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**Title: Fostering Connections at OMERACT 2023: A Collaborative Approach to Core Outcome Set Development**

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**Abbreviations & Definitions:**

OMERACT: Outcome Measures in Rheumatology

PRP: Patient Research Partner

TAG: Technical Advisory Group

COS: Core Outcome Set

OMER-ED: OMERACT Education

SIG: Special Interest Group

ELP: Emerging Leaders Program (ELP)

Stakeholders: Collaborators & Partners: refers to those responsible for or affected by healthcare and healthcare-related decisions. Other terms may include Interested people and groups, end-users, knowledge users, affected groups, decision-makers, and contributors. We previously used the term 'stakeholder' to refer to these individuals. However, OMERACT recognized several negative historical uses of the word "stakeholder," such as its colonial roots in which a stakeholder was the person who drove a stake into the land to demarcate the land they were occupying/stealing from Indigenous territories. In this context, it has been suggested that stakeholders should instead be referred to as "partners" or "rights holders" (Government of British Columbia, 2021). Continued use of the term 'stakeholder' is disrespectful to our Aboriginal and Indigenous partners. In consultation with the MuSE Consortium and others external to this group, we have selected 'collaborators & partners' as a suitable replacement. Throughout this paper, we will shorten this to 'collaborators' to help distinguish this group from others (e.g., external groups).

In 2023, after a three-year delay, OMERACT<sup>1</sup> held its biennial conference in person in Colorado Springs, USA. Initially planned for April 2020, the global COVID-19 pandemic thwarted the initial plans. In 2020, a virtual meeting was organized<sup>2</sup>, ensuring that the momentum and the Spirit of the OMERACT<sup>3</sup> community were maintained. This virtual gathering provided a platform for members to continue their discussions, share findings, and progress their work in an online environment amidst global challenges. The OMERACT 2023 Conference, was a successful event that gathered 157 participants from 14 different countries including rheumatologists, clinical and methods researchers, Patient Research Partners (PRPs), and other healthcare professionals both in-person and online (see figure 1). The conference focused on fostering connections among the OMERACT community, enabling them to share their experiences, knowledge, and perspectives on the development and methodology of Core Outcome Sets (COS) in Rheumatology.

### Pre-Conference Preparation

The preparation for OMERACT 2023 focused on efforts to enhance the conference experience through technological advancements and innovative strategies. A comprehensive set of online learning modules (OMER-ED)<sup>4</sup> was developed to support participants' readiness and comprehension of OMERACT methodologies, offering introductory insights into OMERACT processes and concepts. A shift towards a paperless conference was undertaken in line with sustainability goals, significantly reducing the conference's ecological footprint. This involved reimagining conference materials to integrate into an event app accessible to all attendees. Incorporating this app streamlined access to resources and facilitated interactive engagement, networking, and real-time updates, redefining how participants interacted with conference materials. The dedication and innovation invested in these preparations underscore OMERACT's commitment to advancing the content and delivery of conferences, enriching the experience of all participants.

The OMERACT 2023 conference featured six workshops and 20 Special Interest Group (SIG) sessions to foster connections and interdisciplinary collaboration. These sessions allowed participants to exchange ideas, share expertise, and develop new partnerships.

### Workshop Highlights

1. Empowering Voices: “Patient Engagement Driving Progress in OMERACT” workshop<sup>5</sup> explored the importance of involving PRPs in the research process. The Workshop introduced a framework to facilitate this and an effectiveness scale to quantify successes and next steps that could help improve engagement.
2. The “Championing COS for Impactful Results” workshop<sup>6</sup> brought together experts from PRPs, Healthcare Providers – Pharma & CMS, Health Policy Decision Makers, Payers of Health Research, HTA Collaborators, Policymakers, Regulatory Representatives – FDA & EMA. These collaborators were selected as end-users of COS in their trials, lives, or decision-making. This dissemination effort is a continuation of efforts to promote the use of COS’s<sup>7,8</sup>. The OMERACT

