- > **Position:** Assistant Professor
- > Disclosure (optional): I have nothing to disclose.

Comment:

I think this is an excellent endeavor and will be great to organize and evaluate different nonpharmacologic strategies for adjunctive management for rheumatoid arthritis.

In the setting of COVID (and health-care post COVID), I think it will be important to evaluate both inperson programs AND telehealth/mobile/online programs, particularly for the self-management, mindbody exercise, and mind-body psychosocial PICOS. Results have varied widely and it will be important to inform our patients of the differences based on available data.

If you need more help, I would love to be involved! Dana DiRenzo

Public Comments

- Name: Maximilian Konig
- Institution: Johns Hopkins
- Position: Instructor of Medicine
- > Disclosure (optional): I have nothing to disclose

Comment:

It would be important to evaluate and discuss the current literature on the role of oral hygiene, periodontal treatment, and dental visits on rheumatoid arthritis disease activity. There is emerging data that those interventions (even if not targeted) can decrease disease activity, even though antimicrobial therapies targeting specific microbes with potential roles in RA pathogenesis have not been performed.

- > Name: Elaine Husni
- > Institution: Cleveland Clinic
- > **Position:** Rheumatologist
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

This is such a great effort and important contribution. We have more a comment than specific suggestion. We have had a strong interest in this area and have implemented some novel low cost, high touch platform for our patients at the Cleveland Clinic. We have recently been awarded foundation funding for this work as in the psoriatic disease space. We are completely supportive of reporting on the evidence in a meaningful way which will help empower our patients and create meaningful dialogue. Lifestyle and behaviors can affect the immune system and the more we can study this in immune mediated diseases the better we can care for our patients.

Thank you for working on this very important topic.

Sincerely, Elaine Husni and Len Calabrese Cleveland Clinic

- > Name: Randy Horwitz
- > Institution: University of Arizona/ Andrew Weil Center for Integrative Medicine
- > Position: Professor of Medicine; Medical Director of AWCIM
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

So happy to hear of this endeavor on the part of ACR. I have had the honor of teaching Integrative Rheumatology at the ACR Meetings for many years (pre-pandemic). In addition, the Weil Center for Integrative Medicine at the University of Arizona offers scholarships to train Rheumatologists in Integrative Medicine. The demand has existed for well over a decade. Certainly the patient demand has been immense and overwhelming.

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I do have a major concern regarding your process of evaluating the literature. Your approach is classical in terms of collecting and examining studies, and grading the quality of the work. As a trained basic scientist with a PhD in Molecular Immunology, I appreciate that. However, my second career, as a physician, has taught me that the majority of medicine is an art, and may not translate to making clinical recommendations based upon published studies.

For example, you are proposing to develop guidelines for RA. I don't need to remind you that this is a terribly heterogeneous condition. The inclusions for many published studies are based upon somewhat dated diagnostic criteria that will likely change after precision medicine becomes mainstream. The current criteria are designed to group patients in order to facilitate treatment options, but there are many exceptions (which is why we have more than just 1 drug to treat RA). So, why my diatribe?

In my 17 yrs treating RA patients integratively, there is no "one size fits all." In my clinic, we use a sliding scale of evidence: The greater the potential a treatment has to cause harm, the stricter the standards of evidence it should be held to, in terms of efficacy. This is essential, as we will never have the resources to test every intervention in every combination.

I apologize for the long comment, but I would urge you to relax your critical evaluation a bit before discounting an intervention, or looking simply at "p-values.". In reality, unless the studies that you are examining are using inbred individuals, it is difficult to exclude individual variations. When I entered Medicine (from Basic Sciences), I was shocked at all the conclusions being reached with clinical studies; they surely would not have been allowed in the basic sciences.

- > Name: Simun Singla
- Institution: Rheum to Grow
- > **Position:** Pediatric Rheumatologist
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

1. I do not see any PICO questions on environmental exposure, specifically cigarette exposure. There has been an increasing body of literature on the link between parental smoking during childhood and increased risk of seropositive RA later in life. Can this be looked at through a retrospective questionnaire and if there are positive findings, link it to smoking cessation recommendations?

