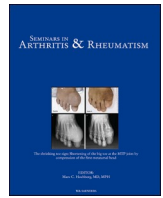




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Embracing unity at OMERACT: Valuing equity, promoting diversity, fostering inclusivity

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ABSTRACT

Objective: To increase awareness and understanding of the principles of Equity, Diversity, and Inclusivity (EDI) within Outcome Measures in Rheumatology's (OMERACT) members. For this, we aimed to obtain ideas on how to promote and foster these principles within the organization and determine the diversity of the current membership in order to focus future efforts.

Methods: We held a plenary workshop session at OMERACT 2023 with roundtable discussions on barriers and solutions to increased diversity within OMERACT. We conducted an anonymous, web-based survey of members to record characteristics including population group, gender identity, education level, age, and ability.

Results: The workshop generated ideas to increase diversity of participants across the themes of building relationships [12 topics], materials and methods [5 topics], and conference-specific [6 topics]. Four hundred and seven people responded to the survey (25 % response rate). The majority of respondents were White (75 %), female (61 %), university-educated (94 %), Christian (42 %), spoke English at home (60 %), aged 35 to 55 years (50 %), and did not report a disability (64 %).

Conclusion: OMERACT is committed to improving its diversity. Next steps include strategic recruitment of members to the EDI working group, drafting an EDI mission statement centering equity and inclusivity in the

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organization, and developing guidance for the OMERACT Handbook to help all working groups create actionable plans for promoting EDI principles.

Introduction

OMERACT is an international, not-for-profit organization that supports the development of core outcome sets in rheumatological conditions. Since its inception in 1992, OMERACT has had international collaboration as one of its core principles; each working group in OMERACT must have co-chairs representing at least three continents. Other inclusive approaches are to involve patient research partners and other interest groups such as industry representatives in all working groups [1]. The rationale for this principle is to capture a wide range of perspectives and experiences thereby leading to increased acceptance by users of core outcomes (e.g., clinical trialists, post-regulatory decision makers, evidence synthesizers, health policy makers) in a global setting. However, we recognize the need to expand the focus of location-based diversity to a more comprehensive representation of diversity across a multitude of characteristics such as race, ethnicity, language, country of origin, gender identity, religious identity, disability, and age.

Previous work of the OMERACT Equity working group focused on developing methodology for assessing whether patient-reported outcome measures (PROMs) have evidence for their use in populations at risk for experiencing inequities and/or oppression. The OMERACT Summary of Measurement Properties Equity table (SOMP-Equity) is a tool that provides transparent reporting of the results of evidence looking at validation studies for PROMs in populations using the PROGRESS-Plus framework [2]. This framework was applied to assess how frequently and to what extent equity has been considered in the development, selection or testing of PROMs in the domains of pain, physical function, disease activity and quality of life for rheumatoid arthritis [3]. This study found important gaps in patient representation from populations at risk for inequities in assessing the measurement properties of PROMs eg a major paucity of qualitative studies or longitudinal studies to determine responsiveness .

At OMERACT 2023, the focus of the working group was redirected to better understand the fundamentals of broad representation using the approach of Equity, Diversity, and Inclusivity (EDI) to promote fairness and equity within an organization. EDI is about creating an environment where everyone is valued and respected, regardless of their background, identity, or experience. Equity refers to the fair treatment of individuals, considering the unique challenges and barriers they may face due to their background, impairments, or identity. Diversity refers to the range of differences that exist among individuals, including differences in, but not limited to, ancestry, race, ethnicity, gender, sexual orientation, age, ability, religion, and socioeconomic status. Inclusivity refers to celebrating diversity and creating an environment where everyone feels welcome and valued, regardless of their cultural, ancestral, gender, and other differences.

Failure to consider the principles of EDI in research has the potential to harm patients and lead to important gaps in knowledge and further disparities in care. By exclusion of certain populations from research, we are not able to understand disease behaviour and course in these populations. Structural racism has been shown to be a root cause of health inequities; the complex interplay of laws, policies, and resource allocation, when combined with the state of economic, educational, and healthcare systems that are under-resourced results in inequities in both physical and mental health [4,5].

Building organizational capacity to advance health equity requires consideration of policies and practices across the organization. Various frameworks are available to help identify strategies and activities to build awareness of EDI principles, measure key metrics, ensure policies are clear and transparent, support diverse membership and leadership, and undertake regular evaluation of progress against established goals

[6,7].

