2021

Investigation into barriers to guideline adherence in axial spondyloarthritis / ankylosing spondylitis

BOSTON UNIVERSITY

SCHOOL OF MEDICINE

Thesis

INVESTIGATION INTO BARRIERS TO GUIDELINE ADHERENCE IN AXIAL SPONDYLOARTHRITIS / ANKYLOSING SPONDYLITIS

by

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B.S., Boston University, 2017

Submitted in partial fulfillment of the

requirements for the degree of

Master of Science

2021

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INVESTIGATION INTO BARRIERS TO GUIDELINE ADHERENCE IN AXIAL SPONDYLOARTHRITIS / ANKYLOSING SPONDYLITIS

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ABSTRACT

Background: A recent study showed low adherence to the published treatment guidelines for axial spondyloarthritis (axSpA) / ankylosing spondylitis (AS). The aim of this study was to determine barriers to guideline adoption that are specific to axSpA / AS.

Methods: A systematic literature review was conducted to learn which general barriers to guideline adoption have been proposed in the literature. A second systematic literature review was conducted to identify strategies to increase response rates in the deployment of electronic surveys. A survey was developed based on the findings from the literature, aimed to interrogate the perspective of rheumatologists on barriers within their practice. A focus group was conducted to gain insight from experts in the field.

Results: The SLR identified 22 primary research articles on barriers to guideline adherence in axSpA / AS, almost all of which focused on drug therapy or physical therapy / exercise. Only 1 of the 22 studies was conducted in the US. The SLR on survey deployment methods identified 52 articles, 40 of which included sufficient information to calculate response rates. The mean response rate for online surveys distributed to rheumatologists was 0.33 with no statistically significant differences between surveys that contacted physicians once, twice or three or more times. From the literature, a framework was synthesized that captures relevant barriers to guideline adherence in 5 categories: guideline factors, health professional factors, patient factors, practice setting

factors and societal factors. A survey was drafted, with questions targeting each of the five categories included in the framework. Suggestions from the experts participating in the focus group resulted in a revised survey consisting of 33 questions. Additionally, the focus group proposed ideas for survey dissemination, including strong support for the utilization of social media in addition to email invitations.

Conclusion: The literature on barriers to guideline adherence in axSpA / AS is limited, in particular in the domains of disease activity monitoring, osteoporosis screening / monitoring, and other non-pharmacologic therapies. Only a single US study on barriers to guideline adherence in axSpA / AS was identified, indicating the need for more research in this field. The focus group provided firsthand perspective, allowing for modification of the survey to capture the most informative data. The focus group also provided insight into survey dissemination methods and ideas to maximize participation. The SLR on electronic survey deployment suggests an expected response rate of 0.33 for surveys administered to rheumatologists via email.

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LIST OF ABBREVIATIONS

ACR…….American College of Rheumatology

AS……..ankylosing spondylitis

ASDAS……...ankylosing spondylitis disease activity score

axSpA……axial spondyloarthritis

BASDAI…….Bath ankylosing spondylitis disease activity index

BU…….Boston University

CDAI……...clinical disease activity index

CRP……...C-reactive protein

DAS28……....28-joint disease activity score

DXA…….dual-energy x-ray absorptiometry

EMR…….electronic medical records

ESR……erythrocyte sedimentation rate

HLA……...human leukocyte antigen

ICD……international classification of diseases

NSAIDs…….non-steroidal anti-inflammatory drugs

PT…….physical therapy

RAPID3……...routine assessment of patient index data 3

SAA……..Spondylitis Association of America

SLR……...systemic literature review

SPARTAN……...Spondyloarthritis Research and Treatment Network

TNF……..tumor necrosis factor

INTRODUCTION

Axial Spondyloarthritis

Axial spondyloarthritis (axSpA) is an inflammatory disease predominantly affecting the spine and sacroiliac joint that includes radiographic and non-radiographic forms. The radiographic form is also known as ankylosing spondylitis (AS) and is detectable by X-ray scans of the sacroiliac joints and / or the spine. AS is characterized by vertebral inflammation, which may lead to bone growth and fusion, detectable by X-ray scans of the sacroiliac joints and / or the spine.[1] Axial spondyloarthritis has been found to mainly affect tissues that are exposed to mechanical strain, such as the sacroiliac joints, the spine and the entheses.[2] As disease progresses, the non-radiographic form may transition into the radiographic form, as sequelae of sacroiliitis become noticeable on radiographs, though this is not the case for all patients. There is a strong genetic link between HLA-B27 and axSpA, and while the exact mechanism is still unclear, HLA-B27 positivity is found in significantly higher prevalence in patients with AS compared with the general population.[1] In fact, 80-90% of patients with AS are HLA-B27 positive compared to 8–10% of the total white population.[1] HLA-B27 status is also associated with disease severity as it pertains to structural damage to the joints and spine.[1] According to Sieper and Poddubnyy, prevalence estimates for axSpA range from 0.32% to 1.4%" across different geographic regions.[2]

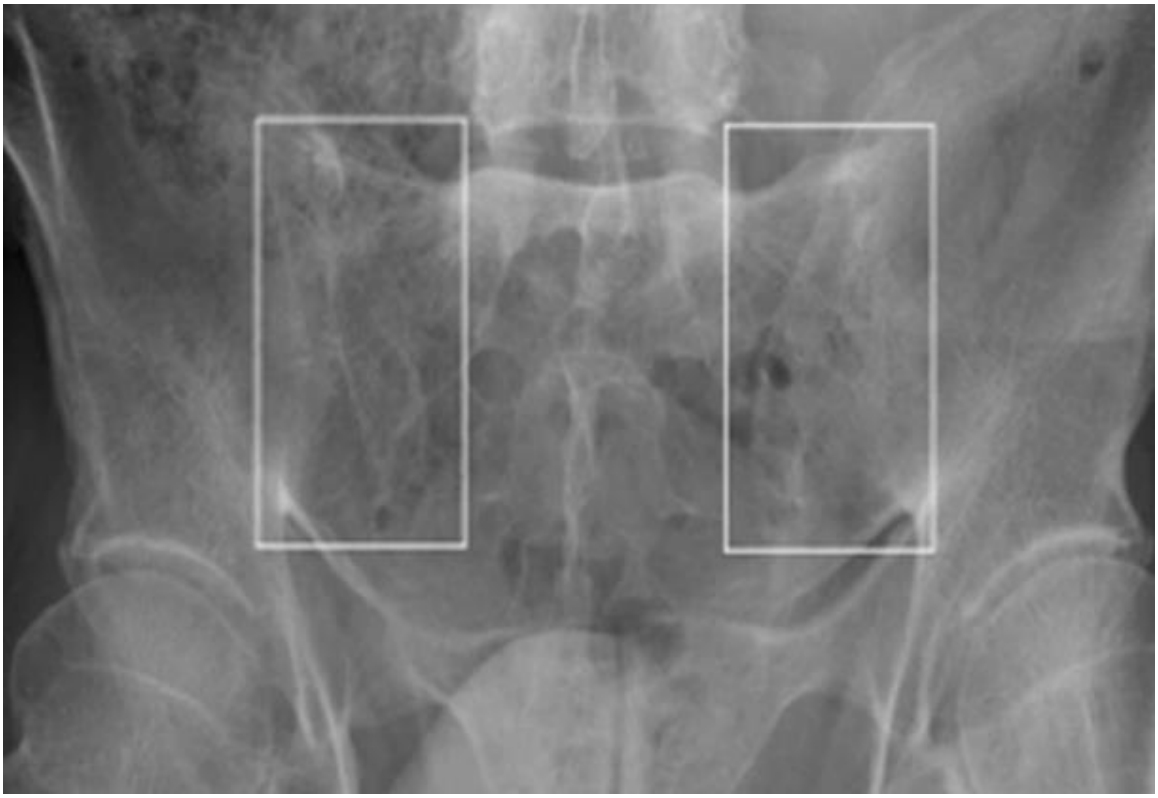

Figure 1. Radiographic Sacroiliitis in Ankylosing Spondylitis. Radiograph of the pelvis showing fusion (ankylosis) of the sacroiliac joints characteristic of ankylosing spondylitis.[3]

Treatment Recommendations for axSpA / AS

In 2016, the American College of Rheumatology (ACR), the Spondylitis Association of America (SAA), and the Spondyloarthritis Research and Treatment Network (SPARTAN) published evidence-based treatment recommendations for patients with AS and non-radiographic axSpA.[4] In 2019, the guidelines were updated in response to newly available medications, which caused reexamination of several recommendations, as well as some additions.[5] According to the ACR / SAA / SPARTAN guidelines, the goal of therapy is to "alleviate symptoms, improve functioning, maintain the ability to work, decrease disease complications, and forestall skeletal damage as much as possible."[5]

Pharmacotherapy is a major focus of the recommendations. Forty-one of the eighty-six specific recommendations focus on pharmacologic treatment, providing guidance on the use of non-steroidal anti-inflammatory drugs (NSAIDs), tumor necrosis factor (TNF) and IL-17A inhibitors, glucocorticoids, tofacitinib, sulfasalazine, and methotrexate. In the guideline publication, Ward et al. further discuss the management of comorbidities, as well as recommendations for physical therapy (PT) and back exercises in patients with both active and stable disease status. A section of the guidelines is dedicated to recommendations for measuring disease activity as well as screening recommendations for osteopenia / osteoporosis.[5]

Adherence to Non-Pharmacologic Treatment Recommendations for axSpA / AS

The following non-pharmacological management recommendations are taken from the 2019 updated ACR / SAA / SPARTAN guidelines, and are identical to the 2016 guidelines[5]:

"20. We strongly recommend treatment with physical therapy over no treatment with physical therapy."

"31. We conditionally recommend advising unsupervised back exercises."

"42. We conditionally recommend the regular-interval use and monitoring of a validated AS disease activity measure."

"43. We conditionally recommend regular-interval use and monitoring of CRP concentrations or ESR over usual care without regular CRP or ESR monitoring."

"45. We conditionally recommend screening for osteopenia / osteoporosis with DXA scan over no screening."

Recently, Patel et al. conducted a retrospective review of medical records at Partners HealthCare, which focused on adherence to the recommendations for disease activity monitoring, PT and osteoporosis screening in adults with AS.[6] Partners HealthCare is a large hospital network in the Boston metropolitan area that includes Brigham and Women's Hospital and Massachusetts General Hospital. Medical records were accessed via Partners HealthCare Epic electronic medical records (EMR) system. In order to be included, patients had to have ≥3 ICD-9 or 10 codes for AS, an imaging confirmed diagnosis of AS, and at least one rheumatology clinic visit for AS between July 2016 and June 2019. 304 patients met these inclusion criteria, and 564 visits were analyzed. Patel et al. discovered a low frequency of adherence to the ACR / SAA / SPARTAN recommendations for disease activity monitoring, PT and osteoporosis screening.[6] They found that a clinical disease activity measure was recorded at 95 / 564 (16.9%) visits, an inflammatory marker blood test (CRP and / or ESR) was ordered at 294 / 564 (52.1%) visits. Evidence of completed, on-going, recommended, or prescribed PT for AS could be found in the records for 50 / 564 (8.9%) visits, while home back exercises were discussed or recommended at 42 / 564 (7.4%) visits. 58 / 304 (19.1%) patients had a DXA scan(s) at any time prior to June 30, 2019. The current study is a follow-up to Patel et al. to begin understand the barriers to implementation of AS treatment guidelines in clinical practice.

General Barriers to Clinical Guideline Adherence

Many studies have looked at guideline adherence in general, from a non-disease specific standpoint. In fact, several studies have developed frameworks which aim to capture and classify the different barriers encountered in clinical practice.

Cabana et al.[7] performed a systematic literature review extracting data from 76 articles, after initially screening 5658 articles[7]. They identified 3 major groups of barriers which they categorized as pertaining to knowledge, attitude or behavior. Knowledge barriers include physician lack of awareness of or familiarity with the guidelines. Attitude barriers include physician lack of agreement, either with the guidelines as a whole or with specific aspects of the guidelines. Also included in this category is a lack of outcome expectancy by the physician, i.e., the idea that following the guideline will not have an impact on disease outcomes, as well as lack of motivation for the physician to comply with new guidelines, which may in part be due to the comfort with the current practice in place. Lastly, a lack of self-efficacy on the part of the physician is also considered an attitude barrier. Behavioral barriers include patient factors, which include, but are not limited to issues related to patient motivation, patient comorbidities, and patient preferences. Other behavioral barriers include guideline factors, such as lack of feasibility or applicability of guidelines in clinical practice. Additionally, environmental factors, such as practice setting and time constraints during visits are considered behavioral barriers. Cabana et al. presented this framework as a flow-chart, which we adapted into a table format below.

Table 1. Barriers to Physician Adherence to Clinical Practice Guidelines. Adapted from Cabana et al.[7]

Knowledge	Attitude	Behavior
• Lack of Awareness • Lack of Familiarity	• Lack of Agreement with Specific Guidelines • Lack of Agreement with General Guidelines • Lack of Outcome Expectancy • Lack of Self-Efficacy • Lack of Motivation / Inertia of Previous Practice	• Patient Factors • Guideline Factors • Environmental Factors

The systematic meta-review conducted by Francke et al.[8], presents a framework that was derived from the analysis of twelve systematic reviews[8]. In their framework, Francke et al. defined 5 categories of barriers. The first, characteristics of the guidelines, includes issues with complexity as well as ease of implementation. The second category deals with characteristics of the implementation strategies. The third category is characteristics of the professionals, which encompasses barriers related to the physician's knowledge and familiarity of the guidelines, as well as factors such as experience which may affect their ability to effectively apply the guidelines. The fourth category, characteristics of the patients, includes barriers related to patient motivation, or patient comorbidities. Lastly, the fifth category describes characteristics of the environment, with barriers such as insufficient staffing, increased costs, and lack of time. Unlike Cabana et al., Francke et al. included factors that facilitate implementation of the guidelines as well as factors that discourage implementation for each category. Initially presented as a bulleted list, the framework has been adapted into a table below[8]:

Table 2. Factors Influencing the Implementation of Clinical Guidelines for Healthcare Professionals. Adapted from Francke et al.[8]

	Facilitates implementation	**Discourages implementation**
Characteristics of the guidelines	• Easy to understand • Easy to try out in practice • Do not require specific resources	• Complexity • Lack of clear scientific base
Characteristics of the implementation strategies	• Multi-faceted strategies • Comprehensive (greater variety and breadth) • Strategies requiring active professional participation	• Single intervention strategy
Characteristics of professionals	• Less experience leads to increased likelihood of following guidelines	• Lack of awareness of guidelines • Lack of familiarity with guidelines • Lack of agreement with guidelines
Characteristics of patients		• Resistance to guidelines • May find recommendation embarrassing or offensive • Comorbidities
Characteristics of the environment		• Insufficient staff • Lack of proper materials • Poor reimbursement • Increased costs • Time constraints

The framework of Flottorp et al., is a synthesis of other frameworks and checklists from the literature[9]. The aim of their paper was to compile a comprehensive checklist of determinants that could affect physician adherence to clinical guidelines. The result was a 57-item checklist of factors, with 7 main categories, which have been adapted into a table below[9].