2. Similar to number 1, I do not see recommendations for CBD use (tropical and/or oral).

3. Regarding acupuncture (line 394, page 14), how is acupuncture being standardized? There are multiple modalities that acupuncture (standard, electroacupuncture, ear acupuncture, moxibustion, fire cupping, gua sha, etc). Additionally, many practitioners of traditional Chinese medicine use herbs in conjunction with acupuncture. Are these accounted for as well?

- > Name: George Munoz, MD
- Institution: American Arthritis and Rheumatology Associates AARA AOTRC

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- > Position: Chief, Integrative Medicine and Rheumatology AARA
- Disclosure (optional): I wish to disclose the following relationships or intellectual conflicts: Speaker Consulting UCB Wellness 4U Programs Speaker Consulting Quest Diagnostics Labs Exagen Lab Chief Medical Officer Oasis Health Chief Medical Officer The Oasis Institute, www theoasisinstitute.com Associate Program Director Larkin Rheumatology Fellowship Program

Comment:

I am a subject matter expert on the entire field of INTEGRATIVE RHEUMATOLGY and as such highly recommended the ACR FINALLY AND FULLY ENDORSE FORMAL recognition of the mind-body, nutritional, stress management, exercise and full Interdisciplinary approaches to comprehensive treatment of RA and all IMIDs in addition to advanced biologic and immunosuppressive meds.

Please see FLORIDA SOCIETY OF RHEUMATOLOGY, FSR, INTEGRATIVE RHEUMATOLGY PRE CONFERENCES I have course direct twice in 2017 and 2021 as EVIDENCE BASED, CME, in conjunction with yearly Florida State SOCIETY Meeting.

I endorse

NUTRITION SECTIONS including

Anti Inflammatory mediterranean diet..evidence based

Vegan Plant Based

Elimination Diets of gluten, red meat, cows milk in some individuals especially in high disease activities

NUTRACEUTICALS

Agree with OMEGA 3 EPA DHA SUPPLEMENTS 2 TO 6 GRAMS MOL DISTILLED DAILY

VIT D3...no single universal dose but rather personalized to achieve OPTIMAL LEVELS 50 TO 60 ng/ml

METHYLATED FOLATE 1-2 mg daily

B12 1 mg daily and B complex

Vit C Extended Release 1000 mg daily

Zinc, Selenium, xalcium magnesium, Vit A

YES ON PROBIOTICS... YES on PREBIOTIC FOODS

MIND-BODY..YES STRESS REDUCTION/MANAGEMENT

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Breathing, mindfulness, journal, exercise, Yoga, Tai Chi etc

EXERCISE PRESCRIPTION TRAINING AND GUIDELINES

Multidisciplinary Ream Approach to include Nutritionist duetician, Mental health, Rheumatology nursing, Social worker, Wellness coaches, Physician Rheumatology and Advanced practitioners (APPs)

Entire Integrative Modem to Interface with Conventional Advanced Biologic Meds, PT, OT.

YES TO ACUPUNCTURE and TCM options for pain control and pts wanting fewer meds when possible

- > Name: Nisha Manek
- > Institution: Avel eCare and Rheumatology Santa Cruz
- Position: Consultant
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

Two thumbs up to the ACR to draw up guidelines for integrative management of RA. This is long overdue! Will benefit our patients and will hugely help conventional care. Thanks, Nisha Manek, MD

- > Name: Nicole Cotter
- Institution: UCHealth
- > Position: Physician, Rheumatology and Integrative Medicine
- > Disclosure (optional): I have nothing to disclose

Comment:

I am thrilled to see these guidelines in development. There are several board-certified rheumatologists in the ACR community who have also completed an Integrative Medicine Fellowship and are also boardcertified in Integrative Medicine (myself included). There is tremendous interest in integrative approaches to Rheumatoid Arthritis (and autoimmune disease in general) in the general public, as well as within the physician rheumatology community. I am happy to see this being taken seriously and that guidelines from our respected college will be available to all. I would like to see more Integrative Rheumatologists involved in the development and implementation of these guidelines because we exist, are available, and have been eager to play a role.

