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Enhancing Equity in Clinical Research: A Multifaceted Proposal for Spondyloarthritis

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ABSTRACT. Clinical research advances medical knowledge and improves healthcare outcomes. However, disparities in research participation hinder progress. The Unmet Research Needs in Spondyloarthritis Conference IV highlighted critical insights and strategies to enhance equity in clinical research. Talks focused on engaging underrepresented communities and addressing disparities in rheumatic diseases, particularly spondyloarthritis (SpA), to ensure research results are generalizable and inclusive. Disparities in SpA management, such as greater back pain severity among Black and Hispanic Americans and sex-based differences in pain management, emphasize the need for equitable research. Dr. Elizabeth Ferucci discussed the racial disparities in rheumatologic care, highlighting the importance of early access to rheumatologists and culturally informed primary care to improve outcomes. Dr. Hani El-Gabalawy's talk on engaging Indigenous communities stressed the importance of community consent and reciprocal benefits. Dr. Sarfaraz Hasni's presentation on mitigating disparities in research participation underscored the need for inclusive practices and strategies to promote diverse representation. Finally, Dr. Edith Williams emphasized institutional approaches to fostering equity, including diverse recruitment practices and institutional review board alignment with diversity priorities. Strategies to enhance equity in clinical research include community engagement, addressing logistical barriers to participation, and ensuring diverse research teams. These approaches can dismantle barriers for underrepresented communities, making research more accessible and reflective of the broader population. The SpA research community must commit to creating structures that foster inclusivity, ensuring medical advancements benefit all populations, especially historically underrepresented groups. The principles and strategies proposed serve as a roadmap for achieving equity in SpA research.

Key Indexing Terms: outcomes, spondyloarthritis

Introduction

Clinical research advances medical knowledge and improves healthcare outcomes. However, achieving meaningful progress requires a concerted effort to address disparities in research participation through enhanced engagement of underrepresented communities. This summary explores insights from 4 talks delivered as part of the Unmet Research Needs in Spondyloarthritis Conference IV, each shedding light on critical aspects of enhancing equity in clinical research. The talks touch on engaging underrepresented communities and existing disparities in the epidemiology and outcomes of rheumatic diseases, while offering strategies that researchers may adopt to mitigate disparities in research participation and strategies for institutions to support equity in research. Such approaches foster inclusivity, improve social justice, and increase the impact of research by ensuring results are generalizable and can be broadly implemented. It is our hope that the principles and strategies proposed in this summary may serve as a roadmap for the spondyloarthritis (SpA) research community in working toward equity in clinical research.

As part of the supplement series Spondyloarthritis Unmet Research Needs Conference IV, this report was reviewed internally and approved by the Guest Editors for integrity, accuracy, and consistency with scientific and ethical standards.

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Although there are limited data on disparities specific to SpA, there is a body of evidence documenting disparities in the management of back pain, the most common presenting feature of SpA. Back pain severity and its interference with social and physical activity is greater among Black and Hispanic Americans, yet clinicians are less likely to evaluate members of these groups with advanced imaging, refer them for physical therapy, or prescribe them opioid analgesics.[1-3] There are sex disparities in the management of pain as well; clinicians underestimate women's pain and are less likely to perform investigations or prescribe analgesics.[4,5] Further, Black Americans are less commonly diagnosed with axial SpA (axSpA), and when diagnosed, have greater disease activity and comorbidity burden than White Americans, suggesting that clinicians' cognitive biases may cause missed diagnoses in milder cases.[6-9] There may be, in part, a biologic basis for racial and ethnic differences in SpA prevalence in that HLA-B27 risk alleles are more common among persons of Eurasian ancestry.[10] However, axSpA is also known to occur in individuals who are HLA-B27 negative (10-40% of axSpA cases), yet the mechanisms underlying disease development in the absence of an HLA-B27 risk allele are not well known.[11]

Owing to the paucity of literature in SpA, we can learn from experiences in other rheumatologic conditions to understand disparities that may be shared, and how the SpA research community may work toward more equity in research participation and clinical outcomes.

Racial disparities in rheumatologic care

Dr. Elizabeth Ferucci discussed racial disparities in rheumatic diseases, including disparities in disease epidemiology, outcomes, and access to care. As we consider disparities in these different dimensions, there are some overarching principles that apply to all rheumatic diseases, including SpA, such as strategies to facilitate access to care and treatment.