Table 3. **Factors that Prevent or Enable Improvements in Healthcare Professional Practice**. Adapted from Flottorp et al.[9]

Guideline factors	Individual health and professional factors	Patient factors	Professional interactions	Incentives and resources	Capacity for organizational change	Social, political and legal factors
• Quality of evidence supporting the recommendation • Strength of the recommendation • Clarity • Cultural appropriateness • Accessibility of the recommendation • Source of the recommendation • Consistency with other guidelines • Feasibility • Accessibility of the intervention • Compatibility • Effort • Trialability • Observability	• Domain knowledge • Awareness and familiarity with the recommendation • Knowledge about own practice • Skills needed to adhere • Agreement with the recommendation • Attitudes towards guidelines in general • Expected outcome • Intention and motivation • Self efficacy • Learning style • Emotions • Nature of the behavior • Capacity to plan change • Self-monitoring or feedback	• Patient needs • Patient beliefs and knowledge • Patient preferences • Patient motivation • Patient behavior	• Communication and influence • Team processes • Referral processes	• Availability of necessary resources • Financial incentives and disincentives • Nonfinancial incentives and disincentives • Information system • Quality assurance and patient safety systems • Continuing education system • Assistance for clinicians	• Mandate, authority, accountability • Capable leadership • Relative strength of supporters and opponents • Regulations, rules, policies • Priority of necessary change • Monitoring and feedback • Assistance for organizational changes	• Economic constraints in the health care budget • Contracts • Legislation • Payer or funder policies • Malpractice liability • Influential people • Corruption • Political stability

The categories identified by Fischer et al. are similar to those of Cabana et al. To develop their framework, Fischer et al. conducted a scoping review of the literature.[10] Their three categories are Personal Factors, Guideline-related Factors, and External Factors. Like Cabana et al., they identified physician knowledge and awareness as barriers, however they categorized both of these factors under the Personal Factors heading. Beyond identifying barriers, they also proposed intervention strategies to combat these barriers. The framework has been adapted into a table below.

Table 4. Barriers in Guideline Implementation. Adapted from Fischer et al.[10]

Personal Factors		**Guideline-Related Factors**	**External Factors**
Physician Knowledge	**Physician Attitude**		
• Lack of awareness • Lack of familiarity	• Lack of agreement • Lack of self-efficacy • Lack of skills • Lack of learning culture • Lack of outcome expectancy • Lack of motivation	• Lack of evidence • Plausibility of recommendations • Complexity (too theoretical) • Poor layout • Access to guideline • Lack of applicability • Focus on patients with single disease entities • Exclusion of patients with complex disease entities • Lack of clear intervention goals • Trialability	• Organizational constraints • Lack of resources (time restrictions, heavy workload, facilitation) • Lack of collaboration • Social and clinical norms

The framework by Correa et al., differs from the frameworks introduced above in that it distinguishes context-dependent barriers and facilitators to guideline adherence [11]. In contrast to the other four frameworks presented here, Correa et al. explore how situational contexts can influence adherence to clinical guidelines. In their paper, the

framework is presented as a chart, alongside several tables of explanations, which have been adapted into one table below.

Table 5. Barriers and Facilitators to the Implementation of Clinical Practice Guidelines. Adapted from Correa et al.[11]

Clinical Practice Guidelines Context	Health Professional Context	Patient Context	Political and Social Context	Health Organizational System Context
Facilitators • Interventions that demonstrated clear and consistent clinical evidence of benefit or good applicability relevant to setting • Guidelines based on clear and solid recommendations **Barriers** • Lack of awareness / clarity of existing guidelines • Incorrect or not enough evidence for guidelines • Guidelines too rigid / impractical to implement • Guidelines restrict clinical judgment & challenge professional autonomy	**Facilitators** • Good communication and behavior change skills of healthcare professionals • Positive attitude toward innovation and evidence **Barriers** • Greater confidence in clinical experience versus guidelines • Resistance to change • Lack of effective communication, research & self learning skills • Physician reluctance • Lack of familiarity • Negative attitude of physician toward guidelines • Lack of autonomy & authority • Belief that intervention is not part of the providers role	**Facilitators** • Structured management plans for patients **Barriers** • Language and literacy problems • Lack of motivation, compliance, and knowledge to follow recommendations • Comorbidities • Financial situation • Depression, anxiety and fear	**Facilitators** • Technology and integrated systems • Clear communication between professionals and management, with defined roles and responsibilities • Positive working relationships between health workers • Financial incentives to achieve some positive goals for the implementation • Adequate communication between the care staff • Telemedicine systems, which provide immediate feedback to patients • Technology support as home tutorials and social networking **Barriers** • Difficulty in prioritizing the health problem • Lack of access to information • Lack of mechanisms and systems to support storing of information	**Facilitators** • Adequate time to promote new practice • Management incorporation to the implementation process • Motivation and consensus building in organizational culture • To ensure that the staff involved have sufficient training on the intervention **Barriers** • Lack of protocols and processes that clearly define roles • Additional workload • Difficulty accessing health services • Difficulty with availability of medicines • Deficiency in continuous education of staff • Deficiencies in patient referrals • Lack of skill and specialist services • Insufficient support from institutions • High turnover of staff • Limitations of existing infrastructure • Lack of availability of interpreter services • Lack of access to information • Lack of mechanisms and systems to support storing of information

Barriers to Guideline Adherence in axSpA / AS

While general guideline adherence is a popular topic in the literature, little is known specifically about guideline adherence in axSpA / AS. A literature review on this topic has not yet been performed. Given the lack of information in the literature about barriers specific to guideline adoption in axSpA / AS, the rheumatologist perspective would be critical in discovering which barriers are of the greatest significance. A common approach for capturing a variety of perspectives in medical research is via survey. Specifically, there are three main types of survey used in medical research, two of which we will utilize; "surveys on attitudes to a health service or intervention and questionnaires assessing knowledge on a particular issue or topic".[12] The third type, epidemiological surveys, will not be used here. Research studies using surveys frequently include a focus group during the planning phase. A focus group is a small group of people who are recruited to partake in a discussion about a certain topic in order to gather data about the topic. Typically, this method of collecting data allows the researcher to tap into a deeper understanding of the behaviors and perspectives of the subjects in a way that is not as obtainable when using surveys, or one-on-one interviews.[13] By utilizing the focus group, one can get firsthand insight into the perspectives of the participating rheumatologists to develop survey questions which more accurately capture what they perceive to be the barriers to guideline adoption.

Objective of the Study

The aim of this study is to discover the barriers to guideline adoption for axSpA, as perceived by rheumatologists. This includes the following sub-aims:

- perform a systematic literature review on barriers to guideline adoption in axSpA
- perform a systematic literature review on online survey deployment methods
- generate a draft of the survey
- conduct a focus group with a panel of experts in the field
- analyze the focus group data
- finalize survey based on feedback received from the focus group

To illustrate the steps that were taken to complete the project, we devised the following flow-chart.

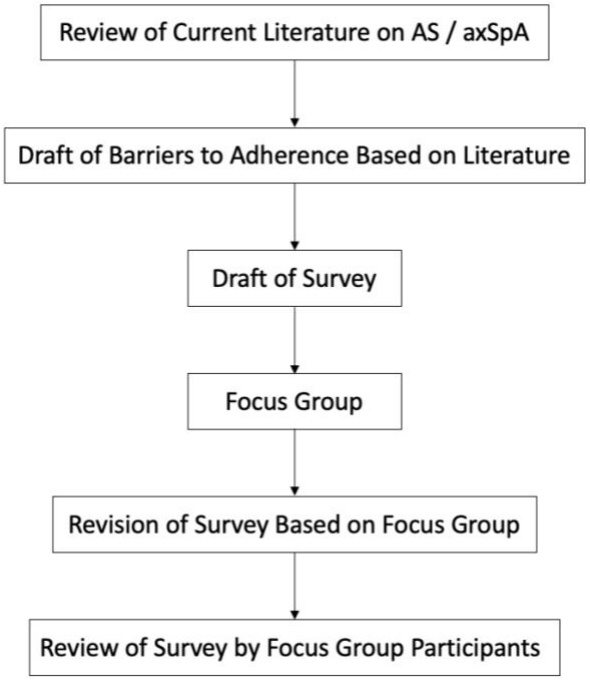

Figure 2. Outline of Research Study.

METHODS

Systematic Literature Review (Barriers)

PubMed and Web of Science were searched using the terms ("guidelines" OR "recommendations") AND ("ankylosing spondylitis" OR "spondyloarthritis") AND ("barrier" OR "adherence" OR "implementation"). Articles published in or before November 2020 were considered. Only English language articles available in full text were included. The articles were screened for relevance by reading the abstracts and / or the full text. Articles were screened out if they were not about the treatment of axSpA, or if they were not about or related to guidelines for axSpA. Articles were classified by two investigators separately. Any discrepancies in classification were reviewed and resolved by consensus.

Systematic Literature Review (Survey Deployment)

A PubMed search was conducted using the search terms ("email" OR "e-mail" OR "social media") AND ("rheumatologist" AND "survey"). Articles published in or before February 2021 were considered. Only English language articles available in full text were included. The articles were screened for relevance by reading the abstracts and / or the full text. Articles were screened out if they were not primary research including an online survey; or if they were not targeted toward physicians who attend to patients with rheumatic diseases. Articles were classified by two investigators separately. Any discrepancies in classification were reviewed and resolved by consensus.

Planning the Focus Group

The focus group was designed to be held virtually over Zoom, with approximately six to ten expert participants. An outline of the PowerPoint presentation to be used during the focus group was drafted, which included the use of breakout rooms to complete activities in smaller groups. The PowerPoint and the corresponding activities were then discussed and revised in multiple rounds. Below is the outline presented to focus group participants.

Table 6. Agenda and Timetable for Focus Group.

Topic	Time
Welcome + Background	5 mins
Study Introduction	5 mins
Barrier Brainstorming Exercise	8 mins
Breakout Exercise 1	15 mins
Framework Presentation	5 mins
Breakout Exercise 2	18 mins
Questionnaire Presentation & Strategy	30 mins
Wrap-Up	4 mins

Conducting the Focus Group

The focus group took place on Monday March 15th, 2021 via Zoom. Eight participants attended including four academic researchers, one rheumatologist in private practice, one clinician rheumatologist at an academic medical center, one rheumatology fellow at an academic medical center, and one medical student. After a round of brief introductions by all participants, a brief summary of the study conducted by Patel et al. was presented via PowerPoint, the results of which led to the development of our study.

The first activity was a whole-group exercise, and participants were tasked with ranking the significance of the barrier to guideline implementation against the importance of the recommendation. There were two breakout group exercises, for which the focus group was divided into two subgroups. For the first exercise, participants were asked to "devise an unsorted list of barriers you perceive to impact the adoption of the guidelines" for the specific aspect of the guideline to which they were assigned. Prior to the second exercise, the moderators presented a framework devised from articles in the literature. This framework, found in Table 7, identified five categories of barriers that impact guideline implementation. For the second exercise, the same subgroups were then asked to sort their barriers into the categories from the framework presentation, as well as rank the significance of these barriers, for example, the most difficult barrier to overcome would rank the highest. Group 1 discussed PT and exercise guidelines. Group 2 discussed disease activity monitoring guidelines. After the breakout session, the groups came together to compare and discuss.

As a whole group, the participants were asked their opinions on ways to maximize response rate for the survey. Additionally, the demographic questions from the drafted survey were presented to the whole group for feedback. At the end of the focus group, participants were asked to review the drafted survey questions on their own time, and to provide feedback on style and content.

The focus group was recorded with agreement by participants, to remove the distraction of taking notes for the moderators and allow investigators to review footage and dialogue later.

Survey Development

The initial draft of survey questions found in Supplemental Document 1 were developed based on barriers presented in the literature and survey questions from the literature found in other questionnaires and surveys. After the conduction of the focus group, the expert opinion of the participants informed changes to the survey, leading to the revision of the original survey. Question style and content were edited based on feedback from the focus group. The revised survey is attached as Supplemental Document 4.

Statistical Analysis

Excel (Microsoft) was utilized for data extraction and analysis. Calculations including mean, median, standard deviation, and ANOVA were performed using statistics tools available in Excel.

RESULTS

SLR for Barriers to Guideline Adherence

An SLR was performed of studies which investigated barriers to guideline adherence for axSpA or AS. The initial search returned 184 studies after duplications between PubMed and Web of Science were removed. One additional article was added from the cited sources of an article being screened, thus leaving 185 studies. Further screening excluded 132 articles, 11 of which were not in English, 91 of which were not related to treatment of axSpA / AS, and 30 of which were not related to axSpA / AS guidelines or recommendations. The full text of the remaining 53 articles was then assessed for eligibility; 12 articles were excluded because they were guideline documents themselves, 9 were excluded due to being reviews or commentaries, and 10 were excluded on the premise of not being primary research, leaving 22 articles for analysis.

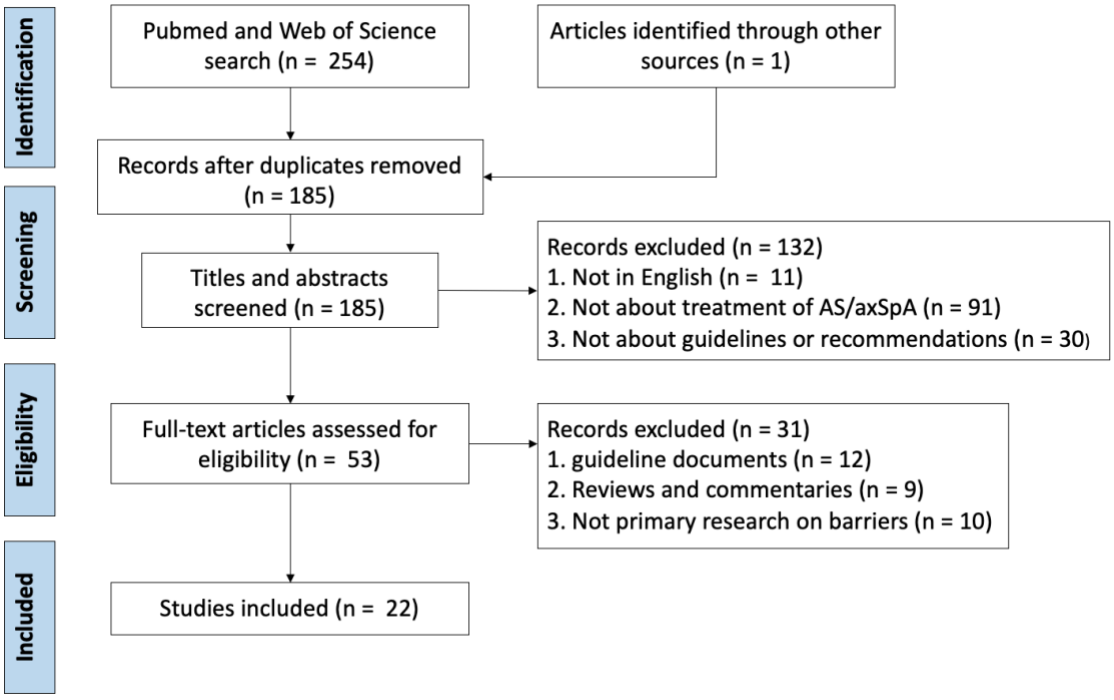

Figure 3. PRISMA Flow Diagram for SLR on Barriers to Guideline Adherence

From the 22 primary research articles, the aspect of the recommendation being addressed was analyzed. Seven addressed drug therapy; 16 addressed PT or exercise; 2 addressed disease activity monitoring; 1 addressed osteoporosis screening or monitoring; and 2 addressed other non-pharmacologic therapies.