OMERACT recognizes the necessity of integrating these considerations more comprehensively into the development of core outcome sets. As a result, we selected EDI as a plenary topic for the OMERACT 2023 conference, to a) increase the attention to EDI throughout OMERACT and b) set an EDI research agenda .

Methods

OMERACT plenary workshop

We organized a plenary workshop at OMERACT 2023, held in Colorado Springs, USA, to describe the fundamentals of EDI principles and then a roundtable approach to elicit and discuss the systemic barriers that can prevent some individuals or groups from fully participating and contributing to OMERACT's mission and goals. We asked participants to discuss the question, "Taking into account barriers, what can OMERACT do to promote inclusivity within OMERACT?". To demonstrate the geographic distribution of meeting attendees, we created a map showing the distribution based on the country provided in the participants' meeting registration details.

Survey of OMERACT members

During discussions at the workshop, a suggestion was made that OMERACT needed to understand the current composition of self-identified diversity within its membership to know where to focus future efforts to increase diversity and inclusion.

Study design

We conducted a cross-sectional, web-based survey to collect demographic data about the self-identified diversity of OMERACT members.

Survey development

We drafted the survey questions based on the United Way Social Identity Wheel [8] and sent the first draft to the OMERACT EDI steering group members for review. We revised the draft in response to comments to create the final version of the survey. The 10 survey questions asked participants to identify their population group, country of origin, gender identity, sexual orientation, language, religious identity, ability, cultural/religious/health dietary considerations, and age [Supplementary materials, Appendix A.1]. We acknowledged to the participants that definitions and descriptions of race, ethnicity, gender, and other characteristics are fluid, influenced by sociocultural contexts, and may vary globally. To address this, we provided an option for participants to complete the survey using terms they prefer and provided an option at the end of the survey for any additional comments. Respondents could select more than one option for questions on population group, gender identity and language.

Administration

The online survey was administered using SurveyMonkey® survey software. Participants could go back and change their answers to prior questions before submission. We did not provide any incentives to complete the survey.

Sample population

The survey was sent to the OMERACT mailing list which consists of 1636 people, and we sent a reminder once a week for three weeks.

Data analysis

We used descriptive statistics to describe the frequency of the category responses for each question.

Ethics

Given this was an internal organizational survey that was anonymous, was optional, and not related to personal health, formal ethics approval was not sought.

Results

OMERACT meeting

The majority of attendees at the OMERACT 2023 meeting were from North America, Western Europe and Australia [Fig. 1]. There were three people from the Middle East, one from South America, and no representation from Asia and Africa.

Participants offered several ideas for OMERACT to implement to promote inclusivity within the organization. These were thematically organized into concepts around membership and engagement, materials/methods, and conference-specific ideas [Box 1].

Survey results

Out of 1636 people who were emailed the survey, 407 responded, a response rate of 24.8 %. Detailed survey results for each question are provided in Supplementary material, Appendix A.2. For the question about population group, 75 % ($n = 305$) of respondents reported 'White'. The next largest population group was 'South Asian' (5.2 %, $n = 21$) followed closely by 'Latin American' (4.7 %, $n = 19$). The 'other' category received 54 responses and the most frequently added category to this question in the survey was 'European'. Others added specific country citizenship to the list, e.g., 'British', 'Nigerian' and two people added 'Jewish'.

The country of origin responses were spread across 60 countries. The highest country of origin reported by participants was the United States of America ($n = 69$, 17 %) followed by the United Kingdom ($n = 51$, 12.5 %) and Australia ($n = 32$, 7.9 %). Both India ($n = 13$, 3.2 %) and Brazil ($n = 11$, 2.7 %) were in the top 10 countries selected but the percent of respondents representing those countries was low. Forty-five countries

had five or fewer respondents. One quarter of the countries (15/60) are considered low or middle-income countries according to the World Bank [9].

The majority of respondents to the gender identity question identified as women ($N = 250$, 61.4 %), followed by men ($N = 150$, 36.9 %). There were few respondents to the rest of the categories: nonbinary ($N = 2$), and one each for genderfluid, genderqueer, and transgender. Four preferred not to answer.

For current sexual orientation, the majority responded their identity as heterosexual/straight ($N = 355$, 87.2 %) with the rest of the categories under 2 %: gay ($N = 7$), asexual ($N = 6$), lesbian ($N = 5$), bisexual ($N = 4$), questioning ($N = 4$), queer ($N = 3$), and pansexual ($N = 2$). Five percent (5 %) of respondents preferred not to answer this question.

The greatest frequency for age range of respondents was 35–54 years old ($N = 204$, 50.1 %) followed by 55–65 years ($N = 98$, 24.2 %) and 65–74 years ($N = 65$, 16.0 %). Less than 6 % were 18–35 years ($N = 24$, 5.9 %) or 75 or older ($N = 14$).

The majority of respondents identified with Christianity ($N = 173$, 42.5 %) with the next most frequent categories being 'I do not identify with any religion' ($N = 92$, 22.6 %), atheism ($N = 35$, 8.6 %) and agnosticism ($N = 28$, 6.9 %). The other religion options were each selected by less than 5 % of participants.

Most respondents held a doctorate or professional degree ($N = 275$, 67.6 %) and 26 % had either a bachelor's or master's degree. Five percent (5 %) had a high school or equivalent education.

Forty-three different languages were spoken at home amongst the respondents with the majority speaking English ($N = 244$, 60 %), followed by Spanish ($N = 26$, 6.4 %) and Dutch ($N = 22$, 5.4 %). The rest of the languages were each spoken by less than 5 % of respondents.

Approximately one-third of respondents (34 %) indicated that they had a disability (defined as including chronic illness or pain, mental illness, neurodivergence, or another health-related condition) while the majority ($N = 262$, 64.4 %) indicated they did not have a disability.

Discussion

OMERACT supports the development of core outcome sets for use in clinical trials and for regulatory approval of new treatments. It is essential that these sets are inclusive and respectful, and not gendered, racialized, or minoritized. There is an intrinsic value to diversity in the research membership to ensure representation of those affected by

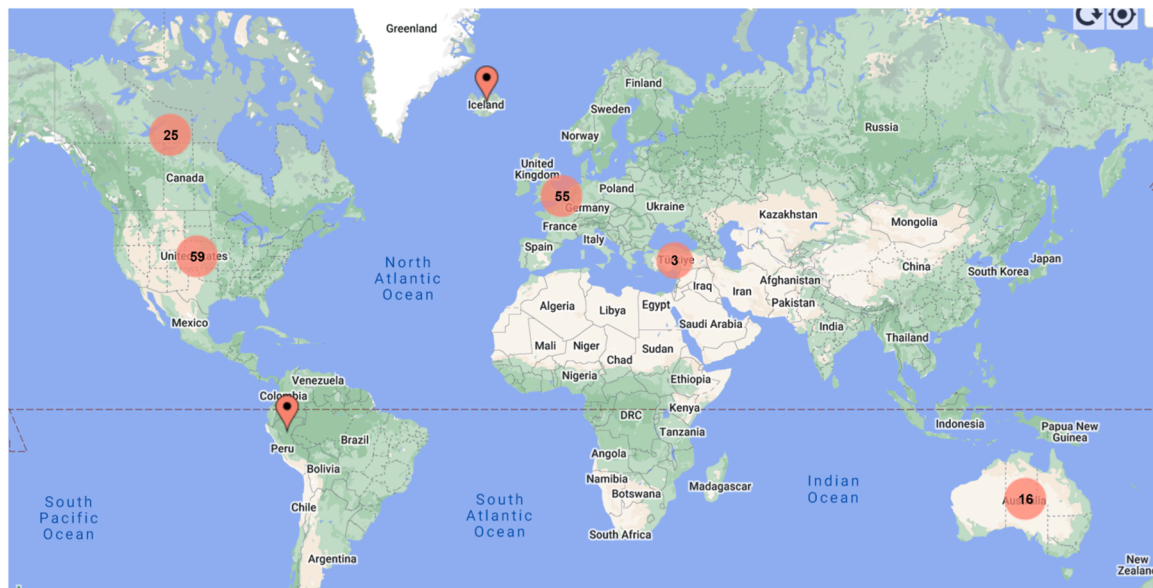


Fig. 1. Map showing the location of where OMERACT 2023 attendees were based.

Box 1

Ideas to Promote Inclusivity within OMERACT

Improve EDI through our Membership and Engagement

- Increase membership diversity by leveraging existing relationships to increase the diversity of OMERACT members.
- Identify community champions.
- Engage patients and patient groups to increase diverse representation.
- Recruit a greater diversity of professions to join OMERACT.
- Increase safe spaces for OMERACT patients.
- Engage OMERACT Fellows and Emerging Leaders.
- Support leaders from Asia, Africa, the Middle East and other underrepresented areas.
- Intentionally recruit members from underrepresented areas (e.g., Asia, Africa, Middle East).
- Develop strategies to personally welcome and support people from new areas.
- Increase diversity of the EDI working group.
- Emphasize cultural competency: “The ability to collaborate effectively with individuals from different cultures.”