Epidemiology of disease. There are disparities in the incidence and prevalence of many rheumatic diseases, including disparities by race, ethnicity, sex, and other sociodemographic characteristics. When considering the reasons for differences in incident disease, research most commonly focuses on genetic and environmental factors (ie, biology). A prototypic rheumatic disease for which disparities are established is systemic lupus erythematosus (SLE), which is most prevalent in American Indian/Alaska Native and Black populations in the United States.[12] Although genetic and environmental factors contribute to SLE incidence, delays in diagnosis occur and may relate to access to rheumatology care. Therefore, access to specialty care for diagnosis of complex rheumatic diseases can influence the measured incidence and prevalence. An example illustrating this point is the recent increase in incidence and prevalence of IgG4-related disease in the US, a condition that was recently identified and for which familiarity has been increasing over time.[13] For SpA, the prevalence of HLA-B27, the most significant genetic association, is high in Indigenous North American (INA) populations in the US, Canada, and circumpolar regions, which likely contributes to the increased recognition of this condition in INA populations.[14] However, it is likely that SpA is underrecognized given the complexity of the diagnosis and limited access to rheumatologists.

Clinical outcomes. Outcomes of many rheumatic diseases also vary by race and ethnicity. One well-studied example is total joint arthroplasty in people with advanced osteoarthritis, which is performed at a higher rate in White than Black individuals in the US, whereas complication rates are higher for Black than White individuals.[15] Another example is mortality in SLE, in which US Medicaid data show high rates of mortality in American Indian/Alaska Native and Black individuals.[16] Many factors contribute to outcomes in rheumatic disease, including biologic factors associated with more severe disease, social determinants of health, access to rheumatologists, rheumatologists' knowledge, access to medication, and the availability of representative clinical data.

Access to care. Given the lack of evidence-based prevention strategies for most rheumatic diseases, early access to appropriate care remains one of the most important modifiable risk factors for improved outcomes. In the US, there is a rheumatology workforce shortage as well as a maldistribution of rheumatologists, favoring urban areas on the East Coast over other areas of the US.[17] Although access to rheumatologists is critical for diagnosis and management of rheumatic disease, other factors are important as well. These include access to high-quality and culturally informed primary care in a location and format that is accessible, testing, medications and other treatments, relevant clinical data, and education for patients and families.

Strategies to improve access to care and clinical outcomes. To improve access to care and clinical outcomes, several different strategies may be effective depending on the setting and local context. Within the rheumatology realm, the use of telemedicine, outreach clinics, and eConsults may be able to address the workforce maldistribution. Within the primary care realm, outreach may include community health workers and culturally informed care. Other strategies involving partnerships between rheumatologists and primary care providers include education for primary care providers, comanagement of rheumatic diseases in the long term, and providing educational resources for patients and families.

Application to SpA. Racial disparities in the epidemiology of SpA are multifactorial and include genetic and environmental factors. Evaluation by a rheumatologist is important for establishing a diagnosis of SpA and may affect measured incidence and prevalence. Disparities in clinical outcomes are multifactorial and social determinants of health should be considered. Access to high-quality and culturally informed primary care and rheumatologists are important, as are relevant clinical trial data. Because biologics play a larger role in the treatment of SpA compared to other forms of arthritis, disparities in access to medications have critical implications to disease outcomes. Potential interventions in the clinical realm could focus on many different stages of the disease course, including earlier recognition and diagnosis, early access to specialists, access to medications including biologics, access to physical therapy, and retention in specialty care. Collaboration between primary care and rheumatologists is important for long-term management.

Engaging Indigenous communities in clinical research

Dr. Hani El-Gabalawy discussed best practices in engaging underrepresented communities, using the example of preclinical rheumatoid arthritis (RA) studies in First Nations (FN) people. Key considerations involve understanding and respecting traditional knowledge systems, ensuring community consent, and fostering reciprocal relationships.

Community engagement is the foundation of research in Indigenous communities. Community engagement is required for research conducted among FN people but should be a part of any community-based research program as background to developing the research question and approach. There are several key principles to community engagement, starting with the researcher actually "showing up" in the community. The research team needs to be physically present and visible in the community, taking the time to develop a trusting relationship and, ultimately, a partnership with the community. Researchers must work to gain an understanding of, and respect for, Indigenous identity, knowledge systems, and customs. Once the research is initiated, the team needs to maintain adaptability in study methods. Research personnel should ideally be hired from within the community, both for the insight they bring to study procedures, and for interconnectedness with community members. Research visits may be aligned with community events such as local health fairs in order to enhance visibility of the research and to be minimally disruptive to participants.