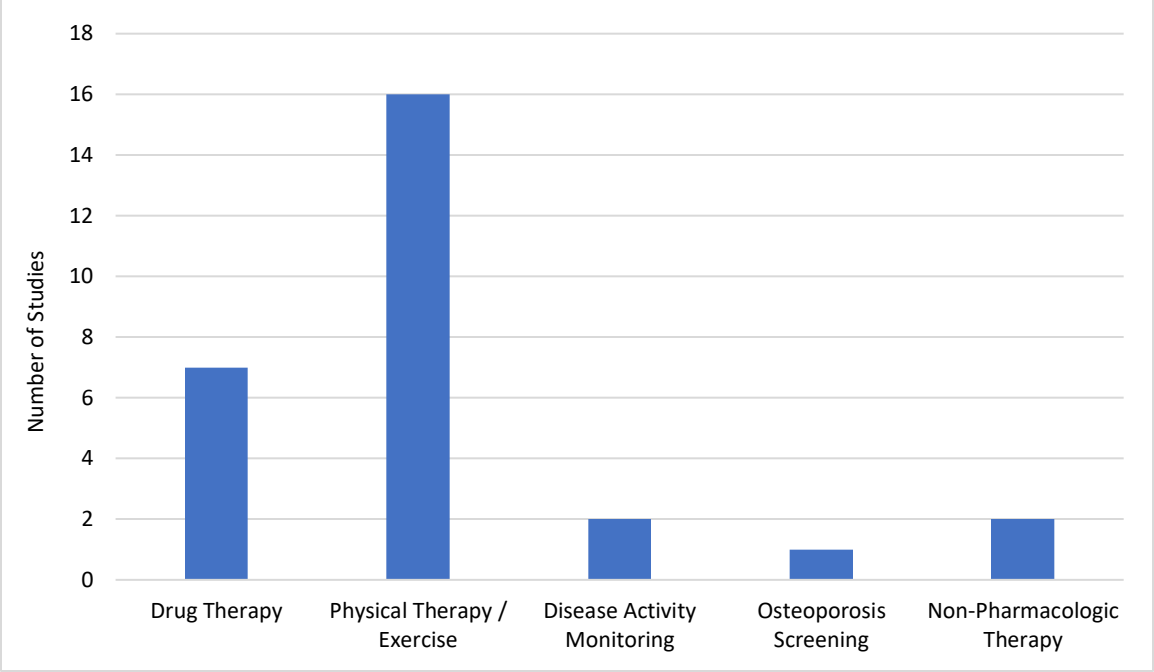

Figure 4. Aspect of Barriers Covered by Primary Research Studies
*In some studies, more than one aspect was covered

The method utilized by the 22 primary research articles was also analyzed. Twelve articles deployed a survey to patients; 6 deployed a survey to providers; 3 conducted patient interviews; 3 conducted provider interviews; 2 conducted an educational intervention with providers designed to improve guideline adherence post-intervention; 1 conducted an educational intervention with patients to determine the role an informative handout designed to be given to patients would play in disease outcomes; and 1 conducted a PT intervention with patients to further promote and develop axSpA specific exercise.

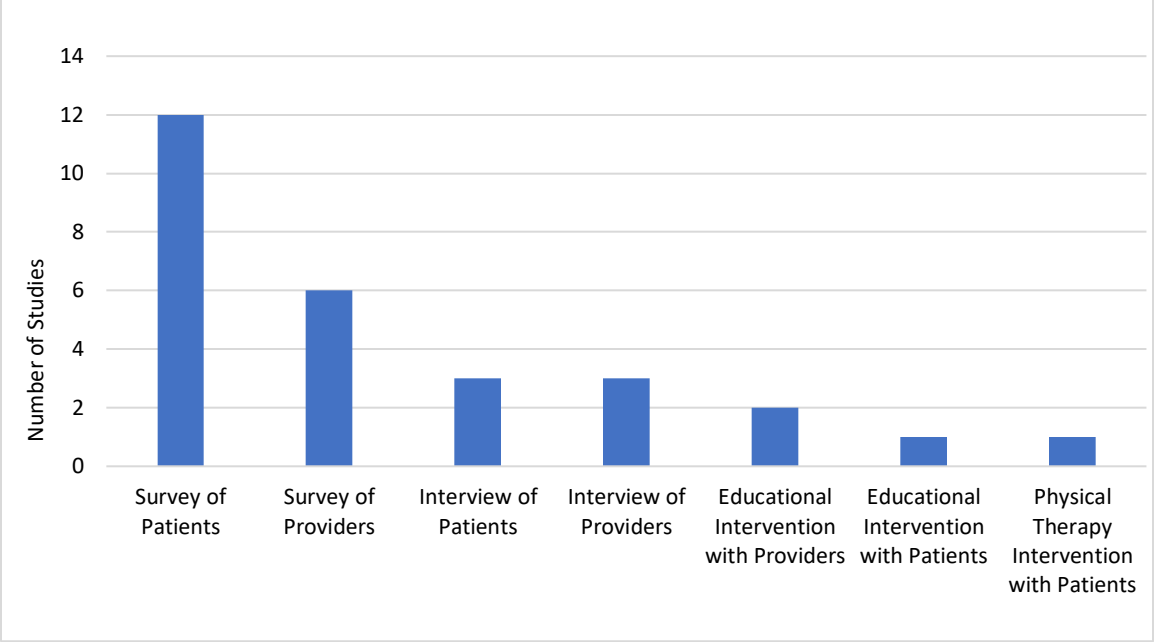

Figure 5. Research Method Utilized in the Primary Research Articles
*Some studies used more than one method.

It was possible to extract the geographic region where the research studies were performed from 20 of the 22 primary research articles. Eighteen of the studies were conducted in Europe; 1 was conducted in Canada; and 1 was conducted in the USA.

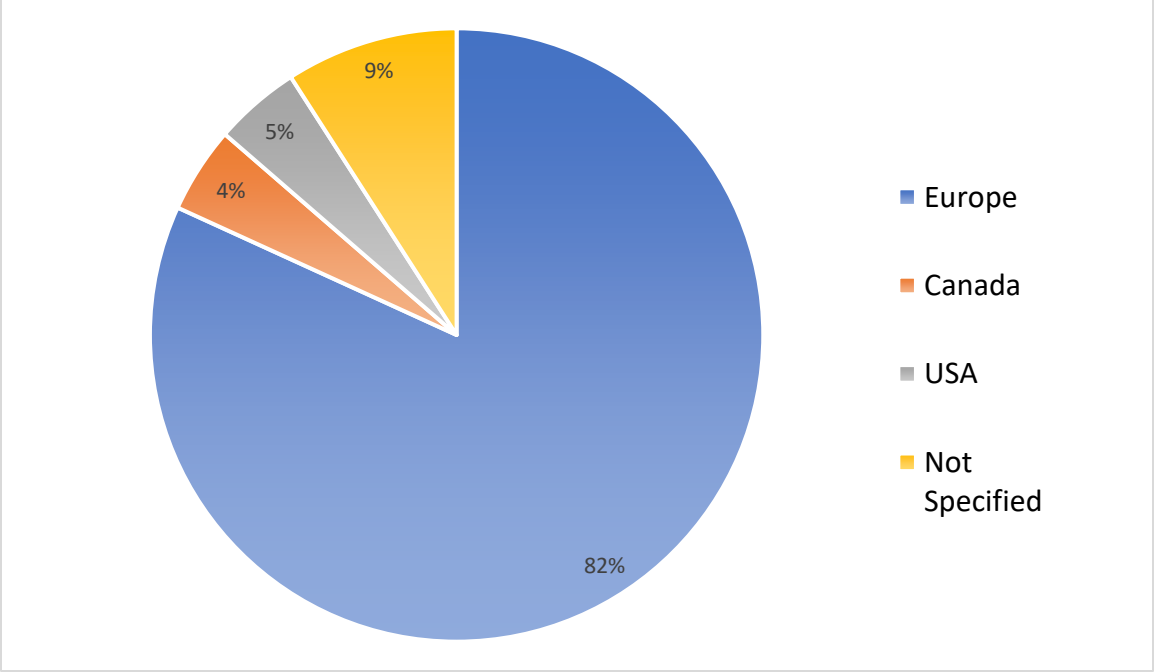

Figure 6. Geographic Regions in which the Research Studies were Conducted

Synthesized Framework

On the basis of prior publications, a framework was devised, which was designed to synthesize the key factors from each of the frameworks presented above. It was determined that five groups of factors were most important when considering barriers to guideline adoption: guideline factors, health professional factors, patient factors, practice setting factors, and societal factors. Guideline factors are issues with the guidelines themselves, such as lack of evidence or clarity, which then pose as barriers to proper application. Health professional factors are those that have to do with the provider themselves, for example their own familiarity with the guideline, or their motivation to follow the guidelines, which then pose as barriers to adherence. Patient factors are those which are directly related to the patient, for example motivation or knowledge, which

serve as barriers to adherence. Practice setting factors include constraints of the practice itself, such as the time allowed for each patient visit, or the EMR template for the visit, which then pose as barriers to adherence. Lastly, societal factors include barriers beyond those specific to a single practice or clinic, such as access to healthcare and the accompanying costs, which all pose as barriers to adherence. The table outlining these factors, as well as which studies highlighted their importance, can be found below.

Table 7. Synthesis of Barriers. Adapted from Frameworks in the Literature as well as Expert Opinion from the Focus Group.

	Cabana	**Francke**	**Flottorp**	**Correa**	**Fischer**
Guideline Factors e.g., clarity, support of scientific evidence	**x**	**x**	**x**	**x**	**x**
Health Professional* Factors e.g., awareness, knowledge, intrinsic motivation, length of time in practice	**x**	**x**	**x**	**x**	**x**
Patient Factors e.g., patient preferences, knowledge, intrinsic motivation, comorbidities	**x**	**x**	**x**	**x**	**x**
Practice Setting Factors e.g., routine of current practice, ease of interactions between health professionals, local implementation strategies, EMR	**x**	**x**	**x**		**x**
Societal Factors e.g., extrinsic incentives, payment, access to health care			**x**	**x**	**x**

*Health Professional refers to any healthcare provider involved in the care of the patient in the clinic

As a visual aid to further explain the factors from the above table, the following schema was also created and presented to the focus group. The schema is designed to show that health professional factors and patient factors can influence each other. Furthermore, the guideline factors and practice setting factors can also influence health professional factors

and patient factors. Societal factors are not immediately at play in guideline adherence; however, they play an overarching role and can have an impact on all the other factors discussed.

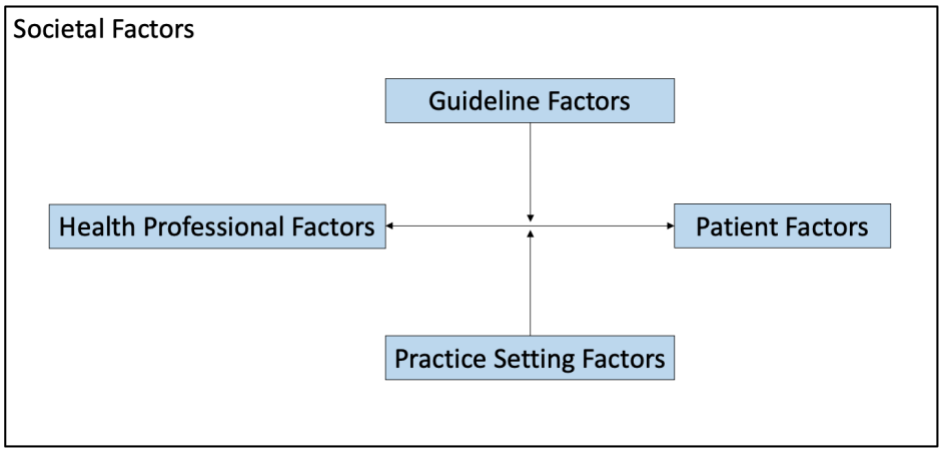

Figure 7. Schema of Factors Influencing Guideline Adoption. Visual representation of Table 7.

From these five categories, we then created a draft survey, which can be found in full in the Appendix of this paper, as Supplementary Document 1. The survey was designed to cover the five groups of factors mentioned above, as well as basic demographic information about the respondents. The number of questions that target each category are included in the table below.

Table 8. Breakdown of Survey Question Categories.

Health Professional Factors	4 questions
Patient Factors	5 questions
Societal Factors	1 question
Guideline Factors	4 questions
Practice Setting Factors	14 questions
Demographics	5 questions

SLR for Survey Deployment Strategy

A second SLR was performed of studies which deployed online surveys targeting physicians who attend to patients with rheumatic diseases. The initial PubMed search returned 86 studies. Screening excluded 34 studies; 3 of which were not in English, 2 were not full text articles, 12 did not involve the use of an online survey, and 17 were not targeted to physicians who attend to patients with rheumatic diseases leaving 52 studies for analysis.

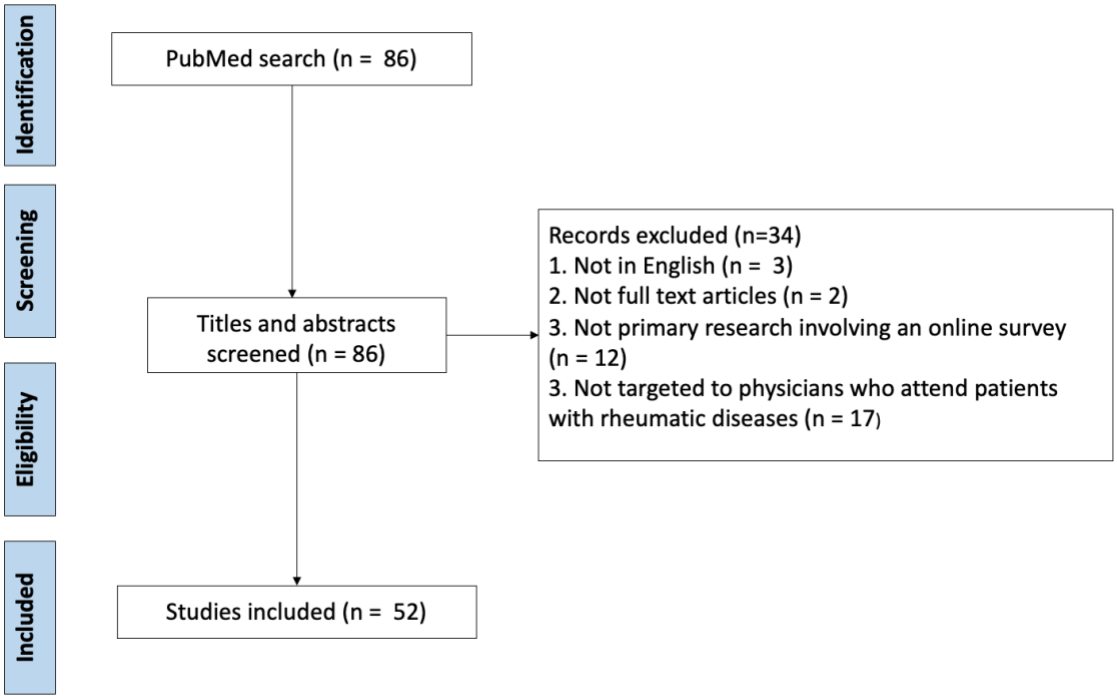

Figure 8. PRISMA Flow Diagram for SLR on Survey Deployment

Of the 52 studies included in the analysis, 40 studies included sufficient data to calculate a participant response rate. The mean response rate was 0.33 with a standard deviation of 0.22. The median response rate was 0.27 with a range from 0.04 to 0.78.

