

OMERACT POLICY MANUAL





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1. INTRODUCTION

1.1. About OMERACT

OMERACT is a global, volunteer-driven, not-for-profit organization committed to improving outcomes for patients with autoimmune and musculoskeletal diseases through advancing the design and quality of clinical studies. Through rigorous methodology and our global Working Groups, OMERACT supports the development of Core Outcome Sets (COS), identifying patient and disease-relevant areas to be measured (domains) and the corresponding measurement instruments for use in clinical trials, including those for regulatory approval of new treatments.

OMERACT brings together researchers, clinicians, methodologists, and patient research partners (PRPs) worldwide through collaborative efforts. These participants develop and implement COSs within specialized working groups. OMERACT integrates PRPs at every stage, fostering patient-centred research. The collective expertise of clinicians, trialists, epidemiologists, statisticians, methodologists, and industry partners ensure the development of robust, patient-relevant outcomes for clinical trials and observational research. OMERACT's methodologies are applicable across medical fields, making it a leader in collaborative decision-making.

1.2. Purpose of the Policy Manual

This manual establishes the policies and procedures that govern OMERACT's operations. It serves purposes:

- 1. Guidance: It provides instructions to OMERACT participants, ensuring all actions align with organizational standards.
- 2. Transparency: The manual promotes openness by outlining the decision-making processes and operational procedures.
- 3. Consistency: It ensures uniform practices across all OMERACT activities and operations.
- 4. Quality Assurance: Detailed standards maintain high-quality performance in all aspects of OMERACT's work.

1.3. Scope and Application

This manual applies to every individual and entity engaged in OMERACT activities. It governs all organizational operations, from developing and endorsing Core Outcome Sets to meeting conduct, publication practices, and sponsorships. As a living document, this manual undergoes regular review and updates to reflect best practices, scientific advancements, and feedback from collaborators.



2. GOVERNANCE and ORGANIZATIONAL POLICIES

2.1. Organizational Structure

OMERACT follows a collaborative governance model, with the Management Group as the central decision-making hub. The organization operates through interconnected streams—Methodology, Finances, Patient Research Partners (PRPs), and Operations. Each stream fulfills a distinct role in advancing OMERACT's mission while coordinating with the Management Group.

Committees and working groups within these streams provide specialized insights and recommendations, guiding OMERACT's strategic planning and decision-making. Through open collaboration, participants exchange knowledge and ideas, ensuring that every voice contributes to achieving the organization's objectives.



Figure 1: OMERACT organizational structure



2.2. Diversity, Equity, Inclusion and Accessibility (DEIA) Commitment

OMERACT integrates DEIA principles across all activities to create a collaborative, inclusive, and accessible environment.

- Work to ensure representation from varied gender, cultural, and geographic backgrounds across leadership roles, working groups, and decision-making bodies.
- Amplifies the voices of PRPs from diverse backgrounds, ensuring research reflects the broad range of lived patient experiences.
- Produces accessible communication materials, including plain-language summaries, to engage a wide audience
 effectively.

The OMERACT Equity, Diversity, and Inclusivity (EDI) Strategic Advisory Working Group plays a pivotal role in supporting OMERACT's commitment to advancing equity, diversity, and inclusion in all processes. This hybrid group functions both as a traditional working group dedicated to EDI-focused projects and as a strategic advisory body to the OMERACT Management Group. This structure allows the group to develop and implement actionable EDI initiatives while also offering expert guidance on OMERACT's policies and practices.

2.2.1. Accessibility Guidelines:

- Ensures that physical and virtual events accommodate participants with disabilities by providing necessary adjustments.
- Offer closed captioning, screen-reader-compatible documents, and other accessible formats to promote equitable participation in online activities.

2.3. Leadership and Advisory Committees

2.3.1 OMERACT Management Group

The Management Group oversees all OMERACT activities and operations. It drives strategic decisions, shapes policies, and ensures the organization's effectiveness. Members assume dual roles: managing OMERACT operations and leading specific organizational streams.

Management Group:

- 1. Peter Tugwell, MSc, MD, FRCPC Ottawa, Canada, Chair Operations
- 2. Dorcas Beaton, BSc OT, PhD Toronto, Canada Chair OMERACT Methods
- 3. Philip Conaghan MBBS, PhD, FRACP, FRCP Leeds, UK, Deputy Chair Operations
- 4. Catherine Hofstetter Toronto, Canada, Chair OMERACT Patient Research Partners
- 5. Lee Simon MD, FACP, MACR Boston, USA, Chair OMERACT Finances
- 6. Shawna Grosskleg Toronto, Canada OMERACT Secretariat

The Management Group operates under the terms outlined in Appendix A.

2.3.1.1. Operational Streams

Operations Stream: The Operations Stream focuses on ensuring the smooth functioning and strategic direction of OMERACT. Its key components include leadership, secretariat management, working group oversight, collaborator engagement, and alignment with core organizational values.

Methodology Stream: This stream ensures the rigorous application of scientific principles throughout OMERACT's activities. Its responsibilities include methodological development, continuous review, integration with other streams, education and training, and transparent reporting.

PRP Stream: The PRP stream reflects OMERACT's commitment to involving patients as co-researchers in developing Core Outcome Sets. This stream emphasizes collaboration, capacity-building, guidance, and advocacy for PRPs. The PRP Support Team, a volunteer-led group chaired by a member of the Management Group, actively promotes PRP engagement, education, and influence.



Finance Stream: This stream safeguards OMERACT's financial health by ensuring budget oversight, financial transparency, resource management, and strategic sponsorship. The Finance Stream builds trust by maintaining sound financial practices that align with OMERACT's mission and objectives.



2.3.2. Technical Advisory Group

The TAG provides expert guidance on Core Outcome Set development and methodology. Comprising experts in patient-centered research, psychometrics, and statistical analysis, the TAG supports working groups by reviewing materials, offering feedback, and ensuring alignment with OMERACT methodology.

The TAG is led by 3 Co-Chairs, including the Chair of Methods from the OMERACT Management Group.

TAG Co-Chairs:

- 1. Dorcas Beaton, BScOT, PhD Toronto, Canada
- 2. Clifton O. Bingham III, MD Baltimore, USA
- 3. George Wells Ottawa, Canada

The TAG co-chairs operate under the terms outlined in Appendix B.

TAG Members:

- 1. Annelies Boonen Maastricht, Netherlands
- 2. Wen-Hung Chen USA
- 3. Ernest Choy Cardiff, United Kingdom
- 4. Robin Christensen Copenhagen, Denmark
- 5. Andrea Doria Toronto, Canada
- 6. Glen Hazelwood Calgary, Canada
- 7. Catherine Hill Adelaide, Australia
- 8. Cathie Hofstetter Toronto, Canada
- 9. Ben Horgan Perth, