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BRIEF REPORT

Assessing Patient Values and Preferences to Inform the 2023 American College of Rheumatology/American College of Chest Physicians Interstitial Lung Disease Guidelines

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Objective. Patient engagement is critical to clinical practice guideline (CPG) development. This work presents our approach to ascertaining patients' values and preferences to inform the American College of Rheumatology guidelines for screening, monitoring, and treatment of interstitial lung disease (ILD) in people with systemic autoimmune rheumatic diseases (SARDs).

Methods. We conducted a cross-sectional qualitative study of a purposefully sampled Patient Panel using a modified content analytic approach. The study team reviewed text transcripts from the Patient Panel discussion to identify themes and develop a clustered thematic schema.

Results. Twenty-one patients (75% women) participated, with a mean age of 53 years (range 33–73). Patients had one or more SARDs: systemic sclerosis (38%), Sjögren disease (38%), idiopathic inflammatory myopathy (33%), rheumatoid arthritis (24%), and mixed connective tissue disease (10%). We identified 10 themes in 4 thematic clusters: communication, screening and monitoring, treatment goals, and treatment adverse effects. Patients prioritized recognizing ILD symptoms, importance of ILD screening and close monitoring, goals of survival and improving quality of life, and willingness to accept treatment risks provided that there is close communication with providers. Patient representatives shared patients' priorities and insight at the Voting Panel meeting, influencing multiple guideline recommendations.

Conclusion. Patient engagement fosters a holistic approach to CPG development, leading to recommendations aiming for the best clinical outcomes while prioritizing outcomes important for patients. The patient-identified themes played a critical role in ILD guideline development and provide core elements for shared decision-making as clinicians make management and therapeutic decisions with patients with SARD-associated ILD.

INTRODUCTION

Clinical practice guidelines serve a fundamental role in current medical practice, with experts systematically evaluating the available evidence and making recommendations that balance benefits against harms and consider patient preferences.[1] Clinical decisions with low-quality evidence or closely balanced benefits/harms are particularly sensitive to patients' values and preferences.

The National Academy of Medicine standards for trustworthy guidelines require patient participation on development committees

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SIGNIFICANCE & INNOVATIONS

- Patient values and preferences regarding interstitial lung disease (ILD) screening, monitoring, and treatment identified from a diverse Patient Panel had an important influence on the 2023 American College of Rheumatology (ACR)/American College of Chest Physicians (CHEST) ILD Guidelines.
- Several themes had a particularly notable influence on Voting Panel discussions and provide valuable guidance for clinician discussions with patients: the importance of strong communication with and among providers; a preference for screening; and the patient prioritization of survival, quality of life, and adverse effects.
- This study describes the current ACR/CHEST model of patient engagement and provides an example for guideline developers in convening and implementing patient panel focus groups.

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and as external reviewers. Similarly, the international standards for guidelines recommend patient involvement.[2,3] Unfortunately, patient involvement in guidelines remains inconsistent and is often superficial when included.[4]

Since 2015, the American College of Rheumatology (ACR) requires patient engagement in all of its guidelines.[5] To identify patient values and inform the 2023 ACR/American College of Chest Physicians (CHEST) Guidelines for the screening, monitoring, and treatment of interstitial lung disease (ILD) in people with systemic autoimmune rheumatic diseases (SARDs), a Patient Panel was convened including representation from all five SARDs of interest; three Patient Panel members were also included on the Voting Panel.[6,7] The objectives of this manuscript are to (1) provide an example for guideline developers on processes for convening and implementing patient panel focus groups, (2) highlight the importance of patient values and preferences in guideline development, and (3) provide clinicians with insight into patient priorities relevant to shared decision-making.

PATIENTS AND METHODS

Study design. We conducted a cross-sectional qualitative study using a modified content analytic approach. This approach has been successfully used in SARDs to identify multidimensional and underlying complex latent constructs that are not easily measured.[8,9]

Sample. Patients with five SARDs of interest (rheumatoid arthritis [RA], systemic sclerosis [SSc], idiopathic inflammatory myopathies [IIM], mixed connective tissue disease [MCTD], and Sjögren disease [SjD]), including those with and at risk of ILD, participated in the 2023 ACR/CHEST ILD Guidelines Patient

Panel.[6,7] Patient nominations came from the 2023 ACR/CHEST ILD Guidelines Core Team, email with individuals from previous ACR guideline Patient Panels, United States (US) rheumatology practice groups, rheumatology and pulmonary colleagues of the Core Team, and several disease foundations. Patient Panel applications included demographics, SARD duration, ILD presence or absence, statement of interest, and a treating physician's attestation of ILD presence or absence. A diverse Patient Panel was purposively sampled based on age, gender, race, specific SARD, ILD presence, disease duration, and US geography.

Patient Panel meeting. Three Core Team rheumatologists (RDM, MBB, and MDG), supported by two ACR staff members experienced with ACR guideline development processes (Amy Turner and Regina Parker), facilitated the four-hour virtual Patient Panel meeting. Patients received an evidence report synopsis and participated in an orientation webinar, providing information and guidance on interpreting the evidence report before the Patient Panel meeting.

The rheumatologist facilitators presented an outline for the overall meeting objectives and introduced three key concepts: (1) limitations in available evidence, often leading to uncertainty regarding level of benefit an intervention may provide; (2) the importance of identifying the highest-priority outcomes for patients; and (3) the need to balance risks and burdens with the benefits of treatments, testing, and procedures. A facilitated discussion started with open-ended guiding questions (Supplementary Tables A and B). The facilitators provided screening and monitoring definitions and described potential screening risks and burdens, including (1) risk of detecting mild ILD that may never progress and (2) risks of incidental findings leading to more testing. In response to discussion prompts by physician facilitators, Patient Panel members shared their stories of presenting symptoms, diagnostic testing, and treatment experiences. Facilitators used open-ended prompts to expand discussion points and engage other panelists.

Data and analysis. ACR staff members recorded comments, including direct quotations made by Patient Panel members. The text transcripts were independently and repeatedly reviewed by the facilitators for accuracy, to achieve immersion, and to obtain a sense of the whole data set. Each facilitator noted themes reflective of thoughts verbalized during the meeting. The results of the three independent analyses were compared to each other and to the ACR staff meeting summary, then organized into meaningful thematic clusters pertaining to screening, monitoring, and treatment. The facilitators resolved disagreements through discussion and consensus. Aggregate results were distributed to Patient Panel members for both comments and confirmation of the analytical thematic schema and accurate summation. This research triangulation was employed to enhance credibility of

the findings and ensure the analysis reflects the full breadth and depth of the data.[10,11]

Voting Panel meeting. To represent patients' values, preferences, and concerns, three Patient Panel members (AA, CMF, and KN) were included as patient representatives on the 2023 ACR/CHEST ILD Guidelines Voting Panel.[6,7] Patients under the care of any of the Core Team or Voting Panel physicians were excluded from participation in the Voting Panel. The Voting Panel meeting occurred virtually over four days. At the start of the discussion for each recommendation, the meeting Chair asked the patient representatives to share their comments. All Voting Panel members, both patients and physicians, voted on each recommendation.

RESULTS

The Core Team received 24 applications and selected 21 patients to comprise the Patient Panel. The median age was 53 years (range 33–73 years); 16 were women (76%), 14 were White (67%), 7 were Black or multiracial (33%), and 2 were Hispanic (10%) (Table 1). ILD was present among 17 patients (81%); underlying SARDs included SSc (n = 8), SjD (n = 8), IIM (n = 7), RA (n = 5), and MCTD (n = 2), with patients often carrying more than one diagnosis. US geographic regions represented included the East Coast (n = 8), West Coast (n = 2), Midwest (n = 1), and South (n = 10). Disease severity varied, with six patients disclosing features of severe ILD (prior transplantation, oxygen dependence, or rapidly progressive ILD).