Forty-eight studies included information on the number of times physicians were contacted to participate. Of those, 24 studies contacted physicians only once, 15 studies contacted physicians twice, and 9 studies contacted physicians three or more times.

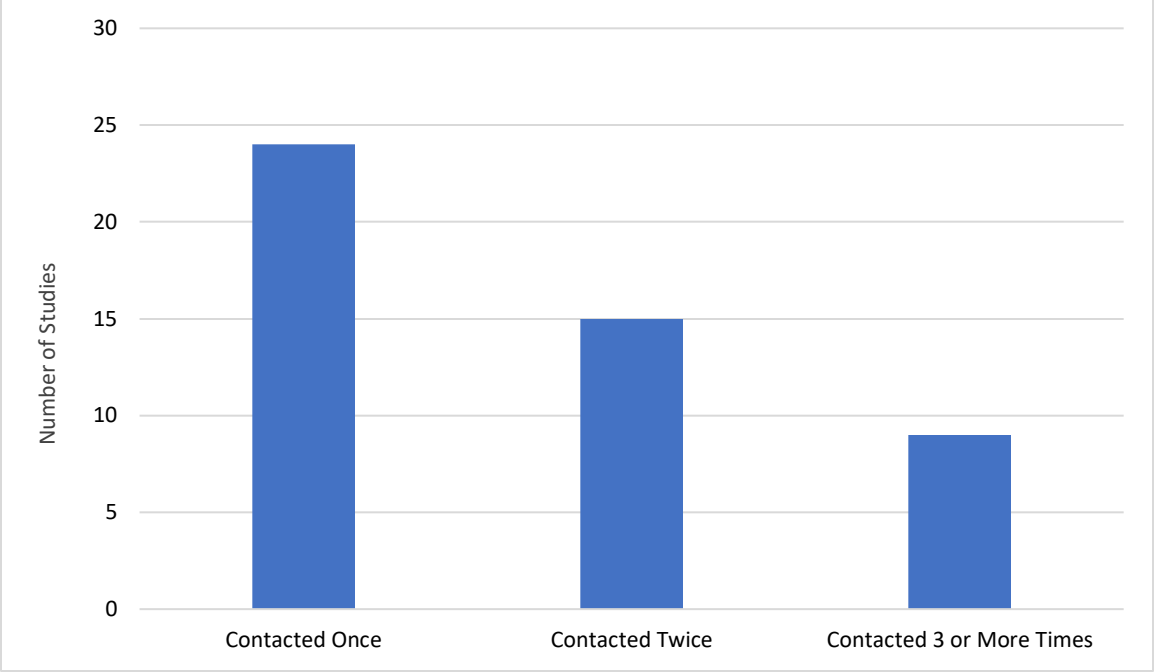

Figure 9. Number of Studies that Contacted Physicians Once, Twice, or Three or More Times.

Thirty-eight of the 40 studies that included enough information to calculate response rate also provided information on the number of times participants were contacted. For the 16 studies that only contacted physicians once the mean response rate was 0.39 with a standard deviation of 0.26. For the 14 of these studies that contacted physicians twice, the average response rate was 0.23 with a standard deviation of 0.2. For the 8 studies that contacted physicians three or more times, the average response rate was 0.39 with a standard deviation of 0.23. There was no statistically significant difference in response rate for the three groups.

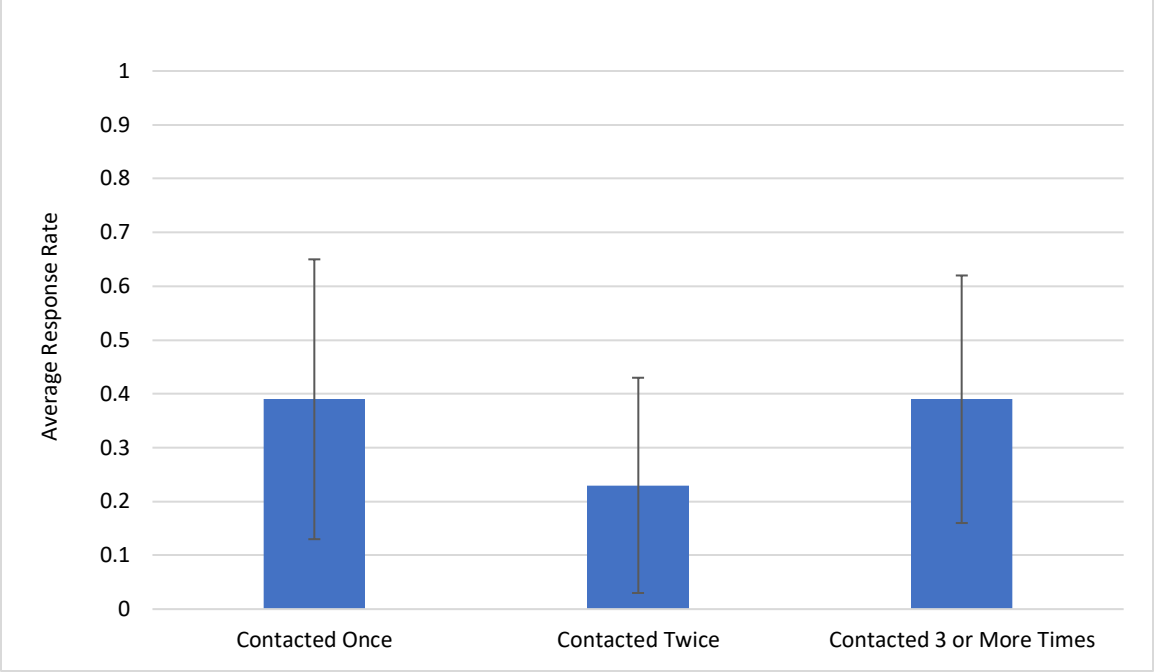

Figure 10. Comparison of Response Rate to the Number of Times Physicians were Contacted to Participate

Fifty studies included information about how participants were contacted and how they received the survey. Thirty-nine studies used email alone to contact physicians, 1 study used only social media, and 10 studies used both social media and email. Types of social media used included Twitter, Facebook, Instagram, LinkedIn, Study-Specific Websites, Online Newsletters, ResearchGate, and WhatsApp.

Forty-nine of the 52 studies provided information on where potential participants were recruited from. Thirty-two studies recruited from national rheumatology or medical organizations, 17 recruited from international rheumatology or medical organizations, 7 recruited from regional rheumatology or medical organizations, and 7 used non-organization-based recruitment methods. The non-organization-based recruitment methods included a database of rheumatologist contacts maintained by the authors, the

distribution of unique emails to contacts, surveys forwarded to colleagues, rheumatologists nominated by members of steering committees, the social media platforms of a Rheumatology journal, a search through the websites of health insurance companies, and general social media posts.

Forty-six studies included the geographic location where the research was conducted. Thirty-two studies were conducted within one country, while 14 studies were multi-national.

Only seven studies included information on the approximate time it would take to complete their survey. This time frame ranged from 3 minutes to 20 minutes, with a median time of 7 minutes.

Thirty-eight studies included enough information to calculate response rate while also providing information on if the study was multinational. The average response rate for the 27 studies conducted in one country was 0.30 with a standard deviation of 0.23, while for the 11 studies conducted in multiple countries it was 0.4 with a standard deviation of 0.19.

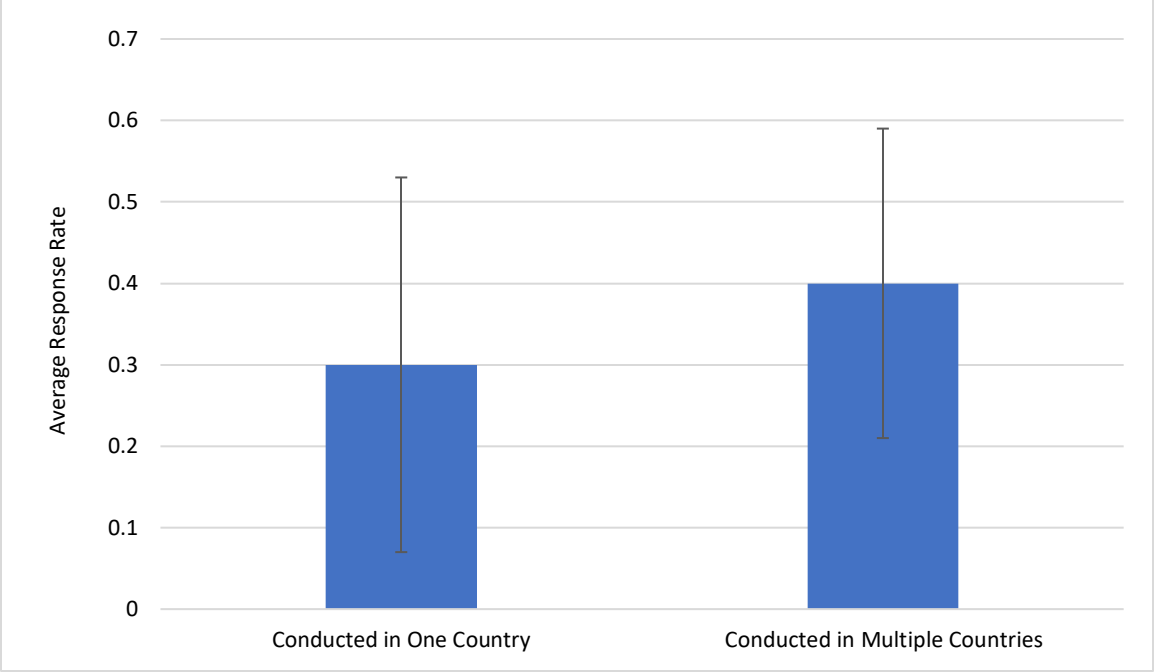

Figure 11. Comparison of Response Rate to National or Multinational Conduction of Research

Focus Group Whole Group Activity

For the initial group exercise, the participants were presented with the graph shown below and asked to suggest placement of the major guideline categories: pharmacotherapy, physical therapy & exercise, other non-pharmacological therapies, disease activity monitoring, counseling and education, and management of comorbidities. In this matrix, the x axis represents the importance of the recommendations, while the y axis represents the height of the barriers hindering their implementation.

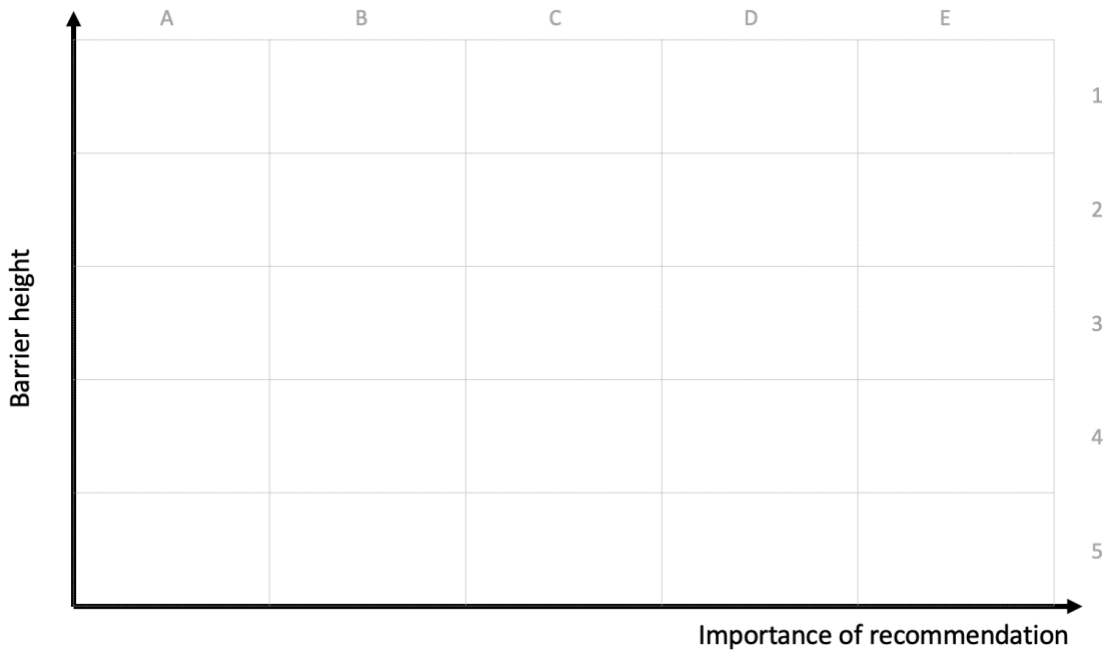

Figure 12. Group Exercise Slide on Barrier Height versus Importance of Recommendation.

The initial full group exercise was designed to be presented as a graph, but due to differing opinions among participants, the results will instead be presented as quotes or as summarized points. The first participant stated that “aside from pharmacotherapy, everything on this list has barriers”. This participant went on to say that since pharmacotherapy is so effective these days, the other aspects of treatment are not as relevant. Furthermore, this participant indicated that disease activity monitoring is not done in other disease types beyond just axSpA / AS, so it is not a problem unique to this disease population. Another participant elaborated on pharmacotherapy, indicating that there is a different barrier that exists which is the knowledge of which step to take next, i.e. if one type isn’t working. One moderator took the point further, asking “considering that so few physicians get disease activity monitoring measures is that because they are

simply further to the left on this scale?" A different participant chimed in to say that they always get a RAPID3 on every patient which is facilitated by the workflow in the clinic; each patient completes a questionnaire in the waiting room before even coming into the exam room. This participant found this to be especially useful in informing conversations with their patients and would stand by the importance of disease activity monitoring measures. This participant added that this approach is useful because it does not take up time during the actual visit, since it is filled out by the patient beforehand, and that not spending time on these measures during the visit itself is critical given the small window of time allotted to follow-up visits. This same participant stated that "counseling and education tend to fall by the wayside", typically because physicians have an agenda when they walk into visits (all of the steps they need to complete for the visit at hand), that having a true conversation with the patient gets pushed to the side. There was general agreement among participants that this aspect had the highest barrier, simply because of all the things that need to happen during a visit (labs, prior authorizations, reviewing results, ordering tests etc.). Another participant chimed in that a major concern with many of the aspects of care was that things were being done for remuneration purposes only instead of being done in a meaningful way. Oftentimes having patients fill things out in the waiting room can be used to increase complexity level of the visit, and therefore bill at a higher rate. Another issue was brought up regarding counseling and education, that oftentimes patients don't understand the goals of therapy because there is a lack of communication with their doctor. This was presented as a huge barrier, because the patient does not know how they are doing even though they may be doing well clinically,

because there is a disconnect with what the objectives are and how the patient feels, or how the patient thinks they should be doing.