Research should be planned to include *reciprocity*, which refers to providing a benefit to the community in exchange for their participation in research. The specific mechanisms of how the community would benefit should be a decision made between community members and leaders and the research team. Examples of reciprocity may include the provision of clinical rheumatology services alongside the research program and sharing the results of research with the community.

Although research in non-Indigenous populations typically requires only individual consent, research in Indigenous communities requires a dual consent process, requiring both individual and community consent. The latter is achieved through ratified research agreements. Ownership, control, access, and possession principles should guide the development of research agreements by addressing plans for reporting and publication, storage and disposal, and secondary use of samples and data, with amendments as needed during the project. An advisory body of community Elders, health leaders, patients, and research personnel is typically required as part of the research agreement.

Preclinical RA studies in FN people. One example of a successful community partnership is the study of preclinical RA in the FN people. It is known that many INA populations have a high prevalence of RA (2-3%).[18] Many INA populations have up to an 80% prevalence of the predisposing shared epitope alleles in the background population, along with a high prevalence of predisposing environmental factors such as smoking and periodontal disease, providing a strong rationale for undertaking a study of preclinical RA in this population. Tanner et al conducted a prospective study of first-degree relatives (FDR) of Canadian and Alaskan FN people with RA.[19] They found that progression to RA was related to the high prevalence of the shared epitope in the population and prevalent anticitrullinated protein antibody (ACPA) or rheumatoid factor positivity in FDR. This study also provided new evidence of ACPA epitope spreading prior to RA onset. Subsequently, it was found that high levels of ACPA-IgG V-domain glycosylation, a feature that is relatively unique to this IgG molecule and demonstrable in most patients with established ACPA-positive RA, was indeed also demonstrable in ACPA-positive FDR who later went on to develop RA (hazard ratio 6.07).[20] These observations indicate that the maturation of the immunological processes underpinning ACPA autoimmunity, as evidenced by epitope spreading and increased ACPA-IgG V-domain glycosylation, may serve as a key indicator of future RA risk and provide new insights into how intervention at this stage may potentially prevent RA onset. The success of this preclinical RA research program is credited to the establishment of partnerships founded on trust and respect with each Indigenous community involved in the study.[19] This collaborative approach has proven instrumental in gaining insights into the complex pathogenesis underlying the development of RA, and it underscores the importance of ethical, culturally sensitive, and community-engaged studies in achieving a greater understanding of disease pathogenesis.

Mitigating disparities in research participation: lessons from SLE

Dr. Sarfaraz Hasni highlighted the pervasive issue of disparities in clinical research participation, with concerning underrepresentation of racial and ethnic minorities, older adults, those with disabilities, and those across the gender spectrum. Current statistics starkly portray a research landscape skewed heavily toward White participants, emphasizing the urgent need for inclusive practices.

The rationale for diverse representation in clinical research. A recent report from the National Academies of Sciences, Engineering, and Medicine[21] described the potential benefits of achieving diverse representation and the consequences of failing to do so, including the following:

- *Limited generalizability of research findings.* For example, response to an investigational drug varies among racial and ethnic minorities, children, women, and older adults as a result of genetic and nongenetic factors. Insufficiently representing these groups leads to clinical decisions not based on evidence and compounds health disparities in underrepresented groups.
- *Economic impact.* Better representation in research would improve quality of life and reduce morbidity in minority populations. The increased participation of underrepresented communities will translate into more years lived without disability, more years in the labor force, and substantial societal cost savings.
- *Trust in medicine.* More representative and inclusive clinical trial participation may increase marginalized groups' trust in clinical research and science, leading to improved clinical outcomes.