Thematic clustering. During the Patient Panel discussion, 10 themes emerged. These were clustered into 4 thematic clusters: "communication" (n = 1), "screening and monitoring" (n =

Table 1. Summary of Patient Panel characteristics*

Characteristics	Patients (n = 21), n (%)
Age, median [range], y	53 [33–73]
Female	16 (76)
Race	
White	14 (67)
Black	5 (24)
Multiple or unspecified	2 (10)
Hispanic	2 (10)
ILD diagnosis[a]	15 (71)
Autoimmune rheumatic disease[b]	
Systemic sclerosis	8 (38)
Sjögren disease	8 (38)
Idiopathic inflammatory myopathy	7 (33)
Rheumatoid arthritis	5 (24)
MCTD	2 (10)

* ILD, interstitial lung disease; MCTD, mixed connective tissue disease.
[a] Each patient submitted a physician attestation to define presence or absence of ILD.
[b] Percentages add up to >100% because some patients had more than one autoimmune rheumatic disease.

3), "goals of treatment" (n = 3), and "adverse effects of treatment" (n = 3) (Table 2, Figure 1).

Communication. One recurring overarching theme was the importance of close communication. This was emphasized in two circumstances: among providers to coordinate care and establish "care teams" and between providers and patients regarding disease manifestations, prognosis, and treatment risks and benefits. Patients expressed (1) the need for comprehensive disease information, (2) greater tolerance for treatment side effects when presented with clear expectations, and (3) need for continuous dialogue with their treatment team.

Screening and monitoring. Three important themes were identified (Table 2). First, patients noted their challenges with recognizing ILD symptoms, noting the importance of having providers ask about symptoms in different ways and educating patients about their diseases. Second, patients generally favored screening to identify ILD early despite the burdens of screening, recognizing that screening may detect subclinical ILD that might never cause symptoms or incidental findings leading to further testing. Third, patients appreciated information from monitoring tests, such as pulmonary function tests (PFTs) and high-resolution computed tomography of the chest (HRCT chest), providing another way to gauge their health. They acknowledged frustration with the variability of PFTs and noted that 6-minute walk distance testing often did not match their daily life activities (eg, hills, stairs).

Goals of treatment. Three themes emerged regarding treatment goals (Table 2). Patients noted that survival was the priority with severe or life-threatening disease. Beyond survival, quality of life was of utmost importance, with a desire to return to work and a pre-disease functional level. Several noted that cough, in addition to dyspnea, reduced quality of life, affecting their ability to laugh and talk. Patients also recognized the occasional need to find a "new normal" in which the goal was stabilization rather than improvement.

Side effects of treatment. Three themes emerged around medication side effects (Table 2). Patients indicated a willingness to accept significant side effects for effective treatment, especially if providers maintained close communication. Patients also recognized that side-effect tolerability varied substantially by disease severity, illness duration, and comorbidities. In cases of severe or life-threatening disease, patients had less concern about potential side effects, although they still highlighted the importance of being well informed (eg, infertility, gastrointestinal issues). General agreement existed that reducing prednisone use and dose was a high priority, although experiences with short-term prednisone varied significantly from feeling very well to experiencing substantial side effects.

Voting Panel Meeting. Patient Panel input influenced recommendations developed by the Voting Panel. For example, during Voting Panel discussions of screening, strong patient

Table 2. Key themes from the Patient Panel regarding preferences and values for SARD-associated interstitial lung disease screening, monitoring, and treatment*