Focus Group Breakout Group Activities

The goal of the first breakout group activity was to get participants thinking about barriers to the specific aspect they were assigned, either PT / exercise or disease activity monitoring. The second breakout group activity was designed to take this a step further. Prior to the second breakout group, the framework from Table 7 was presented by the moderators. The goal of the framework presentation was two-fold; first it was to demonstrate what the literature had provided as a basis for factors that affect guideline adoption in axSpA / AS and leave room for the participants to make edits, second the next breakout group activity was designed based on the presented framework. Participants were asked to sort the barriers they came up with in activity one into 1 of the 5 categories of factors from the framework, as well as rank the importance of each of the barriers within these categories. The resultant table for each group can be found below. A specific comment was made about societal factors, because one of the moderators brought up the fact that in other countries, prescription of biologics is tied to disease activity measurements. One participant said that if that were the case here, there was no doubt that more doctors would do disease activity measurements. Another participant said that since it isn't the case here, a different incentive would be money. Another participant said, "I guess we just have to believe that treat-to-target actually works, and I don't know that everyone does."

Table 9. Group 1 Breakout Exercise from Focus Group. Barriers to adherence to disease activity monitoring guidelines in axSpA / AS ranked by importance.

	Disease Activity Monitoring
Guideline Factors	1. Specificity of inflammatory markers for rheumatic disease versus other causes (e.g., a virus) 2. Justification of when to use and why (convincing providers and demonstrating efficacy) 3. In what clinical context are they most effective (e.g., all of the time, certain scenarios, certain patients)
Health Professional Factors	1. Education (especially for new rheumatologists) a. How to use b. How to collect / document
Patient Factors	1. Stress on the patient by collecting more measures a. need to explain what they are b. what impact they have on their care c. how / if it affects the outcome / prognosis 2. Increased number of lab draws could be burdensome
Practice Setting Factors	1. Technology behind collecting and documenting the disease measures 2. Acceptance by IT infrastructure / administration (e.g., incorporating them into the OMR) 3. Challenge of lab test interpretation 4. Sharing results / communication regarding abnormal results
Societal Factors	1. Loss of physician autonomy / the art of medicine 2. Cultural factors (e.g., a patient who believes that he / she only has a certain amount of blood and does not want to give more for testing)

Table 10. Group 2 Breakout Exercise from Focus Group. Barriers to adherence to PT / exercise guidelines in axSpA / AS ranked by importance.

	Exercise / Physical Therapy
Guideline Factors	1. Guidelines are vague a. No subsets / stratification b. No specifics of PT 2. Guidelines are hard to understand
Health Professional Factors	1. Don't understand what PT entails 2. Belief that PT / exercise is less effective than pharmacologic therapy 3. Don't know how to write a good prescription for PT 4. Inability to convince patients to exercise 5. Unaware of guidelines
Patient Factors	1. Cost of PT 2. Unable to get time off work for PT 3. Don't think it works 4. Would rather have medicine because the time and effort involved is less than that required for PT / exercise 5. Physical distance to location offering PT is too far
Practice Setting Factors	1. In-Network versus Out-Of-Network a. Large group practices (where their insurance accepted) may discourage / prevent patients from going to a more convenient location (where their insurance is not accepted) 2. Most PT clinics do not have PT tailored to inflammatory arthritis
Societal Factors	1. The Pandemic 2. External, structural factors (e.g., race, culture) that impact patient level factors 3. Access in the US 4. Belief that pharmacologic therapy is better than nonpharmacologic therapy (a US issue)

A particularly interesting point came up when the groups reconvened, which was that one participant said patients always ask what else they can do for their disease besides taking drugs. This participant asked how everyone else would answer that question. One participant said they would admit to their bias and say that pharmacotherapy is the best way. Another participant said patients want to know what the "anti-inflammatory diet" is, but that when the topic of exercise comes up, patients give a bunch of reasons for why they cannot do that. Another participant exclaimed "everyone wants a diet but not exercise". There seemed to be consensus that the idea of fad diets and not exercising might be "an American thing". Another participant noted that the idea that you can

change your health significantly with your diet is very unique to the United States. There seemed to be consensus that the barrier to PT might be lower in other countries, because PT is more accessible and widely available in other countries than in the US. One participant shared that patients often say that in other countries it is easy for patients to get PT at their houses, or get massages, whereas in the US you need to go through referrals, and get prescriptions, and it is much more difficult to navigate. Another participant notes that PT preceded pharmacotherapy in Europe, which could be a reason for the high accessibility there compared with the US.

Focus Group Feedback on Response Rate and Survey Questions

The participants were then asked their opinion on methods to maximize the response rate once the survey was deployed. Several areas were highlighted, including survey length, email subject line, and number of invitation / reminder emails to send. There was also the question of incentives. The literature indicated the survey should be between 10-15 minutes maximum, which the focus group participants agreed with. One participant said that an important factor would be number of questions per page, i.e., not just continuous scrolling. Being able to see completion status would be helpful. The participants also said that having a subject line that clearly indicated that this was academic research being done by a student would make target participants more likely to respond. Our research from the literature showed no correlation between response rate and number of times participants were contacted, and focus group participants generally agreed, suggesting "one email and maybe one reminder". The topic of social media was also brought up,

with one participant in particularly in favor of this route. The other participants were in agreement that using social media would be an excellent way to target a larger group of potential participants. Possible methods of social media deployment were also discussed, such as Twitter, LinkedIn, Doximity, and a secret Facebook group mentioned by one participant. The idea that the ACR might broadcast the survey was also suggested. When the question arose of whether or not this might result in the recruitment of non-rheumatologist and / or non-US physician respondents, one participant suggested a specific screening question, i.e., "are you a rheumatologist practicing in the US" to remedy this issue. If no were selected as an answer to the preliminary question, the survey would close. The idea of geographic region was also discussed, however one participant stated that with REDCap it is possible to stratify responses by region, such that any regional differences or biases could also be seen. It was also noted that the larger the pool of potential participants reached, the larger number of responses would be received, especially considering the low expected response rate as noted in the literature. One of the moderators brought up the concern of introducing bias when using social media, i.e., an age determined preference for using social media versus not. A participant responded that bias would be a factor no matter what, and that targeting participants in as many ways as possible would be the best way to limit that bias. Given that the primary interest was to have broad coverage of many practice settings, one participant suggests getting buy-in from larger groups to help disseminate. Another participant recapped "you're better off with the largest possible number of participants and the shortest possible survey".

The demographic questions were then presented to the participants, with a focus on the question asking how many axSpA / AS patients are seen per week. This prompted one participant to note that if focus group participants were to answer that question themselves, their number would be quite small, even though a large proportion of their patients had axSpA or AS, simply because they are an academic researcher and do not see many patients in general. To better capture the purpose of the question, one participant suggested "what is the primary focus of your practice as a rheumatologist" with options of all rheumatology cases without restriction, emphasis on spondyloarthritis, emphasis on lupus or similar autoimmune disorders, mostly osteoarthritis and fibromyalgia, or emphasis on RA. Since the purpose of this question was to gauge the axSpA / AS expertise of the answering physician, the proposed wording would capture just that.

At the end of the focus group, participants were asked if they would review and comment on all the questions drafted thus far for the survey. Participants were asked to do this on their own time, and to send their responses back so that the investigators could edit the survey accordingly. The revised survey can be found in full in the Appendix of this paper, Supplementary Document 4. Changes made from the original draft of the survey are italicized in the revised survey.

DISCUSSION

Summary

The results have shown that little research has been done to investigate barriers to guideline adoption for axSpA / AS. Only 1 of the 22 studies identified in the SLR was conducted in the US, demonstrating the need for further research in the US. Furthermore, almost all of the studies identified focused on drug therapy or PT / exercise. The SLR on survey deployment methods identified 52 articles, 40 of which included sufficient information to calculate response rates. The mean response rate for electronic surveys distributed to rheumatologists was 0.33; there was no statistically significant difference in response rate for studies which contacted physicians once, twice, or three or more times. From the available literature, a framework was synthesized, that captures 5 major categories of barriers to guidelines adherence: guideline factors, health professional factors, patient factors, practice setting factors, and societal factors. A survey was drafted, with questions targeting each of the 5 categories included in the framework. Suggestions from the expert participants of the focus group resulted in a revised survey consisting of 33 questions. From the literature we were able to analyze methods used to recruit survey participants, as well as strategies to improve response rate for electronic survey deployment. Additionally, the focus group proposed ideas for survey dissemination, including strong support for the utilization of social media in addition to email invitations.

Dearth of Literature on Barriers in axSpA / AS

In the research that has been conducted on barriers to guideline adoption in axSpA / AS, there tends to be a focus on the pharmacologic and PT / exercise components of the guidelines. In contrast, very few studies have investigated barriers to the adoption of guidelines for disease activity monitoring, osteoporosis screening, and other non-pharmacologic treatments. There is also a large discrepancy in the number of studies that conducted research on barriers in Europe compared to those conducted in the US. Since the healthcare system of the US is different than those in Europe, it is possible that the results of the European studies, and their proposed solutions, would neither be relevant nor feasible in the US. This indicates a need for more studies investigating barriers specific to physicians and patients within the US healthcare system.

Strategies to Maximize Response Rate for Electronic Surveys

The results of our study indicate that there was no benefit to contacting participants more than once, since the response rate for studies in which physicians were contacted was the same as for studies in which physicians were contacted 3 or more times. The focus group participants agreed with the premise that the majority of responses will be received after the initial invitation is sent out, and that one follow-up is all that should be done.

It is also worth noting that the calculated average response rate of 0.3 for electronic survey deployment had a very wide standard deviation of 0.22. Thus, there are likely other factors attributing to response rate beyond those addressed in our analysis. One of these factors may be how important the physician perceives the survey to be. If he or she believes the topic of the survey is worth studying, it is more likely that he or she would

respond. This was emphasized by focus group participants, who agreed that a targeted participant would be more likely to respond to a survey if they knew they were helping someone, i.e., a student conducting research.

Strengths and Limitations

One of the major strengths of this study was the use of expert opinions in the development and refinement of survey questions. By utilizing experts in the field of axSpA / AS for the focus group, it was possible to capture the perspective of the target audience for the survey. Another strength of the study is that since barriers to guideline adoption for axSpA have not been widely studied, this study may bring more attention to gaps between the intention of the guideline and the actual implementation of the guideline in medical practices.

A major limitation is that we were not able to distribute the survey to the target group of rheumatologists due to time constraints. Therefore, we have no results for the survey questions. Another potential weakness of the study is the limited size of the focus group. Having a smaller group may mean that the feedback we received is not representative of all perspectives of rheumatologists. Therefore, the barriers signified as most important from above may not accurately reflect the perspective of the overall population of rheumatologists in the US.

Conclusion

The SLR conducted to identify barriers to guideline adherence in axSpA / AS demonstrated a dearth of information specific for this disease entity, indicating a need for further research. The focus group provided firsthand perspective, allowing for modification of the survey to capture the most informative data. Furthermore, the focus group provided insight into survey dissemination methods and ideas to maximize the response rate. Administering the survey to rheumatologists should be the next step.

APPENDIX

Supplementary Document 1: Draft of Survey Prior to Conduction of Focus Group

Section A: Clinical Scenario (Health Professional Factors)

1. A 32-year-old male with axial spondyloarthritis (diagnosis 5 years ago, HLA-B27 positive, unequivocal findings of sacroiliitis on pelvic radiographs) returns for routine f / u. He has no extraspinal disease manifestations and no other medical problems. His disease-related symptoms have been well controlled with a TNF inhibitor. Please describe what you would do for this patient in your clinical practice. Select all that apply.
    - ☐ Assess disease activity in qualitative terms (e.g., excellent, good, stable, better, worse)
    - ☐ Measure disease activity using a validated questionnaire (e.g., BASDAI)
    - ☐ Review vaccination record.
    - ☐ Review smoking status.
    - ☐ Perform a physical examination including peripheral joints and spine.
    - ☐ Record spinal mobility measurements (e.g., Schober, occiput to wall distance)
    - ☐ Discuss exercise and recommend physical therapy
    - ☐ Order CRP and / or ESR.
    - ☐ Order spinal radiographs (if not performed during the last 2-5 years)
    - ☐ Other: write in box

2. The patient is doing well. His disease has been well controlled. He rarely takes Ibuprofen. He has been on a stable dose of the TNF inhibitor for 5 years. Which management approach would you choose? Select your single best answer.
    - o Keep on same dose of TNF inhibitor, f / u in 3-6 months
    - o Keep on same dose of TNF inhibitor, f / u in 1 year
    - o Discuss and Implement dose reduction of the TNF inhibitor, f / u in 3-6 months
    - o Recommend discontinuation of the TNF inhibitor, f / u in 3-6 months

3. Under which circumstances do you order a DXA scan for patients with axial spondyloarthritis? Select all that apply.
    - ☐ All Women with AS above age 40
    - ☐ All patients with AS at least once
    - ☐ Every 5 years after the diagnosis of AS
    - ☐ History of spine fracture or recent non-spinal fracture
    - ☐ X-ray reports commenting on low bone density
    - ☐ Other: write in box

4. Which of the following disease scores have utility to measure disease activity in patients with axial SpA / AS?

	Not at all useful for axSpA / AS	Not very useful for axSpA / AS	Neutral	Very useful for axSpA / AS	Extremely useful in axSpA / AS	Don't know it
ASDAS						
BASDAI						
CDAI						
DAS28						
RAPID3						

Section B: Patient and Societal Factors

Patient Factors

5. Do you provide any patient facing handouts regarding guidelines to treatment at clinic visits?
    - Yes
    - No

6. Using the scale below, approximately what percentage of the axSpA / AS patients in your clinic come prepared with knowledge of the guidelines? Select the best answer.

None	25%	50%	75%	100%

7. Approximately what percentage of your patients with axSpA / AS do regular strengthening exercises and or stretching on their own at home? Select the best answer.

None	25%	50%	75%	100%

8. Approximately what percentage of your patients with axSpA / AS engaged in organized PT over the past year? Select the best answer.

None	25%	50%	75%	100%

9. What barriers do you perceive that prevent your patients from exercising to the recommended amount (choose all that apply)?
    - ☐ Time
    - ☐ Cost
    - ☐ Pain
    - ☐ Lack of Awareness of recommendation
    - ☐ Other: write in box

Societal Factors

10. In your opinion, should the prescription of biologics be linked to specific thresholds of disease activity scores?
    - o Yes
    - o Neutral
    - o No

Section C: Guideline Factors

11. Which resources do you consult for the questions regarding the management of patients with axSpA / AS (choose all that apply)?
    - ☐ ACR / SAA / SPARTAN guidelines
    - ☐ ASAS guidelines
    - ☐ Up-to-Date
    - ☐ Pubmed
    - ☐ Textbooks (e-books or hardcopy)
    - ☐ Other: write in box

12. For which aspects of the management of axSpA / AS patients do you reference guidelines (choose all that apply)?
    - ☐ Pharmacological therapy
    - ☐ Disease activity monitoring
    - ☐ Physical therapy / exercise
    - ☐ Osteoporosis screening / management
    - ☐ Diet and lifestyle
    - ☐ Vaccination
    - ☐ Other: write in box

13. How did you learn about the ACR / SAA / SPARTAN guidelines (choose all that apply)?
    - ☐ Arthritis & Rheumatology publication
    - ☐ Arthritis Care & Research publication
    - ☐ ACR Annual Meeting
    - ☐ The Rheumatologist
    - ☐ Online source, e.g., Rheum Now
    - ☐ Educational seminars or conferences, e.g., SPARTAN-GRAPPA symposia
    - ☐ Social media, e.g., Twitter
    - ☐ Other: write-in box

14. Please rate the guidelines based on how satisfied you are with each of the following criteria?

	Extremely Dissatisfied	Somewhat Dissatisfied	Neutral	Somewhat Satisfied	Extremely Satisfied
Evidence-Based					
Relevance in Clinical Practice					
User Friendliness					

Section D: Practice Setting Factors

15. Do you routinely collect patient-reported data using patient facing tablets / electronic devices / web interface?
    - o Yes
    - o No

16. Which electronic medical record system does your clinic / institution use?
    - o Allscripts
    - o athenahealth
    - o Cerner
    - o eClinicalworks
    - o EPIC
    - o Meditech
    - o NextGen
    - o Other: write-in box

17. Does your EMR have templates for disease activity monitoring (e.g., BASDAI)?
    - Yes
    - No
    - Don't know

18. Does your EMR provide handouts or other educational material for patients with axSpA / AS that can be printed out or sent electronically?
    - Yes
    - No
    - Don't know

19. Please rate the ease of application of the following aspects of the guidelines in your practice from 1 to 5.

	Extremely Difficult	Somewhat Difficult	Neutral	Somewhat Easy	Extremely Easy
Disease Activity Monitoring					
Physical Therapy					

20. Please rank the following barriers to implementing guidelines in order, with the top of the list being the most significant? Please drag and drop the items from the left hand side into the box on the right hand side.