Barriers to research participation. Various socioeconomic factors, biases, and historical reasons preclude minority groups from participating in clinical research. For example, those with lower household income are less likely to participate in clinical trials.[22] Members of minority communities are more likely to receive hourly wages, requiring sacrificed income to participate in research. Other logistical challenges disproportionately burden minority groups, including lack of access to reliable transportation, dependent care, and sick leave. Clinicians and researchers may hold biases, such as the belief that individuals from some subgroups cannot adhere to a study protocol, and therefore may not offer study participation.[23] Minority group members may have limited health literacy, requiring researchers to provide resources to support study participation. There has been a long history of medical and scientific exploitation of minorities, especially Black communities. Consequently, minority communities may lack trust in their healthcare providers and perceive that they are asked to take on most of the risks associated with medical research.[24] Despite historical abuses, several studies have found that mistrust is not necessarily associated with a lack of willingness to participate in research.[25] Further, patients from racial and ethnic minority backgrounds are more likely to trust a provider from a similar background, yet demographics of the rheumatology workforce do not match those of the US population.[26]

Strategies to reduce disparities in research participation. Multiple strategies have been proposed to promote diversity in clinical trial participation, including those addressing research communication, reciprocity, compensation, and flexibility of research visits. Research literacy can be enhanced among underrepresented minorities by designing research materials in a culturally competent manner.[27] Researchers can engage community members early in the research process to address concerns and thereby promote trust and willingness to participate. Researchers can discuss the benefits of research participation, such as access to expert care, increased knowledge about their condition, and greater scientific knowledge to society. Researchers can provide adequate compensation for transportation, dependent care, and participants' time to facilitate participation. Finally, researchers can provide flexibility for research visits to be less disruptive to participants, such as visits after typical work hours or by telemedicine, and they can use mobile technology rather than in-person visits to capture selected research data.

Successful programs to mitigate disparities in research participation in SLE. Training to Increase Minority Enrollment in Lupus Clinical Trials With Community Engagement (TIMELY) is an initiative by the American College of Rheumatology to educate healthcare providers and community health workers on addressing barriers to clinical trial enrollment. As part of the program, interactive training modules improve clinical research literacy and build partnerships with providers and organizations to remove barriers to trial referral. Examples include hybrid virtual/in-person SLE clinical trial summits that bring patients, clinical researchers, and pharmaceutical representatives together to discuss diverse trial participation. Peer-to-peer mentoring extends an existing model that was successful in disease management to provide culturally sensitive social support for research participation among minority people with SLE. This initiative on community-engaged research in SLE connects academic institutions with community organizations to improve health research literacy and develop community trust.

Institutional approaches to equity in research

Dr. Edith Williams explored institutional approaches aimed at fostering equity in research. The cornerstone of equity lies in creating environments that prioritize relationships. Strategies to promote equity including recruitment practices that yield a research team with diverse backgrounds and aligning institutional review boards (IRBs) with diversity, equity, and inclusion priorities. Researchers should also be provided protected time for relationship building and engagement with communities of interest in a meaningful manner in advance of developing research programs.

The rationale for equity. Creating environments conducive to research equity requires a focus on diversity at many levels, including in both research participants and the investigative team. A diverse body of research participants promotes social justice, while simultaneously reducing bias and improving generalizability of the research findings.[28,29] Evidence also supports the value of diversity in research teams. Teams with greater diversity tend to focus more on facts, make fewer errors in decision making, and are more adept at processing information meticulously.[30,31] Hiring individuals from diverse backgrounds can prevent conformity and encourage innovative thinking. Fostering an inclusive workplace is necessary to reap the full spectrum of benefits that diversity brings, enhancing intellectual potential, and contributing to organizational success.

Diverse recruitment of research team members requires that institutions strategically consider many factors, including placement of recruitment materials and the optimal structure of job postings. They may also reevaluate required qualifications to accommodate less traditional roles, such as community health workers and liaisons. Institutions should ensure they offer competitive wages.[32] Specific strategies include identifying avenues to integrate and sustain less traditional roles, such as partnerships with clinical units to support community health workers, patient advocates, and peer health coaches as members of the clinical care team. Recruitment of qualified team members with relevant experience will also require creativity with regard to marketing and advertising positions. Instead of traditional academic advertising strategies like journal advertisements and booths at professional meetings, hiring units may want to consult community partners for endorsement, participate in local community events, or leverage relevant social media platforms and networks.

To recruit more diverse research participants, institutions can ensure that research materials are developed for those with limited general and health literacy in mind, and they can design less daunting and more inclusive incentive and remuneration processes.[33] For example, some institutions offer participants physical prepaid gift cards at the end of research visits due to barriers participants may face with other forms of remuneration (eg, unstable housing precludes later mailing payment, lack of access to email makes electronic gift cards unreliable, lack of a bank account to deposit or cash a check). Cash payments may also be ideal for certain populations, but restrictive institutional policies may preclude petty cash accounts and disbursements, which may necessitate policy discussions with institutional leadership.