Theme	Representative quote
Communication	
Communication with providers about disease manifestations, disease course, and treatment risks and benefits is critical.	"*My doctor helps me see the big picture of how I could benefit from the medicine, what we are trying to avoid longer term.*"
	"*I have a great care team, but sometimes they don't tell me all of the side effects.*"
	"*Decision trees/algorithms are important, not only for physicians but also for patients to understand, so it's more transparent, and patients can make more informed decisions.*"
Screening and monitoring	
Recognizing the symptoms of interstitial lung disease can be challenging, and patients may not always think to mention new symptoms.	"*With autoimmune diseases, things just come up, and sometimes you don't even think to mention it, as a patient. So, screening can be important, even just on history, to catch things that may otherwise be overlooked.*"
Benefits of early diagnosis outweigh potential burdens and adverse outcomes from screening.	"*I thought [my] shortness of breath was just fear and dermatomyositis. Early detection is very key and important.*"
PFTs and CT are helpful for monitoring disease progression and can be reassuring, although the inexact nature of PFTs can be frustrating.	"*I personally don't mind the monitoring and lab tests. I pore over them. I want to keep on top of what's going on with my body. It's reassuring to me personally.*"
	"*My FVC might improve by 3%, but I can no longer walk up a flight of stairs without becoming breathless. During treatment and monitoring—the data doesn't [sic] always align with quality of life and what patients value; this isn't something that has been focused on in my care.*"
Goals of treatment	
With severe and life-threatening illness, survival and stabilization of disease is the priority.	"*My goal was to survive, then achieve small life goals with my children, go back to work, talk without choking, smell flowers again.*"
	"*I am okay with taking multiple medicines if my doctor recommends it and it will benefit me or have a positive outcome for me; I will deal with side effects after.*"
Beyond survival, quality of life is very important, with a goal of returning to previous activity and working.	"*I want life to be like what it was and have the quality of life I had before… I don't think I will get there but haven't fully accepted that yet.*"
Patients recognize a need, at times, to find a "new normal," in which stabilization is the goal.	"*It's hard to come to terms with your new normal but it was a relief when I did, in order to move forward…[I] had to change my goals.*"
Side effects of treatment	
When disease is severe or life-threatening, side effects are less of a consideration, although communication about potential risks (eg, infertility) remains important.	"*If you aren't stable, you're just in survival mode.*"
	"*I have been on ALL of the meds you have mentioned over the course of my disease journey—in the beginning I took whatever they gave me because I just wanted to stop progression. Now 21 years in, I am more selective, in what I am willing to go along with. In the end it depends on how sick I am and how badly I need to manage my disease symptoms.*"
Acceptable risks depend on illness duration and severity; some may be willing to tolerate significant side effects if a treatment is effective.	"*To me the tradeoff was worth it, to not get worse. It is what you can deal with personally…Where you are in your journey impacts your decisions.*"
Reducing prednisone is a high priority, recognizing that side effects vary substantially from person to person.	"*I hate prednisone, it's a pseudo-sense of wellness.*"
	"*I felt great on prednisone.*"

* CT, computed tomography; FVC, forced vital capacity; PFT, pulmonary function test; SARD, systemic autoimmune rheumatic disease.

preference for early detection of ILD, even if ILD might be subclinical or might not progress over time, was an important factor in recommendations for screening patients at high risk of ILD using PFTs and HRCT chest.

Another influential contribution made by the Patient Panel during Voting Panel discussions related to cyclophosphamide use. There was substantial variability around cyclophosphamide among the physician Voting Panel members after reviewing the available data, given significant concern about potential adverse effects (infection, cytopenias, hemorrhagic cystitis, and infertility).[12] Patient Panel representatives, however, voiced their willingness to receive cyclophosphamide despite these risks if it could be life-saving. Again, patients emphasized the importance of upfront toxicity discussions, specifically around infertility and infections. Influenced by this input, the Voting Panel conditionally recommended cyclophosphamide as one of the first-line treatment options for SARD-ILD.