21. If there are any barriers you observe in your practice that were not on the list, please include them here:
    - Write in box

22. Are there other healthcare providers involved in care of the patient at each visit besides you?
    - Yes
    - No

23. Are the disease activity monitoring assessments completed by you (the physician) or by another healthcare provider?
    - Me
    - Someone else

24. If the disease activity monitoring assessments are completed by someone else, what is their title (choose all that apply)?
    - ☐ NP
    - ☐ RN
    - ☐ PA
    - ☐ MA
    - ☐ Other: write in box

25. If you find that time is a barrier – is this true for all clinic visits or specifically your AS patients?
    - o All visits
    - o Just AS patient visits

26. Is there a specific implementation plan for the AS guidelines within your practice (e.g., continuous education, checklist etc.)?
    - o Yes
    - o No

27. [If above answer was yes] what is it?
    - o Write in box

28. If you advise a patient to engage in back exercises at home, what kind of resources do you provide this patient to guide them?
    - o Printed Handout
    - o Website Resource Link
    - o Other: write in box

Section E: Demographic Questions

29. What gender do you identify with?
    - o Male
    - o Female
    - o Prefer not to disclose
    - o Prefer to self-describe: write in box

30. What is your level of training?
    - o Board-certified rheumatologist
    - o Rheumatology fellow
    - o Physician assistant or nurse practitioner
    - o Other: write in box

31. [If Board-certified rheumatologist selected]: Year you completed your rheumatology subspecialty training?
    - drop down menu

    [If Rheumatology fellow selected]: Year you started fellowship training
    - drop-down menu

    [If PA, NP or Other]: skip

32. Select the option that best describes the setting in which you practice:
    - Academic Medical Center
    - Hospital-based practice
    - Group practice
    - Solo practice
    - Retired
    - Other: write-in box

33. On average, how many axSpA / AS patients do you see per week?
    - < 5
    - 5 - 10
    - > 10

Supplementary Document 2: Table of References from SLR on Barriers to Guideline Adherence

Citation	Aspect of Guideline Being Addressed				
	Drug Therapy	Disease Activity Monitoring	PT / Exercise	Osteoporosis Screening / Management	Other non-pharmacologic Therapies
Gossec Ann Rheum Dis 2008[14]	x	x	x	x	
Che Clin Exp Rheumatol 2015[15]	x	x			
Nota Arthritis Res Ther 2016[16]	x				x
Pereira-Gillon J Rheumatol 2018[17]	x				x
Ozgocmen Open Rheumatol J 2012[18]	x				
Spadaro Clin Exp Rheumatol 2014[19]	x				
Gossec Joint Bone Spine 2020[20]	x				
Niedermann Arthritis Care Res (Hoboken) 2019[21]			x		
Fongen Musculoskeletal Care 2015[22]			x		
Freid ACR Open Rheumatol 2020[23]			x		
Durcan J Rheumatol 2012[24]			x		
Hilberdink Arthritis Care Res 2020[25]			x		
O'Dwyer J Phys Act Health 2016[26]			x		
Davergne Rheumatol Int 2020[27]			x		
Hammer Rheumatology 2018[28]			x		
Osthoff Ann Rheum Dis 2019[29]			x		
Rasmussen Musculoskeletal Care 2020[30]			x		
Zarco Rheumatol Clin 2016[31]			x		
Fabre Rheumatol Int 2016[32]			x		
Hilberdink Patient Educ Couns 2020[33]			x		
Hilberdink Rheumatol Int 2020[34]			x		
Passalent J Rheumatol 2010[35]			x		

Supplementary Document 3: Table of References from SLR on Survey Deployment

Citation	Response Rate	Number of Times Contacted	Recruitment Source	Type of Contact Made	Number of Countries Included in the Study	Time Needed to Complete the Survey
Castrejón Arthritis Care Res (Hoboken) 2012[36]	0.04	1	International Rheumatology organization	email	1	not given
Palestine J Pediatr Ophthalmol Strabismus 2016[37]	0.04	1	International Rheumatology organization AND national medical organization	email	1	not given
Garneau Arthritis Res Ther 2011[38]	0.05	2	National medical organization	email	1	not given
Ogdie Arthritis Care Res (Hoboken) 2015[39]	0.08	2	International Rheumatology organization	email	1	not given
Palestine J Clin Rheumatol 2016[40]	0.08					
Barnabe J Rheumatol 2020[41]	0.11	2	National Rheumatology organization	email	1	not given
Mangat Intern Med J 2010[42]	0.13	1	National Rheumatology organization AND national medical organization	email	2	not given
Barra Open Access Rheumatol 2017[43]	0.13	2	National Rheumatology organization	email	1	20 minutes
Panchal Rheumatol Int 2013[44]	0.14	2	National Rheumatology organization and Regional rheumatology organization	email	4	not given
Glauser Rheumatol Ther 2014[45]	0.14	1	National medical organization	email and fax	1	not given
De Vera BMC Rheumatol 2019[46]	0.15	3	National Rheumatology organization	email	1	not given

Correll Pediatr Rheumatol Online J 2015[47]	0.15	3	Regional medical organization	email	1	not given
Schallhorn Ophthalmology 2013[48]	0.17	1	National medical organization and International Rheumatology organization	email	1	not given
Toka Rheumatol Int 2019[49]	0.18	3	National Rheumatology organization	email	1	not given
Ablin Rambam Maimonides Med J 2016[50]	0.19	1	National Rheumatology organization	email	1	not given
Hopkins Clin Rheumatol 2017[51]	0.20	2	National Rheumatology organization	email	1	not given
Curtis J Rheumatol 2018[52]	0.23	2	non-organization based recruitment	email	1	10 minutes
Cettomai J Rheumatol 2010[53]	0.23	2	International Rheumatology organization	email	1	not given
Fitzcharles BMC Musculoskelet Disord 2014[54]	0.25	2	National Rheumatology organization	email	1	not given
Ingegnoli Rheumatol Int 2017[55]	0.25	2	International Rheumatology organization	email	not given	not given
Ziadé Clin Rheumatol 2020[56]	0.28	1	International Rheumatology organization	email and social media	15	3 minutes
Moulay Berkchi Rheumatol Int 2020[57]	0.29	1	National Rheumatology organization	email	1	not given
Puchner PLoS One 2016[58]	0.32	2	National medical organization	email or postal mail	1	not given
Larché Clin Rheumatol 2011[59]	0.33	2	National Rheumatology organization	email	1	not given
Magni-Manzoni Rheumatology (Oxford) 2014[60]	0.36	3	International medical organization AND National Rheumatology organizations	email	not given	10-15 minutes

Yazici Arthritis Rheum 2003[61]	0.40	2	International Rheumatology organization	email and social media	1	not given
Butt Clin Rheumatol 2011[62]	0.43	3	National Rheumatology organization AND National medical organization	email	1	not given
Omair Int J Rheum Dis 2017[63]	0.45	2	National Rheumatology organization	email	1	5-7 minutes
Weiss Pediatr Rheumatol Online J 2010[64]	0.46	1	National Rheumatology organization	email	2	not given
Janta Med Ultrason 2016[65]	0.47	1	International medical organization	email	17	not given
De Vries-Bouwstra J Rheumatol 2020[66]	0.47	5	International consortiums AND National consortium AND non-organization based recruitment	email	not given	not given
Gupta J Clin Rheumatol 2008[67]	0.50					
Fraenkel J Rheumatol 2001[68]	0.56	1	International Rheumatology organization	email	1	not given
Hugle Pediatr Rheumatol Online J 2013[69]	0.63	4	International Rheumatology organization AND National rheumatology organization	email	3	not given
Cox Int J Rheum Dis 2017[70]	0.63	1	non-organization based recruitment	email	2	not given
Taylor Ann Rheum Dis 2005[71]	0.64	1	non-organization based recruitment	email	not given	not given
Ghosh N Z Med J 2014[72]	0.65	1	National Rheumatology organization	email	1	not given
Chédeville J Rheumatol 2007[73]	0.76	1	National Rheumatology organization	email	1	not given

Vargas-Santos PLoS One 2015[74]	0.78	7	National Rheumatology organization	email (and phone call reminders)	1	not given
Batthish Pediatr Rheumatol Online J 2013[75]	0.78	1	Regional medical organization	email	1	not given
Nikiphorou Ann Rheum Dis 2017[76]		1	International Rheumatology organization	email and social media	47	not given
Gupta Rheumatol Int 2020[77]		1	non-organization based recruitment	social media	3	5 minutes
Mehta Semin Arthritis Rheum 2020[78]		1	National or Regional Rheumatology organizations	email and social media	1	not given
Alegre Reumatol Clin 2019[79]		1	National Rheumatology organization AND non organization based recruitment	email	1	not given
Najm RMD Open 2020[80]		1	International Rheumatology organization AND National rheumatology organization	email and social media	36	not given
Mehta RMD Open 2020[81]		1	International / National / Regional Rheumatology organizations AND non organizations baed recruitment	email and social media	64	not given
Jassim Mediterr J Rheumatol 2020[82]		1	non-organization based recruitment	email and social media	1	not given
Akintayo Rheumatology (Oxford) 2021[83]		1	International / National / Regional Rheumatology organizations	email and social media	20	6 minutes
Kaspar Int J Nephrol 2018[84]		4	Regional medical organization AND	email	2	not given

			Regional Rheumatology organization			
Miyamae Mod Rheumatol 2017[85]			National Rheumatology organization	email	1	
Nikiphorou Clin Exp Rheumatol 2017[86]				email and social media	39	
Nicolaou Open Rheumatol J 2012[87]		2	National Rheumatology organization	email and social media	1	not given

Supplementary Document 4: Revised Survey Post Conduction of Focus Group
*Note that changes made from the draft survey from Supplementary Document 1 are italicized.

Section A: Clinical Scenario (Health Professional Factors)

1. A 32-year-old male with axial spondyloarthritis (diagnosis 5 years ago, HLA-B27 positive, *unequivocal findings of structural damage in the sacroiliac joints*) returns for routine f / u. He has no extraspinal disease manifestations and no other medical problems. His disease-related symptoms have been well controlled with a TNF inhibitor. Please describe what you would do for this patient in your clinical practice. Select all that apply.
    - ☐ Assess disease activity in qualitative terms (e.g., excellent, good, stable, better, worse)
    - ☐ Measure disease activity using a validated questionnaire (e.g., BASDAI, ASDAS)
    - ☐ Review *and discuss* vaccination record.
    - ☐ Review *and discuss* smoking status.
    - ☐ Perform a physical examination including peripheral joints and spine.
    - ☐ Record spinal mobility measurements (e.g., Schober, occiput to wall distance)
    - ☐ Discuss exercise and recommend physical therapy
    - ☐ Order CRP and / or ESR *and / or CBC and / or BMP / CMP*.
    - ☐ Order spinal radiographs (if not performed during the last 2-5 years)
    - ☐ Other: write in box

2. The patient is doing well. His disease has been well controlled. He rarely takes Ibuprofen. He has been on a stable dose of the TNF inhibitor for 5 years. *The patient asks for your recommendation*; which management approach would you choose? Select your single best answer.
    - o Keep on same dose of TNF inhibitor, f / u in 3-6 months
    - o Keep on same dose of TNF inhibitor, f / u in 1 year
    - o Discuss and Implement dose reduction of the TNF inhibitor, f / u in 3-6 months
    - o Recommend discontinuation of the TNF inhibitor, f / u in 3-6 months

3. Under which circumstances do you order a DXA scan for patients with axial spondyloarthritis. Select all that apply.
    - ☐ All Women with AS above age 40
    - ☐ All patients with AS at least once
    - ☐ Every 5 years after the diagnosis of AS
    - ☐ History of spine fracture or recent non-spinal fracture
    - ☐ X-ray reports commenting on low bone density
    - ☐ *Family history of osteoporosis*
    - ☐ *History of long-term steroid / glucocorticoid use*

- Other: write in box

4. *In your opinion*, which of the following disease scores have utility to measure disease activity in patients with axial SpA / AS?

	Not at all useful for axSpA / AS	Not very useful for axSpA / AS	Neutral	Very useful for axSpA / AS	Extremely useful in axSpA / AS	Don't know it
ASDAS						
BASDAI						
CDAI						
DAS28						
RAPID3						

Section B: Patient and Societal Factors

Patient Factors

5. Do you provide any patient facing handouts regarding guidelines to treatment at clinic visits?
   - Yes
   - No

6. Using the scale below, approximately what percentage of the axSpA / AS patients in your clinic come prepared with *knowledge of specific guideline recommendations*? Select the best answer.

None	25%	50%	75%	100%

7. Approximately what percentage of your patients with axSpA / AS do regular strengthening exercises and or stretching on their own at home? Select the best answer.

None	25%	50%	75%	100%

8. Approximately what percentage of your patients with axSpA / AS engaged in organized PT over the past year? Select the best answer.