- > Name: Riteesha Reddy
- > Institution: North Texas Preferred Health Partners
- Position: Physician
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

As an integrative medicine fellowship-trained rheumatologist, I am thrilled to see the ACR support this important work.

Public Comments

- > Name: Catherine Lee
- > Institution: Washington Permanente Medical Group and University of WA, School of Medicine
- > Position: Rheumatologist, Clinical assistant professor
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

As a rheumatologist, I am very excited about this project. It's clear that DMARDs alone are insufficient to control disease in most patients, and we need to start spending more time and resources looking at integrative approaches for RA. There is enough information now on isolated treatments, e.g. mindfulness, diet, activity, that have demonstrated impact on quality of life for RA patients that we need to study this further.

- > Name: You Tak Leung
- Institution: Thomas Jefferson University
- > **Position:** Assistant professor
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

This is a wonderful and long awaited progress to help provide comprehensive care for our patients. Integrative rheumatology is invaluable in guiding our patients towards a healthier life.

- Name: Olga Kromo
- Institution: Fsr, Rheumwell
- > **Position:** President, physician
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

Integrative medicine strategies are safe, effective and essential to support traditional allopathic approaches to Ra treatment and our focus on remission and cure. Need to be payer supported.

- > Name: Beth Biggee
- Institution: Rheumatology at Orthopaedics Northeast, PC
- Position: Integrative Rheumatologist, Owner, Partner
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

Only other thought is any evidence for sleep deprivation and RA flare. adequate sleep enhance RA function and response- just another domain of health missing but likely not much data. Awesome otherwise !!

- > Name: Alice Chu
- Institution: Private practice over 30 years
- Position: Owner

Public Comments

> Disclosure (optional): I have nothing to disclose.

Comment:

I would like to comment on the plan #23, the question of "should pts with RA use Acupuncture"

I am a huge advocate of using acupuncture in RA.

I am currently studying medical acupuncture, a student of Acumed (osteopathic school of New England) because I saw the need in holistic approach in treating RA. I truly believe treating RA pts need mind body approach and acupuncture can provide that essence of true mind body healing and also I find it very helpful in treating RA patients especially those patients having side effects of western allopathic medications. During recent years with help of MRI there seemed to have been ample collection of scientific data's to support the use of acupuncture in mind body healing

- Name: Jose A. Pando
- > Institution: Delaware Arthritis
- > Position: MD
- > **Disclosure (optional):** I have nothing to disclose.

<u>Comment</u>:

Thank you for initiating a Project that is so needed. Most of our patients use Integrative approaches daily. From Dietary changes to Botanicals, movement and mind- body interventions they have been demonstrated to be helpful.

A trigger that is recently being recognized is the role of stress in activation and perpetuation of the immune response. This is specially important in children. In children and adults the use of mind body approaches can potentially modify the course of disease

- > Name: Paulette Hahn
- Institution: University of Florida / current fellow University of Arizona Integrative Medicine Fellowship
- > **Position:** Associate Professor
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

I strongly endorse the 2022 American College of Rheumatology (ACR) Guideline for Physical, Psychosocial, Mind-body, and Nutritional Interventions for RA: An Integrative Approach to Treatment. Treatment that looks at the individual both from medical illness as well as health will enhance effective treatment. The interprofessional approach is key in the care of our patients with rheumatologic disease and certainly in rheumatoid arthritis. It is exciting to see this effort brought forward through the ACR.

- > Name: Tiffany Westrich-Robertson
- > Institution: International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
- Position: CEO

Public Comments

Disclosure (optional): I have nothing to disclose.Comment:

As persons living with autoimmune/autoinflammatory arthritis diseases, two of which are diagnosed with rheumatoid arthritis, we applaud the ACR for your efforts to put forth recommendations to integrate non-pharmacologic therapies into treatment regimens. For years patients have expressed a need to seek out alternative methods of intervention yet have never received guidance from their rheumatologist or they are impeded by the insurance process. We believe this initiative is a necessary step to overcome barriers to access of alternative treatments, particularly as both medical professionals and payers look to data and established guidelines to justify implementation.