As a third example, the Patient Panel noted that gastrointestinal side effects (specifically diarrhea) were a significant consideration for nintedanib, with a need to plan life's activities in close proximity to a bathroom. Patients were, however, willing to accept gastrointestinal side effects if actively discussed and closely monitored by their physicians, particularly if the medication could
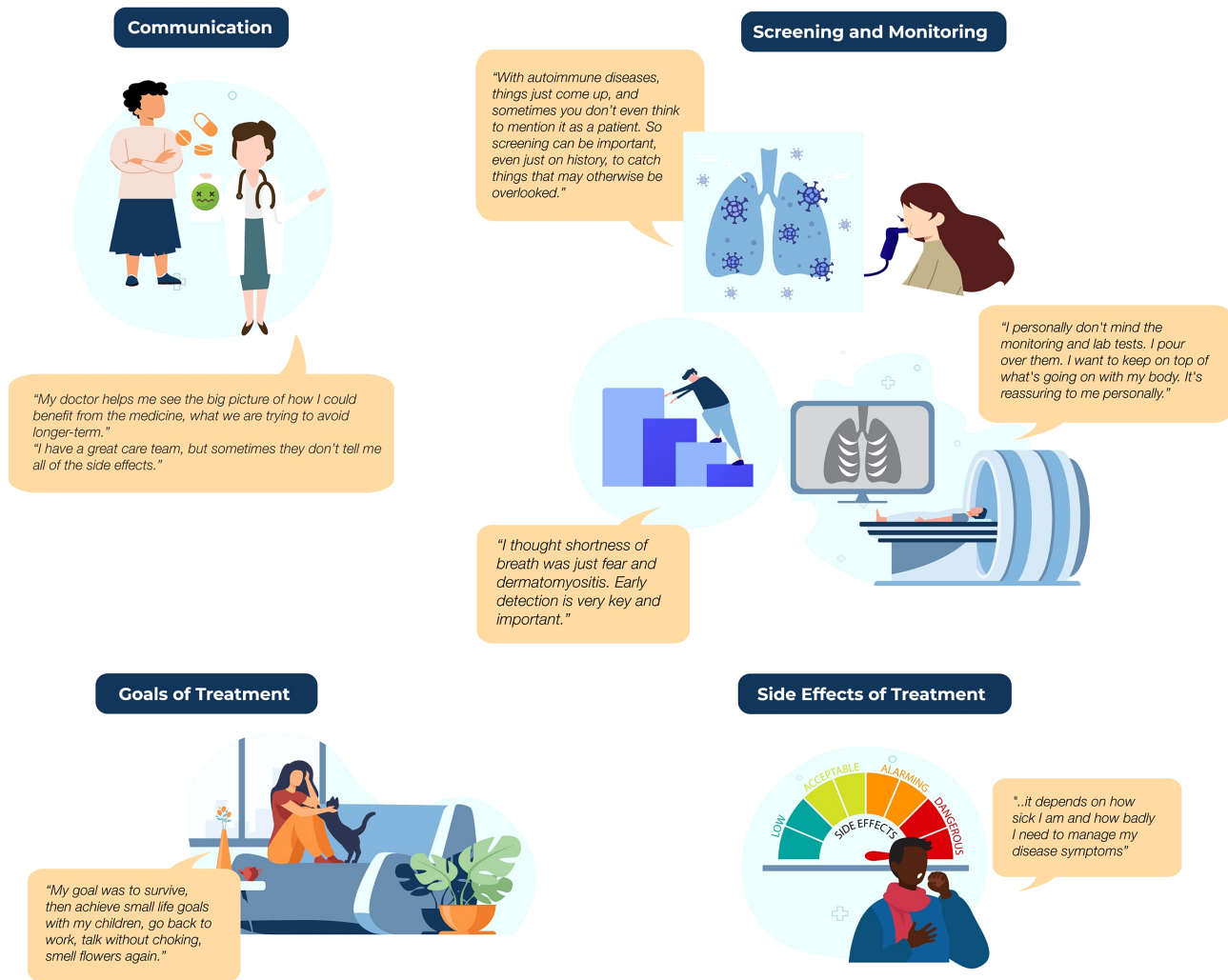
Figure 1. Illustrative summary of key themes from the Patient Panel for SARD-associated interstitial lung disease screening, monitoring, and treatment. SARD, systemic autoimmune rheumatic disease.

provide substantial benefit. This input, combined with the evidence review, contributed to the Voting Panel recommending nintedanib as a first-line treatment option in SSc-ILD but conditionally recommending other medications (including mycophenolate, rituximab, cyclophosphamide, and tocilizumab) over nintedanib.

DISCUSSION

A large Patient Panel was convened to inform the 2023 ACR/CHEST ILD Guidelines for the screening, monitoring, and treatment of ILD in people with SARDs and led to the identification of 10 patient-important themes relating to communication, screening and monitoring, goals of treatment, and treatment-related harms.[6,7] These themes, along with input from the three patient members of the Voting Panel, provided important contributions to Voting Panel discussions and final recommendations. Distinguishing these themes provides helpful context for the

2023 ACR/CHEST ILD Guidelines and can inform physicians, creating increased awareness around patient values and preferences when managing patients with SARDs who have or are at risk for ILD.[6,7]

Evidence supports patient involvement in guideline creation. Armstrong et al designed a unique randomized controlled trial to evaluate the influence of patient inclusion on a dementia guideline, finding that patient involvement led to important differences in guideline scope, outcome selection, implementation, and dissemination.[13] Nonetheless, patient involvement in guidelines work remains poorly implemented, and when patients are included, it is often only superficial. Of 101 guideline organizations evaluated in 2017, only 8 required patient or public involvement.[4] A 2022 systematic review of patient and public involvement in musculoskeletal guidelines found that 6 of 10 evaluated guidelines had low-level involvement.[14]