None	25%	50%	75%	100%

9. What barriers do you perceive that prevent your patients from exercising to the recommended amount (choose all that apply)?
    - ☐ Time
    - ☐ Cost
    - ☐ Pain
    - ☐ Other: write in box

Societal Factors

10. In your opinion, should the prescription of biologics be linked to specific thresholds of disease activity scores (*i.e., requirement of a specific BASDAI score to prescribe biologics)?*
    - ○ Yes
    - ○ Neutral
    - ○ No

Section C: Guideline Factors

11. Which resources do you consult for the questions regarding the management of patients with axSpA / AS (choose all that apply)?
    - ☐ ACR / SAA / SPARTAN guidelines / *corresponding website*
    - ☐ ASAS guidelines / *corresponding website*
    - ☐ Up-to-Date
    - ☐ Pubmed
    - ☐ Textbooks (e-books or hardcopy)
    - ☐ *Colleagues*
    - ☐ Other: write in box

12. For which aspects of the management of axSpA / AS patients do you reference guidelines *when considering these management options* (choose all that apply)?
    - ☐ Pharmacological therapy
    - ☐ Disease activity monitoring
    - ☐ Physical therapy / exercise
    - ☐ Osteoporosis screening / management
    - ☐ Diet and lifestyle
    - ☐ Vaccination
    - ☐ Other: write in box

13. How did you learn about the ACR / SAA / SPARTAN guidelines (choose all that apply)?
    - ☐ Arthritis & Rheumatology publication
    - ☐ Arthritis Care & Research publication
    - ☐ ACR Annual Meeting
    - ☐ The Rheumatologist
    - ☐ Online source, e.g., Rheum Now, *EBRheum, Rheuminations*
    - ☐ Educational seminars or conferences, e.g., SPARTAN-GRAPPA symposia
    - ☐ Social media, e.g., Twitter
    - ☐ Other: write-in box

14. Please rate the guidelines based on how satisfied you are with each of the following criteria?

	Extremely Dissatisfied	Somewhat Dissatisfied	Neutral	Somewhat Satisfied	Extremely Satisfied
Evidence-Based					
Relevance in Clinical Practice					
User Friendliness					

Section D: Practice Setting Factors

15. Do you routinely collect patient-reported data (*i.e., RAPID3*) using patient facing tablets / electronic devices / web interface *including MyChart*?
    - o Yes
    - o No

16. Which electronic medical record system does your clinic / institution use?
    - o Allscripts
    - o athenahealth
    - o Cerner
    - o eClinicalworks
    - o EPIC
    - o Meditech
    - o NextGen
    - o Other: write-in box

17. Does your EMR have templates for disease activity monitoring (e.g., BASDAI)?
    - Yes
    - No
    - Don't know

18. Does your EMR provide handouts or other educational material for patients with axSpA / AS that can be printed out or sent electronically?
    - Yes
    - No
    - Don't know

19. Please rate the ease of application of the following aspects of the guidelines in your practice from 1 to 5.

	Extremely Difficult	Somewhat Difficult	Neutral	Somewhat Easy	Extremely Easy
Disease Activity Monitoring					
Physical Therapy					

20. Please rank the following barriers to implementing guidelines in order, with the top of the list being the most significant? Please drag and drop the items from the left hand side into the box on the right hand side.

21. If there are any barriers you observe in your practice that were not on the list, please include them here:
    - Write in box

22. Are there other healthcare providers involved in care of the patient at each visit besides you?
    - Yes
    - No

23. Are the disease activity monitoring assessments completed by you (the physician) or by another healthcare provider?
    - Me
    - Someone else

24. If the disease activity monitoring assessments are completed by someone else, what is their title (choose all that apply)?
    - NP
    - RN
    - *LPN*
    - PA
    - MA
    - Other: write in box

25. If you find that time is a barrier – is this true for all clinic visits or specifically your AS patients?
    - All visits
    - Just AS patient visits

26. Is there a specific implementation plan for the AS guidelines within your practice (e.g., continuous education, checklist etc.)?
    - Yes
    - No

27. [If above answer was yes] what is it?
    - Write in box

28. If you advise a patient to engage in back exercises at home, what kind of resources do you provide this patient to guide them?
    - Printed Handout
    - Website Resource Link
    - Other: write in box

Section E: Demographic Questions

29. What gender do you identify with?
    - Male
    - Female
    - Prefer not to disclose
    - Prefer to self-describe: write in box

30. What is your level of training?
    - Board-certified rheumatologist, practicing
    - Board certified rheumatologist, retired
    - Rheumatology fellow
    - Physician Assistant or Nurse Practitioner
    - Other: write in box

31. [If Board-certified rheumatologist selected]: Year you completed your rheumatology subspecialty training?
    - drop down menu

    [If Rheumatology fellow selected]: Year you started fellowship training
    - drop-down menu

    [If PA, NP or Other]: skip

32. Select the option that best describes the setting in which you practice:
    - Academic Medical Center
    - Hospital-based practice
    - Group practice
    - Solo practice
    - Retired
    - Other: write-in box

33. *What is your primary practice focus as a Rheumatologist?*
    - *All rheumatology cases, no restrictions*
    - *Emphasis on Spondyloarthritis*
    - *Emphasis on Lupus and similar autoimmune diseases*
    - *Emphasis on RA primarily*
    - *Mostly osteoarthritis and fibromyalgia*

LIST OF JOURNAL ABBREVIATIONS

ACR Open Rheumatol.	ACR Open Rheumatology
Ann R Coll Surg Engl.	Annals of the Royal College of Surgeons of England
Ann Rheum Dis.	Annals of the Rheumatic Diseases
Arthritis Care Res (Hoboken)	Arthritis Care & Research (Hoboken)
Arthritis Res Ther.	Arthritis Research & Therapy
BMC Musculoskelet Disord.	BMC Musculoskeletal Disorders
BMC Rheumatol.	BMC Rheumatology
Clin Exp Rheumatol.	Clinical Experimental Rheumatology
Clin Rheumatol.	Clinical Rheumatology
Int J Nephrol.	International Journal of Nephrology
Int J Rheum Dis.	International Journal of Rheumatic Diseases
J Clin Rheumatol.	Journal of Clinical Rheumatology
J Pediatr Ophthalmol Strabismus	Journal of Pediatric Ophthalmology & Strabismus
J Rheumatol	The Journal of Rheumatology
JAMA	JAMA: The Journal of the American Medical Association
Med Ultrason.	Medical Ultrasonography
Mediterr J Rheumatol.	Mediterranean Journal of Rheumatology
Mod Rheumatol.	Modern Rheumatology

N Z Med J.	New Zealand Medical Journal
Open Access Rheumatol.	Open Access Rheumatology
Open Rheumatol J.	The Open Rheumatology Journal
Pediatr Rheumatol Online J.	Pediatric Rheumatology Online Journal
PLoS One.	Public Library of Science One
Rambam Maimonides Med J.	Rambam Maimonides Medical Journal
Reumatol Clin.	Reumatología Clínica
Rheumatol Int.	Rheumatology International
Rheumatol Ther.	Rheumatology and Therapy
RMD Open	RMD Open
Semin Arthritis Rheum.	Seminars in Arthritis and Rheumatism
Singapore Med J.	Singapore Medical Journal

REFERENCES

1. Sieper J, Braun J, Dougados M, Baeten D. Axial spondyloarthritis. *Nature Reviews Disease Primers*. 2015;1(1):1-16. doi:10.1038 / nrdp.2015.13

2. Sieper J, Poddubnyy D. Axial spondyloarthritis. *The Lancet*. 2017;390(10089):73-84. doi:10.1016 / S0140-6736(16)31591-4

3. Laloo F, Herregods N, Jaremko JL, et al. MRI of the axial skeleton in spondyloarthritis: the many faces of new bone formation. *Insights into Imaging*. 2019;10(1):67. doi:10.1186 / s13244-019-0752-4

4. Ward MM, Deodhar A, Akl EA, et al. American College of Rheumatology / Spondylitis Association of America / Spondyloarthritis Research and Treatment Network 2015 Recommendations for the Treatment of Ankylosing Spondylitis and Nonradiographic Axial Spondyloarthritis. *Arthritis Care & Research*. 2016;68(2):151-166. doi:10.1002 / acr.22708

5. Ward MM, Deodhar A, Gensler LS, et al. 2019 Update of the American College of Rheumatology / Spondylitis Association of America / Spondyloarthritis Research and Treatment Network Recommendations for the Treatment of Ankylosing Spondylitis and Nonradiographic Axial Spondyloarthritis. *Arthritis & Rheumatology*. 2019;71(10):1599-1613. doi:10.1002 / art.41042

6. Patel A, Sizheng SZ, Ermann J. Adherence to Non-Pharmacological Management Recomendations for Ankylosing Spondylitis in Clinical Practice.

7. Cabana MD, Rand CS, Powe NR, et al. Why Don't Physicians Follow Clinical Practice Guidelines?: A Framework for Improvement. *JAMA*. 1999;282(15):1458-1465. doi:10.1001 / jama.282.15.1458

8. Francke AL, Smit MC, de Veer AJ, Mistiaen P. Factors influencing the implementation of clinical guidelines for health care professionals: A systematic meta-review. *BMC Medical Informatics and Decision Making*. 2008;8(1):38. doi:10.1186 / 1472-6947-8-38

9. Flottorp SA, Oxman AD, Krause J, et al. A checklist for identifying determinants of practice: A systematic review and synthesis of frameworks and taxonomies of factors that prevent or enable improvements in healthcare professional practice. *Implementation Science*. 2013;8(1):35. doi:10.1186 / 1748-5908-8-35

10. Fischer F, Lange K, Klose K, Greiner W, Kraemer A. Barriers and Strategies in Guideline Implementation—A Scoping Review. *Healthcare (Basel)*. 2016;4(3). doi:10.3390 / healthcare4030036

11. Correa VC, Lugo-Agudelo LH, Aguirre-Acevedo DC, et al. Individual, health system, and contextual barriers and facilitators for the implementation of clinical practice guidelines: a systematic metareview. *Health Research Policy and Systems*. 2020;18(1):74. doi:10.1186 / s12961-020-00588-8

12. Jones T, Baxter M, Khanduja V. A quick guide to survey research. *Ann R Coll Surg Engl*. 2013;95(1):5-7. doi:10.1308 / 003588413X13511609956372

13. Wong LP. Focus group discussion: a tool for health and medical research. *Singapore Med J*. 2008;49(3):256-260; quiz 261.

14. Gossec L, Dougados M, Phillips C, et al. Dissemination and evaluation of the ASAS / EULAR recommendations for the management of ankylosing spondylitis: results of a study among 1507 rheumatologists. *Ann Rheum Dis*. 2008;67(6):782-788. doi:10.1136 / ard.2007.080077

15. Che H, Etcheto A, Dernis E, Nataf H, Boumier P, Breuillard P. Evaluation of collected outcome measures in axial spondyloarthritis in daily-care rheumatology settings: the experience of the RHEVER network. Clin Exp Rheumatol. Published 2015. Accessed March 16, 2021. https: / / www.clinexprheumatol.org / abstract.asp?a=9194

16. Nota I, Drossaert CHC, Taal E, Vonkeman HE, Haagsma CJ, van de Laar MAFJ. Evaluation of a patient decision aid for initiating disease modifying anti-rheumatic drugs. *Arthritis Res Ther*. 2016;18. doi:10.1186 / s13075-016-1138-3

17. Pereira-Gillion C, Marot M, Griffoul-Espitalier I, Andras L, Goupille P, Salliot C. Application of Recommendations Regarding the Use of Subcutaneous Tumor Necrosis Factor Inhibitors in Spondyloarthritis by Rheumatologists in Daily Practice. *The Journal of Rheumatology*. 2018;45(4):491-497. doi:10.3899 / jrheum.170587

18. Ozgocmen S, Akgul O, Akıncı A, et al. Agreement of Turkish Physiatrists with the Assessment in Spondyloarthritis International Society and the European League Against Rheumatism Recommendations for the Management of Ankylosing Spondylitis and Rheumatoid Arthritis. *Open Rheumatol J*. 2012;6:1-5. doi:10.2174 / 1874312901206010001

19. Spadaro A, Lubrano E, Marchesoni A, Cauli A, Cantini F. The adherence to ASAS classification criteria and to ASAS recommendations for the use of anti-TNH-alpha agents in axial spondyloarthritis. Clin Exp Rheumatol. Published 2014. Accessed March 16, 2021. https: / / www.clinexprheumatol.org / abstract.asp?a=7527

20. Gossec L, Molto A, Beauvais C, et al. Agreement with the French 2019 recommendations on treatment adherence in rheumatic diseases among 357 health

professionals. *Joint Bone Spine*. 2020;87(5):513-515. doi:10.1016 / j.jbspin.2020.04.008

21. Niedermann K, Nast I, Ciurea A, Vlieland TV, Bodegom-Vos L van. Barriers and Facilitators of Vigorous Cardiorespiratory Training in Axial Spondyloarthritis: Surveys Among Patients, Physiotherapists, and Rheumatologists. *Arthritis Care & Research*. 2019;71(6):839-851. doi:https: / / doi.org / 10.1002 / acr.23705

22. Fongen C, Sveaas SH, Dagfinrud H. Barriers and Facilitators for Being Physically Active in Patients with Ankylosing Spondylitis: A Cross-sectional Comparative Study. *Musculoskeletal Care*. 2015;13(2):76-83. doi:https: / / doi.org / 10.1002 / msc.1088

23. Freid LM, Ogdie A, Baker JF. Physical Activity Patterns in People With Inflammatory Arthritis Indicate They Have not Received Recommendation-Based Guidance From Health Care Providers. *ACR Open Rheumatol*. 2020;2(10):582-587. doi:10.1002 / acr2.11183

24. Durcan L, Wilson F, Conway R, Cunnane G, O'Shea F. Increased Body Mass Index in Ankylosing Spondylitis Is Associated with Greater Burden of Symptoms and Poor Perceptions of the Benefits of Exercise | The Journal of Rheumatology. Published 2012. Accessed March 16, 2021. https: / / www-jrheum-org.ezproxy.bu.edu / content / 39 / 12 / 2310.long

25. Hilberdink B, van der Giesen F, Vliet Vlieland T, van Gaalen F, van Weely S. Supervised Group Exercise in Axial Spondyloarthritis: Patients' Satisfaction and Perspective on Evidence-Based Enhancements. *Arthritis Care Res (Hoboken)*. 2020;72(6):829-837. doi:10.1002 / acr.23892

26. O'Dwyer T, McGowan E, O'Shea F, Wilson F. Physical Activity and Exercise: Perspectives of Adults With Ankylosing Spondylitis. *Journal of Physical Activity and Health*. 2016;13(5):504-513. doi:10.1123 / jpah.2015-0435

27. Davergne T, Moe RH, Fautrel B, Gossec L. Development and initial validation of a questionnaire to assess facilitators and barriers to physical activity for patients with rheumatoid arthritis, axial spondyloarthritis and / or psoriatic arthritis. *Rheumatol Int*. 2020;40(12):2085-2095. doi:10.1007 / s00296-020-04692-4

28. Hammer NM, Midtgaard J, Hetland ML, Krogh NS, Esbensen BA. Physical activity behaviour in men with inflammatory joint disease: a cross-sectional register-based study. *Rheumatology*. 2018;57(5):803-812. doi:10.1093 / rheumatology / kex498

29. Osthoff A-KR, Vlieland TV, Braem R, Walker B, Schneider KN. Fri0700-Hpr Lessons Learned from Pilot Implementation of Physical Activity Recommendations

in Axspa Exercise Group Therapy – Less May Be More. *Annals of the Rheumatic Diseases*. 2019;78(Suppl 2):1049-1049. doi:10.1136 / annrheumdis-2019-eular.7188

30. Rasmussen JO, Primdahl J, Fick W, Bremander A. Physical activity in people with axial spondyloarthritis and the impact of overall attitudes, barriers, and facilitators: A cross-sectional study. *Musculoskeletal Care*. 2020;18(4):510-518. doi:https: / / doi.org / 10.1002 / msc.1495

31. Zarco P, Florez M, Almodóvar R. Expert Opinion of Spanish Rheumatologists About the Role of Physical Exercise in Ankging Spondylitis and Other Rheumatic Diseases. *Reumatol Clin*. 2016;12(1):15-21. doi:10.1016 / j.reumae.2015.11.009

32. Fabre S, Molto A, Dadoun S, et al. Physical activity in patients with axial spondyloarthritis: a cross-sectional study of 203 patients. *Rheumatol Int*. 2016;36(12):1711-1718. doi:10.1007 / s00296-016-3565-5