Additionally, we thank you for this opportunity to add public comments on the project plan for the development of these 2022 ACR Guidelines for Physical, Psychosocial, Mind-body, and Nutritional Interventions for RA: An Integrative Approach to Treatment. This review was conducted by three persons affiliated with the International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis) – Tiffany Westrich-Robertson, B.S., CEO/Axial Spondyloarthritis; Katie Simons, M.P.A., Senior Programs Manager/Rheumatoid Arthritis; Deb Constien, B.S., Medically Retired Dietitian, Organization Volunteer/Rheumatoid Arthritis.

Recommendations for Reconsideration in Wording

1. Under OBJECTIVES, if a final domain includes Adjunctive therapies (line 33), consider a different adjective in the BACKGROUND Line 13:

• Line 13/14: "Together with pharmacologic treatment options, physical, psychosocial, mind-body, and nutritional interventions are considered as potential adjunctive treatments for RA." (Recommendation – coordinated).

OR

• Line 33: Adjunctive therapies (e.g., acupuncture, massage therapy), if keeping "adjunctive treatments" is the background overview, consider changing the name of domain f (Coordinated, complimentary).

2. Under OBJECTIVES, line 32 e. Psychosocial and vocational treatments.

• "Vocational treatments", as a subfield of occupational therapy to help patients remain in or return to the workforce, is very specific as opposed to psychosocial (generalized). Furthermore, while psychosocial advising is a key element of vocational treatment, we feel since the PICO in this case is a potentially different and specific audience (as not all RA patients can work), we recommend subcategorizing Vocational under Psychosocial, in lieu of a shared domain title.

• Depending on the context, "vocational" could fall under rehabilitation.

Considerations to PICO that may impact literature searches (Ref: Line 106 - PICO questions will be revised into drafted recommendation statements)

Nutritional Q1: (Line 157) "Should patients with RA use a formally defined diet?" The word diet often has a negative connotation to patients ("You should be on a diet – lose weight, you'll be healed.") Also, diet suggests temporary change, not a lifestyle change. Suggestion: dietary regimen.

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Q1 & Q2 – dietary related

• Lines 163 and 174 "O" mentions treatment-related harms. Is this harm related to this intervention or to existing treatment interaction? Suggestion: treatment-related harms, considerations of contraindications with existing treatments.

• Lines 165 and 176 – "Potential effect modifiers/subgroup – why isn't comorbidities or multimorbidity (other diseases with medications or therapies that could contradict) mentioned?

Q3 - Should patients with RA who are overweight or obese receive a weight loss intervention?
Line 187 - Potential effect modifiers/subgroup analyses currently says "None". However, given OA can be caused by continued pressure on weight bearing joints, it's possible an obese RA patient may also have OA/degeneration to consider in any intervention.

Psychosocial and vocational

• As mentioned previously, we strongly believe these are two separate domains OR should be nested under either Psychosocial or Rehabilitation (if part of returning to the work force).

• The list of self-management programs is not consistent with vocational therapy (peer mentoring/support groups?).

• Furthermore the "O" list (generally copy/pasted from other PICOs) seems to have just inserted "work status" to accommodate the addition to the domain. Is it relevant in the broader psychosocial umbrella? If so, what about those who work from home, are domestic engineers, etc.? Again, this needs to be split in two. Perhaps vocational is its own domain entirely.

Q 21 – (Line 372) Should patients with RA, who are currently employed or want to become employed, use vocational rehabilitation?

• Shouldn't this include "or returning to the workforce"?

Q 22 –Should patients with RA, who are currently employed or want to become employed, receive work site evaluations and modifications?

• We are certain those on the recommendations panel are aware that in Europe these recommendations are engrained and enforced under 'social responsibility' (in their governance as a union). While systems differ, there are many studies not only on implementation but also refusal by patients to use these if given the opportunity (fear of being judged, losing promotions, etc.). (We have much more we can add to this, from a patient perspective, if needed).