Develop Materials and Methods that Foster EDI

- Ensure OMERACT materials are written to be more accessible (e.g., literacy level).
- Translation of e-learning modules and other key materials into a variety of languages.
- Include non-English speaking groups in qualitative research.
- Include non-English literature in literature searches.
- Address barriers to joining working groups (e.g., financial and systemic)

Develop Policies and Programs that Facilitate EDI at our Conferences

- Address financial constraints for attendance (e.g., offer scholarships, reduce registration fees, offer different levels of registration, offer low-cost events).
- Provide translation services for conference sessions.
- Provide a range of culturally appropriate foods, drinks, etc.
- Consider greater representation in geographic location of OMERACT events.
- Consider the accessibility of physical layout of location.
- Improve the virtual experience and offer hybrid meeting opportunities.

rheumatic disease reflects community needs.

The fact that the survey results showed the majority of OMERACT members are White, well-educated, English-speaking, and originally from North America, Europe, and Australia is not surprising given the origins of OMERACT. OMERACT was created thirty years ago in response to significant therapeutic advances in rheumatoid arthritis. Most of the OMERACT meetings have been held in High Income Countries. Established research networks and collaborations are more prevalent in these countries and there is easier access to mentorship and collaboration opportunities as well as funding opportunities. Also, technologies for easier communication (e.g., conference calls and more recently video-conferencing) have historically been more available in these continents which leads to easier and sustained collaboration. English is the working language for scientific journal publications. These are some examples of factors which help to explain the characteristics of the existing OMERACT membership.

Bias, whether implicit or explicit can have lasting impact on both those experiencing harm and those dependent on the data produced. It is essential for OMERACT, as an organization, to analyze areas of potential structural bias, racism (both overt or vicarious) as well as micro-aggressions that can impact the optimal performance of OMERACT members, and their experience. Implicit bias training, while helpful to the individual is insufficient to induce sustained and meaningful change in organizations and ignores the role of structure in framing the beliefs and actions of individuals and the rules, regulations and policies that govern institutions [10].

Racialization in medicine, or race-based medicine, can lead to racial health inequities in multiple ways, including non-diverse epidemiological studies incorrectly inferring that race may have biological significance which perpetuates health-based stereotyping and reinforces erroneous biological concepts of race. As well, presumptions about

effectiveness of treatments in one race versus another or application of primarily white data to other racial groups without knowing if there may be resulting differences in response can result in health inequities. In contrast, applying the principles of EDI facilitates the study of the effects of structural racism, and the consequences on health outcomes and health disparities [11–14]. Matsui et al. [15] has developed an antiracist framework for racial and ethnic health disparities research that lays out how poorly defining the concept of race and inferring race to have biological significance can influence the spectrum of research, beginning with medical education through to clinical practice and lead to racial health inequities. They position race-conscious medicine as a solution where the effects of structural racism are analyzed and taught during medical training along with advocating for support to overcome structural barriers in clinical practice.

Research must draw on the social psychology of implicit racial bias and incorporate racial and ethnic minority patient perspectives that can inform the development of clinical research and education of health care providers. Health care provider communication offers a means of addressing racial health disparities in healthcare and systemically. Including patients from racially and ethnically diverse groups in patient-provider communication research, can create a more comprehensive understanding of the role that provider communication behaviors play in health outcomes of diverse patient populations [16–19].

Furthermore, health outcomes may be improved by equity integration in rheumatology clinical practice guidelines and research design. Guidance and resources for better recruitment and engagement of diverse patient populations at the site level in clinical trials has been developed [20]. GRADE has developed recommendations for considering health equity during guideline development. These include standardized race reporting and inclusion of multiple racial terms to reflect the prevalence within a disease state, enforce consistency and accuracy

for definitions of race and ethnicity terms, remove conflation of race with ethnicity or genetic ancestry (be clear about appropriate use and limitations), and add country-of-origin information for demographic data [21,22].