Taken together, these strategies for recruitment of research staff and participants collectively aim to dismantle barriers that might impede the participation of individuals from underrepresented communities, making the research landscape more accessible, inclusive, and, ultimately, reflective of the broader population (see the section on barriers to research participation above).

Institutional offices, such as the IRBs, have a pivotal role in promoting inclusion in clinical research. Drawing on the insights from the American Association for the Advancement of Science, it is clear that ethical oversight provided by IRBs must encompass diversity considerations.[34] The need for diversity is not just in research participants but also within other institutional boards, departments, and committees, such as those involved in nominating and governance, human resources, and compensation, to ensure that a broad range of employee backgrounds are represented. One approach could be to provide a table of participant characteristics to ensure they match the population served by the institution or the larger population.[35] For institutions in which this marks a culture shift, a period of training or skill development may be necessary.[36]

Support for community engagement. Institutions can support equity through attention to equity in policies and practices. Funders and sponsors can mandate a priori engagement with communities of interest and can support research team efforts and roles for relationship building. Employers of researchers can incentivize faculty for meaningful activity and visibility in the community and recognize such work in their tenure and promotion process. Resources like the Urban Institute toolkit may be helpful as guidance for developing equitable and sustainable partnerships as the cornerstone of impactful research.[37] The importance of fostering relationships with an equity lens is reiterated through insights from EdTrust, further underscoring the transformative potential of strong relationships in positively shaping racial, cultural, and ethnic identity development.[38]

Prioritizing basic needs. Meeting the basic needs of communities of interest is necessary before approaching them for research involvement. Individuals who are struggling for survival or to meet basic needs (food, housing, utilities, medications) may not be able to participate in nonessential clinical research. One strategy to facilitate research participation in a major research institution was to establish a patient navigator who linked patients to essential services, such as prescription cost-reduction programs, transportation, housing services, emergency childcare, and food service programs. Implementation of the navigator had a profound impact to engender trust and receptiveness to conversations about research.[39]

Conclusions and proposed strategies to enhance equity in clinical research in SpA

Key principles presented by experts at the Unmet Research Needs in Spondyloarthritis Conference IV are highlighted in the Box. There is an urgent need to adopt and implement strategies to improve diversity among participants in clinical research and research teams in SpA. The SpA research community should collectively commit to creating structures that actively engage underrepresented communities, thereby fostering a research landscape that reflects the diversity of those affected by SpA. Strategies may include requirements for community engagement, protected researcher time to establish trusting community partnerships, linking a service to the community with the research program, addressing barriers to participation, developing research materials for those with limited health literacy in mind, and ensuring that the benefits of SpA research are disseminated and implemented in all appropriate populations. Simultaneously, the SpA research community must work to ensure that the research community reflects the diversity of the broader population. Institutions, researchers, and communities must collaborate to create an equitable research landscape, ensuring that medical advancements benefit all populations, especially subgroups that have been historically underrepresented.

Box. Key principles to improve equity in spondyloarthritis clinical research.

- Diverse research participation improves the impact of research by improving generalizability of results to broader populations; broad implementation improves disease outcomes and has a greater societal benefit.
- Research teams must engage communities that are historically underrepresented and develop partnerships based on mutual trust and transparency to guide development of each research question and approach.
- Partnerships require investment of researcher effort over time with iterative evolution through the project life cycle.
- Effective and productive community engagement requires the in-person presence of the research team to gain understanding of community identity, knowledge systems, customs, and barriers to research participation.
- Research team members should include members of the communities being studied, whenever possible.
- Researchers should aspire to achieve reciprocity, in which they offer a benefit or service to the community in exchange for participation in research (eg, clinical rheumatology services).
- Research visits may be aligned with clinical care or community events to be minimally disruptive to participants.
- Barriers to participation in research include historical exploitation of minorities, biases among healthcare professionals, unmet basic needs, and poor access to primary or rheumatology care. Addressing barriers to research requires attention from researchers, institutions, and legislators.
- Institutions including funders, sponsors, and universities can mandate community engagement as the first step in research, provide for researchers' protected time for community engagement, and recognize community work in their tenure and promotions processes.

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