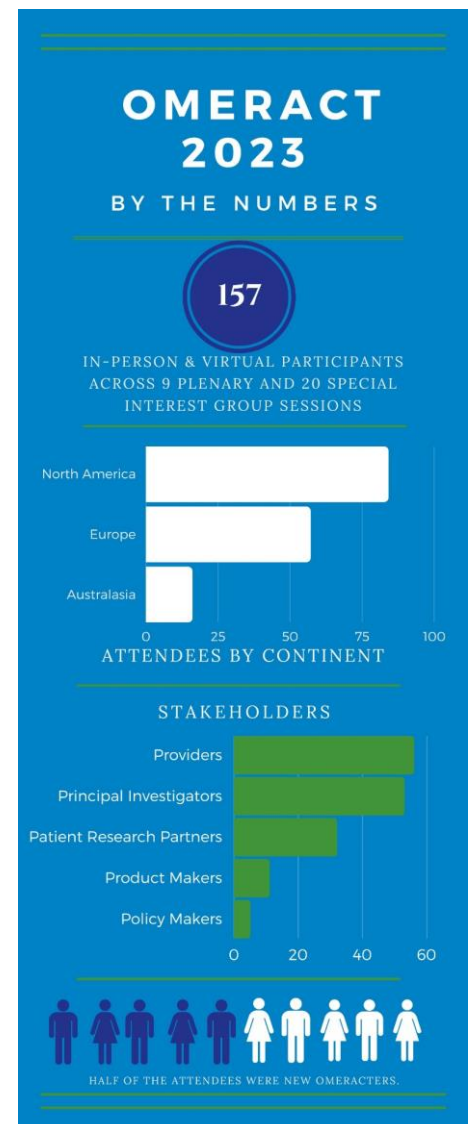


Figure 1. OMERACT 2023 by the numbers

2023 workshop explored the perspectives of various collaborators regarding the utilization of OMERACT's COS. It aimed to align a COS with diverse collaborators to understand their priorities. The session was designed to cultivate conversations about COS implementation and generate practical insights to facilitate improved acceptance and application of COS.

3. In the "Embracing Unity: Advancing Equity, Diversity, and Inclusion Workshop"<sup>9</sup> Dr. Grace Wright delivered an impactful talk shedding light on the significance of EDI and its implications for creating a welcoming environment where everyone is valued and respected, regardless of their background, identity, or experience. Participants engaged in discussions on systemic barriers that can hinder full participation and contribution to OMERACT's mission and goals, enhancing their understanding of the importance of cultivating an inclusive community.
4. The Mastering Methodology: "Reinforcing Our Domains with Detailed Definitions Workshop"<sup>10</sup> centered around defining core domains within COS. This session highlighted the importance of establishing precise and universally understood domain definitions to ensure consistency across COSs. Attendees were presented with the challenges of defining domains and the potential impact of standardized definitions on reducing research duplication and enhancing evidence synthesis.
5. In the Beyond the Surface: "Exploring the Complexities of Pain Workshop,"<sup>11</sup> participants explored the multifaceted realm of Pain. Experts in the field shared their insights covering three distinct types: Nociceptive, Neuropathic, and Nociplastic pain. The session concluded with a discussion about the implications of these pain types on outcome measurement. OMERACT has multiple working groups in which pain is a core domain in their Core Domain Set. The session explored the many facets of pain and attempted to determine whether the same single outcome measure would suffice for any of these working groups, particularly if all three types of pain were being experienced.
6. In the final Workshop, "Introduction to the World of Composite Outcomes,"<sup>12</sup> participants were introduced to the methodology behind composite outcome measures, which combine multiple domains and their instruments into a single combined score to capture complex concepts in health conditions<sup>13</sup>. Utilizing the experience of working groups developing composites, the session explored the challenges and steps involved in creating and validating these measures. Notably, one issue was exploring if individuals and groups of individuals agree on the type of weights that should be assigned in creating a composite. Exercises like this draw attention to the influence methods of weighting have on the composite scores and the importance of thinking through each step of creating these complex composites.

### **OMERACT 2023 Focused Programs**

1. The OMERACT Newcomer Program, established in 2014<sup>14</sup>, is an initiative designed for participants new to the OMERACT community attending the conference for the first time. This program offers sessions and activities that provide orientation to OMERACT's unique features, methodologies, and collaborative environment. Participants engage in daily sessions on OMERACT methodology, COS development, and conference navigation, empowering them to contribute to OMERACT's initiatives. Networking events facilitate connections with experienced members to support integration into the. While the initial session witnessed a notable no-show rate, subsequent sessions had increased attendance and active engagement. For participants

who engaged, their contributions were valuable, adding to discussions and the overall program experience.