33. Hilberdink B, van der Giesen F, Vliet Vlieland T, Nijkamp M, van Weely S. How to optimize exercise behavior in axial spondyloarthritis? Results of an intervention mapping study. *Patient Education and Counseling*. 2020;103(5):952-959. doi:10.1016 / j.pec.2019.12.017

34. Hilberdink B, Vlieland TV, van der Giesen F, et al. Adequately dosed aerobic physical activity in people with axial spondyloarthritis: associations with physical therapy. *Rheumatol Int*. 2020;40(9):1519-1528. doi:10.1007 / s00296-020-04637-x

35. Passalent LA, Soever LJ, O'shea FD, Inman RD. Exercise in Ankylosing Spondylitis: Discrepancies Between Recommendations and Reality. *The Journal of Rheumatology*. 2010;37(4):835-841. doi:10.3899 / jrheum.090655

36. Castrejón I, McCollum L, Tanriover MD, Pincus T. Importance of patient history and physical examination in rheumatoid arthritis compared to other chronic diseases: Results of a physician survey. *Arthritis Care & Research*. 2012;64(8):1250-1255. doi:https: / / doi.org / 10.1002 / acr.21650

37. Palestine AG, Singh JK, Kolfenbach JR, Ozzello DJ. Specialty Practice and Cost Considerations in the Management of Uveitis Associated With Juvenile Idiopathic Arthritis. *J Pediatr Ophthalmol Strabismus*. 2016;53(4):246-251. doi:10.3928 / 01913913-20160505-01

38. Garneau KL, Iversen MD, Tsao H, Solomon DH. Primary care physicians' perspectives towards managing rheumatoid arthritis: room for improvement. *Arthritis Res Ther*. 2011;13(6):R189. doi:10.1186 / ar3517

39. Ogdie A, Shah AA, Makris UE, et al. Barriers and Facilitators of a Career as a Physician Scientist Among Rheumatologists in the United States. *Arthritis Care Res (Hoboken)*. 2015;67(9):1191-1201. doi:10.1002 / acr.22569

40. Palestine AG, Kolfenbach JR, Ozzello DJ. Rheumatologists and Ophthalmologists Differ in Treatment Decisions for Ocular Behçet Disease. *J Clin Rheumatol*. 2016;22(6):316-319. doi:10.1097 / RHU.0000000000000424

41. Barnabe C, Chomistek K, Luca N, et al. National Priorities for High-quality Rheumatology Transition Care for Youth in Canada. *The Journal of Rheumatology*. 2021;48(3):426-433. doi:10.3899 / jrheum.200790

42. Mangat P, Conron M, Gabbay E, Proudman SM. Scleroderma lung disease, variation in screening, diagnosis and treatment practices between rheumatologists and respiratory physicians. *Internal Medicine Journal*. 2010;40(7):494-502. doi:https: / / doi.org / 10.1111 / j.1445-5994.2009.01990.x

43. Barra L, Liang P, Benseler SM, et al. Variations in the clinical practice of physicians managing Takayasu arteritis: a nationwide survey. *Open Access Rheumatol*. 2017;9:91-99. doi:10.2147 / OARRR.S132080

44. Panchal S, Khare M, Moorthy A, Samanta A. Catch me if you can: a national survey of rheumatologists and obstetricians on the use of DMARDs during pregnancy. *Rheumatol Int*. 2013;33(2):347-353. doi:10.1007 / s00296-012-2418-0

45. Glauser TA, Ruderman EM, Kummerle D, Kelly S. Current Practice Patterns and Educational Needs of Rheumatologists Who Manage Patients with Rheumatoid Arthritis. *Rheumatol Ther*. 2014;1(1):31-44. doi:10.1007 / s40744-014-0004-5

46. De Vera MA, Baldwin C, Tsao NW, et al. Management of Inflammatory Arthritis in pregnancy: a National Cross-Sectional Survey of Canadian rheumatologists. *BMC Rheumatol*. 2019;3. doi:10.1186 / s41927-019-0065-8

47. Correll CK, Spector LG, Zhang L, Binstadt BA, Vehe RK. Barriers and alternatives to pediatric rheumatology referrals: survey of general pediatricians in the United States. *Pediatr Rheumatol Online J*. 2015;13. doi:10.1186 / s12969-015-0028-6

48. Schallhorn J, Haug SJ, Yoon MK, Porco T, Seiff SR, McCulley TJ. A National Survey of Practice Patterns: Temporal Artery Biopsy. *Ophthalmology*. 2013;120(9):1930-1934. doi:10.1016 / j.ophtha.2013.01.052

49. Toka B, Eminler AT, Gönüllü E, et al. Rheumatologists' awareness of hepatitis B reactivation before immunosuppressive therapy. *Rheumatol Int*. 2019;39(12):2077-2085. doi:10.1007 / s00296-019-04437-y

50. Ablin JN, Elkayam O, Fitzcharles M-A. Attitudes of Israeli Rheumatologists to the Use of Medical Cannabis as Therapy for Rheumatic Disorders. *Rambam Maimonides Med J*. 2016;7(2). doi:10.5041 / RMMJ.10239

51. Hopkins AM, Wiese MD, O'Doherty CE, Proudman SM. Putting recommendations into practice: Australian rheumatologists' opinions on leflunomide use in rheumatoid arthritis. *Clin Rheumatol*. 2017;36(4):791-798. doi:10.1007 / s10067-016-3488-2

52. Curtis JR, Chen L, Danila M, Saag KG, Parham K, Cush J. Routine Use of Quantitative Disease Activity Measurements among U.S. Rheumatologists: Implications for Treat to Target Management Strategies in Rheumatoid Arthritis. *J Rheumatol*. 2018;45(1):40-44. doi:10.3899 / jrheum.170548

53. Cettomai D, Gelber AC, Christopher-Stine L. A Survey of Rheumatologists' Practice for Prescribing Pneumocystis Prophylaxis. *The Journal of Rheumatology*. 2010;37(4):792-799. doi:10.3899 / jrheum.090843

54. Fitzcharles M-A, Ste-Marie PA, Clauw DJ, et al. Rheumatologists lack confidence in their knowledge of cannabinoids pertaining to the management of rheumatic complaints. *BMC Musculoskelet Disord*. 2014;15:258. doi:10.1186 / 1471-2474-15-258

55. Ingegnoli F, Ughi N, Dinsdale G, et al. An International Survey on non-invasive techniques to assess the microcirculation in patients with Raynaud's phenomenon (SUNSHINE survey). *Rheumatol Int*. 2017;37(11):1879-1890. doi:10.1007 / s00296-017-3808-0

56. Ziadé N, Hmamouchi I, el Kibbi L, et al. The impact of COVID-19 pandemic on rheumatology practice: a cross-sectional multinational study. *Clin Rheumatol*. Published online September 30, 2020:1-9. doi:10.1007 / s10067-020-05428-2

57. Moulay Berkchi J, Rkain H, Benbrahim L, et al. Management of gout by Moroccan rheumatologists: a Moroccan Society for Rheumatology National Survey. *Rheumatol Int*. 2020;40(9):1399-1408. doi:10.1007 / s00296-020-04599-0

58. Puchner R, Edlinger M, Mur E, et al. Interface Management between General Practitioners and Rheumatologists—Results of a Survey Defining a Concept for Future Joint Recommendations. *PLoS One*. 2016;11(1). doi:10.1371 / journal.pone.0146149

59. Larché MJ, McDonald-Blumer H, Bruns A, et al. Utility and feasibility of musculoskeletal ultrasonography (MSK US) in rheumatology practice in Canada: needs assessment. *Clin Rheumatol*. 2011;30(10):1277-1283. doi:10.1007 / s10067-011-1743-0

60. Magni-Manzoni S, Collado P, Jousse-Joulin S, et al. Current state of musculoskeletal ultrasound in paediatric rheumatology: results of an international survey. *Rheumatology*. 2014;53(3):491-496. doi:10.1093 / rheumatology / ket368

61. Yazici Y, Erkan D, Paget SA. Monitoring by rheumatologists for methotrexate-, etanercept-, infliximab-, and anakinra-associated adverse events. *Arthritis & Rheumatism*. 2003;48(10):2769-2772. doi:https: / / doi.org / 10.1002 / art.11277

62. Butt U, Amissah-Arthur M, Khattak F, Elsworth CF. What are we doing about septic arthritis? A survey of UK-based rheumatologists and orthopedic surgeons. *Clin Rheumatol*. 2011;30(5):707-710. doi:10.1007 / s10067-010-1672-3

63. Omair MA, Omair MA, Halabi H. Survey on management strategies of rheumatoid arthritis in Saudi Arabia: a Saudi Society for Rheumatology Initiative. *International Journal of Rheumatic Diseases*. 2017;20(9):1185-1192. doi:https: / / doi.org / 10.1111 / 1756-185X.12735

64. Weiss JE, Uribe AG, Malleson PN, Kimura Y. Anesthesia for intra-articular corticosteroid injections in juvenile idiopathic arthritis: A survey of pediatric rheumatologists. *Pediatr Rheumatol Online J*. 2010;8:3. doi:10.1186 / 1546-0096-8-3

65. Janta I, Terslev L, Ammitzbøll-Danielsen M, Kosevoi-Tichie A, Berner-Hammer H, Naredo E. EFSUMB COMPASS for Rheumatologists dissemination and implementation--an international survey. *Med Ultrason*. 2016;18(1):42-46. doi:10.11152 / mu.2013.2066.181.iuj

66. Vries-Bouwstra JK de, Allanore Y, Matucci-Cerinic M, Balbir-Gurman A. Worldwide Expert Agreement on Updated Recommendations for the Treatment of Systemic Sclerosis. *The Journal of Rheumatology*. 2020;47(2):249-254. doi:10.3899 / jrheum.181173

67. Gupta D, Zachariah A, Roppelt H, Patel AM, Gruber BL. Prophylactic antibiotic usage for Pneumocystis jirovecii pneumonia in patients with systemic lupus erythematosus on cyclophosphamide: a survey of US rheumatologists and the review of literature. *J Clin Rheumatol*. 2008;14(5):267-272. doi:10.1097 / RHU.0b013e31817a7e30

68. Fraenkel L, Felson DT. Rheumatologists' attitudes toward routine screening for hydroxychloroquine retinopathy. *The Journal of Rheumatology*. 2001;28(6):1218-1221.

69. Hugle B, Haas J-P, Benseler SM. Treatment preferences in juvenile idiopathic arthritis – a comparative analysis in two health care systems. *Pediatr Rheumatol Online J*. 2013;11:3. doi:10.1186 / 1546-0096-11-3

70. Cox A, Piper S, Singh-Grewal D. Pediatric rheumatology consultant workforce in Australia and New Zealand: the current state of play and challenges for the future. *Int J Rheum Dis*. 2017;20(5):647-653. doi:10.1111 / 1756-185X.12802

71. Taylor W. Preliminary identification of core domains for outcome studies in psoriatic arthritis using Delphi methods. *Ann Rheum Dis*. 2005;64(Suppl 2):ii110-ii112. doi:10.1136 / ard.2004.030874

72. Ghosh SK, Corkill MM, Hart HH, Ng KP. Screening for pulmonary arterial hypertension in patients with scleroderma--a New Zealand perspective. *N Z Med J*. 2014;127(1400):30-38.

73. Chédeville G, Scuccimarri R, Duffy CM. Survey on the use of methotrexate by pediatric rheumatologists in Canada. *The Journal of Rheumatology*. 2007;34(4):818-822.

74. Vargas-Santos AB, Castelar-Pinheiro G da R, Coutinho ESF, Schumacher HR, Singh JA, Schlesinger N. Adherence to the 2012 American College of Rheumatology (ACR) Guidelines for Management of Gout: A Survey of Brazilian Rheumatologists. *PLoS One*. 2015;10(8). doi:10.1371 / journal.pone.0135805

75. Batthish M, Bassilious E, Schneider R, Feldman BM, Hyman A, Tse SM. A unique, interactive and web-based pediatric rheumatology teaching module: residents' perceptions. *Pediatr Rheumatol Online J*. 2013;11:22. doi:10.1186 / 1546-0096-11-22

76. Nikiphorou E, Studenic P, Ammitzbøll CG, et al. Social media use among young rheumatologists and basic scientists: results of an international survey by the Emerging EULAR Network (EMEUNET). *Annals of the Rheumatic Diseases*. 2017;76(4):712-715. doi:10.1136 / annrheumdis-2016-209718

77. Gupta L, Gasparyan AY, Zimba O, Misra DP. Scholarly publishing and journal targeting in the time of the Coronavirus Disease 2019 (COVID-19) pandemic: a cross-sectional survey of rheumatologists and other specialists. *Rheumatol Int*. Published online October 13, 2020:1-8. doi:10.1007 / s00296-020-04718-x

78. Mehta B, Jannat-Khah D, Mancuso CA, et al. Geographical variations in COVID-19 perceptions and patient management: a national survey of rheumatologists. *Semin Arthritis Rheum*. 2020;50(5):1049-1054. doi:10.1016 / j.semarthrit.2020.06.017

79. Alegre C. Private rheumatology in Catalonia, Spain. *Reumatol Clin*. 2019;15(3):170-172. doi:10.1016 / j.reuma.2017.07.016

80. Najm A, Kostine M, Pauling JD, et al. Multidisciplinary collaboration among young specialists: results of an international survey by the emerging EULAR network and

other young organisations. *RMD Open*. 2020;6(2). doi:10.1136 / rmdopen-2020-001398

81. Mehta B, Jannat-Khah D, Fontana MA, et al. Impact of COVID-19 on vulnerable patients with rheumatic disease: results of a worldwide survey. *RMD Open*. 2020;6(3). doi:10.1136 / rmdopen-2020-001378

82. Jassim NA, Yasiry D, Hummadi YA. Attitude of Iraqi Rheumatologists While Managing Rheumatic Diseases in the Era of COVID-19: An Online Survey. *Mediterr J Rheumatol*. 2020;31(Suppl 2):299-303. doi:10.31138 / mjr.31.3.299

83. Akintayo RO, Akpabio AA, Kalla AA, et al. The impact of COVID-19 on rheumatology practice across Africa. *Rheumatology (Oxford)*. Published online October 6, 2020. doi:10.1093 / rheumatology / keaa600

84. Kaspar CDW, Sanderson K, Ozen S, et al. Pediatric Nephrology and Rheumatology Practice Patterns in Granulomatosis with Polyangiitis: A Midwest Pediatric Nephrology Consortium Study. *Int J Nephrol*. 2018;2018. doi:10.1155 / 2018 / 8413096

85. Miyamae T, Takei S, Itoh Y, Yamanaka H. Survey of attitudes of non-pediatric rheumatologists among councilors of the Japan College of Rheumatology regarding transitional care. *Mod Rheumatol*. 2017;27(6):1047-1050. doi:10.1080 / 14397595.2017.1285846

86. Nikiphorou E, Galloway J, van Riel P, et al. The spectrum of early rheumatoid arthritis practice across the globe: results from a multinational cross sectional survey. *Clin Exp Rheumatol*. 2017;35(3):477-483.

87. Nicolaou M, Armstrong R, Hassell AB, Walker D, Birrell F. Musculoskeletal Health Professional Use of Internet Resources for Personal and Patient Education: Results from an Online National Survey. *Open Rheumatol J*. 2012;6:190-198. doi:10.2174 / 1874312901206010190

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