Other Q 28. Should patients with RA who are current smokers engage in a smoking cessation program? • Since persons with RA who smoke tend to have worse outcomes, rationale for inclusion is understandable. If this does not fall under any of the current domains, and the team still wants to include it, perhaps it could be its own domain, leaving room open for future expansion into CBD, alcohol use, or vaping?

Methods

We appreciate that patients are incorporated into the process, both phases, and including a patient panel who will separately convene prior to the voting panel meeting. We would like the committee to consider the following in the design of this phase:

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• Recommended: the two patients from the voting panel should be included as observers and clarification liaisons and should not be included in the total number of patients participating in the panel.

• Recommended: Patients in the panel should represent the genuine patient perspective (i.e., are not also rheumatologists, who can bias the responses).

• Question: What methods are put into place to ensure the perspectives, opinions, concerns expressed in the patient panel are assessed and properly presented and considered "days later" in the voting panel meeting?

Re: the Voting Panel Will there be weighted voting (for example, if both patients vote higher than the remaining panel, yet they are the only two voting higher, will their perspectives be outweighed by other stakeholder participants?

Additional Considerations

There is no doubt the efforts by the ACR to provide recommendations to help integrate complimentary means of therapy to the treatment regimen will be well-received by the RA community. However, there will still be obstacles and challenges to overcome that will be outside of our control (for example insurance regulations and health disparity challenges). These challenges may heighten as recommendations are provided and patients are not able to gain access.

Examples:

• Q 9 and Q 10: (Bracing/splinting/orthoses) our reviewers (both with experience using these items) stressed in some cases this requires OT and follow up that insurance may not cover (amount of time/length of use).

• Q 18: Should patients with RA participate in a comprehensive physical therapy program? This was a topic covered at ACR22, our organization did an entire session report on it, inclusive of conversations with patients. Most of us felt this option was unrealistic, as we could not incorporate PT into our regular therapeutic management plan due to insurance barriers. There was also a question at what state would this happen (onset, late disease progression, etc.), which we understand the committee designing the recommendations will consider.

In saying this, we know the first step to changing access to alternate therapies is to provide insurance companies robust, credible data alongside guidance from a reputable source. So thank you to the ACR for taking the lead to provide both!

Again, we thank the ACR for this opportunity. If you have any clarifying questions, please contact Tiffany Westrich-Robertson at tiffany@aiarthritis.org. If the ACR is still recruiting for members of the patient panel, we hope you will consider a member from our AiArthritis team.

- Name: Akemi Torin
- Institution: na
- > Position: na
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

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I am just an RA patient who believes practicing an anti-inflammatory diet leads me to the remission.

Would you consider to analyze the following paper in your perspective and include the guideline?

I wasted too much time to reach the anti inflammatory diet since my rheumatologist did not gave me such information at all when I was diagnosed. I feel if I were practicing the diet much sooner, the time to remission would have taken much shorter. I am so sorry that other people who had no knowledge about it are suffering while eating junk foods, sweets innocently. I believe ACR has responsibilities to educate the importance of diet to your patients.

Akemi Torin, the patient

Effect of Anti-Inflammatory Diets on Pain in Rheumatoid Arthritis: A Systematic Review and Meta-Analysis

https://www.mdpi.com/2072-6643/13/12/4221

- > Name: Christy Park
- > Institution: Univ Tennessee Graduate School of Medicine
- > **Position:** Assistant Professor
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

I am very excited to hear of this timely initiative from the ACR. Our field of rheumatology is particularly appropriate place to apply integrative strategies to conventional treatments in patient care to achieve optimal outcomes. The topics to be reviewed are great place to start. I support this endeavor, as many of us in ACR that practice integrative medicine!! thank you!

- Name: Micah Yu
- > Institution: Dr. Lifestyle Clinic
- **Position:** Rheumatologist
- > **Disclosure (optional):** I have nothing to disclose.

Comment:

Respondent skipped this question