EDI approaches [that include not only race and ethnicity but also socio-economic status, gender identity, occupation, education] need to be developed to promote fairness and equity within an organization that creates an environment where everyone is valued and respected regardless of their background, impairments, identity, or experience. As such, the organization can support participatory initiatives, leverage the knowledge and experience of diverse members and be inclusive in all aspects of development and evaluation of its tools. The discussions during the plenary workshop provided practical considerations for promoting inclusivity within OMERACT, including a focus on building relationships, accessibility of training materials, and ideas specific to the biennial conference including reasonable adjustments.

One limitation of the survey is the response rate; we only received responses from a quarter of those on the OMERACT mailing list. However, the results of a predominantly White, middle-aged, well-educated membership is similar to what we expected to find, though whether our finding of a majority of women is true for the entire organization is unclear. We found a fairly large number of countries listed in the responses regarding the country of origin (60, of which 25 % are from low- and middle-income countries) and this broad geographic participation may help us in efforts to ensure broad representation in our research. This survey was focused on OMERACT members, and not those who participate in the research conducted by the individual working groups; therefore, we do not have the data to comment on the diversity of that level of engaged stakeholders. We did not ask participants to self-identify as an OMERACT patient research partner or other stakeholder so we cannot assess the results by these two groups.

Our next steps involve enhancing diversity within the OMERACT EDI working group itself to help ensure a broad group of voices to move this work forward. We will formulate an EDI mission statement that places a strong focus on equity, diversity, and inclusivity within the organization. We will create guidance on practical strategies to advance EDI principles for working groups and embed this in the OMERACT Handbook.

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CRediT authorship contribution statement

Lara J Maxwell: Conceptualization, Methodology, Investigation, Writing – original draft. **Grace C Wright:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing. **Grayson Schultz:** Conceptualization, Methodology, Writing – review & editing. **Shawna Grosskleg:** Conceptualization, Methodology, Writing – review & editing. **Jennifer L Barton:** Conceptualization, Writing – review & editing. **Willemina Campbell:** Conceptualization, Methodology, Writing – review & editing. **Francis Guillemain:** Conceptualization, Methodology, Writing – review & editing. **Catherine Hofstetter:** Conceptualization, Methodology, Writing – review & editing. **Beverley J Shea:** Conceptualization, Methodology, Writing – review & editing. **Lee S Simon:** Conceptualization, Writing – review & editing. **Adewale Adebajo:** Conceptualization, Writing – review & editing. **Cheryl Barnabe:** Conceptualization, Methodology, Writing – review & editing. **Niti Goel:** Writing – review & editing. **Patricia Hurley:** Writing – review & editing. **Elena Nikiphorou:** Writing – review & editing. **Jennifer Petkovic:** Conceptualization, Writing – review & editing. **Peter Tugwell:** Conceptualization, Methodology, Writing – review & editing.

Declaration of competing interest

GS, AA, JLB, SG, CH, CB, EN, PH, JP, BJS have no relevant conflicts of interest to disclose.

LJM is a paid staff member of OMERACT.

GCW has received fees, research grants from AbbVie, AstraZeneca, Bristol-Myers Squibb, Eli Lilly and Company, Gilead Sciences, GSK, Janssen Biotech, Novartis, Pfizer, Sanofi Genzyme, UCB

FG received a grant from NOVARTIS paid to his institution.

WC reports payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events from Abbvie and Einstein Medical College; support for attending meetings and/or travel for previous OMERACT and GRAPPA meetings; and was past GRAPPA PRP Chair.

NG reports support by OMERACT to attend the 2023 OMERACT in person meeting. Owner of stock in Abcuro and UCB and stock option grant at TrialSpark. TrialSpark grant expires 11 Oct 2023. Minority holder in all companies. Former employee of TrialSpark, Inc. (position terminated 11 Jul 2023).

LSS is on the Management Committee of OMERACT and is Chair, Finance Committee of OMERACT.

PT: Consulting Fees from Reformulary Group. An independent Committee Member for clinical trial Data Safety Monitoring Boards for FDA approved trials being conducted by: UCB Biopharma GmbH & SPRL, Parexel International, Prahealth Sciences. I am [unpaid] Chair of the Management Group of a registered non-profit independent medical research organization, OMERACT, whose goal is to improve and advance the health outcomes for patients suffering from musculoskeletal conditions. OMERACT receives arms-length funding from 11 companies: Abbvie, Astra Zeneca, Aurinia, BMS, Centrexion, GSK, Horizon Pharma Inc, Janssen, Novartis, Pfizer & Sparrow.

Supplementary materials

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