The ACR has included Patient Panels in its guidelines since 2015. Since then, three ACR guidelines have published findings

and experiences from their Patient Panels.[15–17] Although the overall methodology was similar to previous guideline Patient Panels, the broad scope and large number of population, intervention, comparator, and outcomes (PICO) questions in the ILD guidelines compared to previous guidelines led us to focus our Patient Panel on eliciting key values and preferences rather than individually reviewing each PICO question. This approach allowed a capture of preferences applicable to a wide set of both PICO questions and clinical scenarios.

The Patient Panel convened for the 2023 ACR/CHEST ILD Guidelines comprised a large number of patients with representation of age, sex, race/ethnicity, and associated SARDs.[6,7] This group worked collaboratively, anchoring on self-reflection regarding personal illness experiences as well as group discussion of shared experiences. The scope of this Patient Panel differed from prior work because this group represented five different SARDs and included those at risk for ILD as well as those with ILD, thus broadening the perspective. Patient experiences were comparable across different diseases, and similar preferences and values were shared by many; key areas of variability included risk tolerance (dependent on disease severity) and experiences with glucocorticoids.

Several themes had a particularly notable influence on Voting Panel discussions and are also important for physicians to recognize. Patients highlighted the importance of strong communication with and among their providers as well as the desire to be provided with as much information as possible about their disease. A preference for ILD screening and monitoring despite the burdens of testing influenced Voting Panel discussions about screening and monitoring. Although physicians may at times de-emphasize potential medication side effects during patient counseling, patients saw communication about side effects as critically important; patients expressed a willingness to accept potentially serious side effects if a medication could help their disease improve, as long as they were informed and could work with providers to identify and manage side effects. Willingness to accept side effects was noted to vary substantially among patients, but those with greater disease severity expressed greater willingness to accept potential risks. These perspectives influenced discussions about medications such as antifibrotics, associated with significant gastrointestinal side effects, as well as for therapies such as cyclophosphamide with potentially serious adverse effects. Finally, the importance of both survival and quality of life, including symptoms such as cough that may interfere substantially with daily activities, are important for physicians to consider and discuss with patients.

Several limitations are important to note. Although the Patient Panel was large, goals and values likely vary substantially among individuals, and the Panel may not represent the views of all patients. Although the Patient Panel was demographically diverse, there was less certainty about the diversity of socioeconomic status and health literacy, and the geographic areas were predominantly Eastern and Southern United States. With only a small number of patients without ILD included, the views on screening for ILD may have been skewed by a patient group enriched for those with ILD and thus a more severe disease course. Additionally, this study does not include a systematic qualitative analysis or consideration of financial costs.

Study strengths include the size of the Patient Panel, particularly notable for the representation of five different SARDs across a spectrum of ILD from those at risk for ILD to those with rapidly progressive ILD and lung transplantation. Patients were included in the entire voting process. All votes on guideline recommendations, including patients and physicians, were anonymous and held equivalent weight.

In conclusion, this study describes the current ACR model of patient engagement and its impact on shaping clinical practice guidelines. In the 2023 ACR/CHEST ILD Guidelines, the Voting Panel included patient representatives and carefully considered the values and preferences expressed by the Patient Panel regarding communication, screening and monitoring, treatment goals, and treatment side effects.[6,7] In at least three cases, patient input played a decisive role in the outcome of the Voting Panel's recommendations. In addition to playing an important role in guideline development, patient goals and values also serve as a starting place for providers caring for patients with or at risk for ILD because they work to distinguish each individual's specific preferences and develop diagnostic and therapeutic plans through shared decision-making.[18]

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr Mirza had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Mirza, Bolster, Johnson, Allen, Chung, Danoff, Falardeau, Guyatt, Ivlev, Khanna, Nesbitt, Turner, George.
Acquisition of data. Mirza, Bolster, Johnson, Allen, Chung, Falardeau, Nesbitt, Turner, George.
Analysis and interpretation of data. Mirza, Bolster, Johnson, Allen, Bernstein, Danoff, Ivlev, Khanna, Uhl, George.

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