2. The PRP Support Team initiated a plan to redefine the OMERACT 2023 PRP Program in 2021, focusing on skill development, resource enhancement, and engagement within Working Groups. Pre-conference efforts involved a website overhaul<sup>15</sup>, resource compilation, Terms of Reference creation, and more. During OMERACT 2023, PRPs engaged in all plenaries and workshops and developed and led a plenary session on Patient Engagement in OMERACT, recommending the implementation of the Patient Engagement in Research PEIRs Framework. The daily sessions included a "Connection Carousel" with Fellows and a joint session with the Emerging Leaders to enhance PRP engagement in OMERACT Working Groups. Positive feedback was garnered from PRP evaluations, highlighting successes like education sessions, peer connections, and the fellow's poster judging contest.
3. The OMERACT Fellows Program<sup>16</sup> is an important part of OMERACT. The program, designed for early-stage researchers, offers training, mentorship, and sessions to enhance skills in OMERACT methods. The program includes various components such as e-learning modules, pre-meeting sessions, mentoring, lightning talks, poster presentations, and more. Positive feedback from participants indicates the program's success in networking, knowledge exchange, and skill development in the field of outcome measurement in rheumatology.
4. The Emerging Leaders Program (ELP)<sup>17</sup> is designed to nurture future leaders within OMERACT. The program aims to provide training, mentoring, and skill development to participants who have previously participated in the Fellows program. The ELP includes daily sessions during the OMERACT conference, offering skills training, mentorship, and opportunities for participants to moderate plenary sessions. Feedback from OMERACT 2023 Emerging Leaders<sup>18</sup> indicates that the program was well-received, addressing areas of improvement from previous iterations and contributing to the development of future OMERACT leaders.

The OMERACT 2023 Conference featured various Special Interest Group (SIG) sessions. These sessions brought together experts, researchers, PRPs, and healthcare professionals from multiple disciplines to engage in discussions. Covering a diverse spectrum of topics, the SIG sessions included Chronic Nonbacterial Osteomyelitis, Contextual Factors<sup>19</sup>, Flares in Osteoarthritis<sup>20,21</sup>, Foot & Ankle Disorders<sup>22,23</sup>, Immune-Related Adverse Events<sup>24</sup>, Juvenile Idiopathic Arthritis and its Magnetic Resonance Imaging implications<sup>25</sup>, Medication Adherence<sup>26</sup>, Myositis<sup>27,28</sup>, Patient Outcomes in Longitudinal Observational Studies – with a focus on Rheumatoid Arthritis<sup>29</sup>, Safety considerations<sup>30</sup>, Scleroderma Vascular Disease<sup>31,32</sup>, Shared Decision Making<sup>33,34</sup>, Sjogren's Syndrome<sup>35,36</sup>, Synovial Tissue assessment, Systemic Lupus Erythematosus<sup>37</sup>, Ultrasound applications<sup>38</sup>, Vasculitis, and Worker Productivity. These SIG sessions collectively represented a thriving platform for collaborative learning, idea exchange, and the formulation of progressive approaches in the field, exemplifying OMERACT's mission to improve outcomes for patients with autoimmune and musculoskeletal diseases through advancing the design and quality of outcomes measured in clinical studies.

Additional information and publications by Working Groups can also be found on the OMERACT Website [www.omeract.org](http://www.omeract.org). The OMERACT Handbook<sup>39</sup> contains methodological and organizational information and has encouraged readers to become more engaged by explaining various OMERACT procedures and practices. The OMERACT Handbook is currently being reviewed, and soon, an updated version of the

OMERACT Handbook will be available. It will continue to provide a significant reference resource for all those interested in outcome measure development.

In conclusion, the successful realization of the OMERACT 2023 Conference, despite a three-year delay caused by the global COVID-19 pandemic, exemplifies the commitment of the OMERACT community to advancing the field of rheumatology and outcome measurement. This biennial event, held in Colorado Springs, USA, brought together participants from diverse backgrounds, fostering connections and facilitating the exchange of experiences, knowledge, and perspectives on the development and methodology of COS in Rheumatology. Overall, OMERACT 2023 marked a significant milestone in the organization's 30-year journey, reinforcing its role in shaping the landscape of outcome measurement in rheumatology and driving collaborative advancements that contribute to improved patient outcomes.

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We extend our thanks to everyone involved in making OMERACT 2023 a success. Special appreciation goes to the chairs, patient research partners, emerging leaders, and fellows for their invaluable contributions. Your collaborative spirit makes our conferences a success and propels our mission forward. Thank you for your dedication and vibrant discussions shaping the future of outcome measurement in rheumatology.





**OMERACT 2023 — International Consensus Conference, in Colorado Springs, USA**



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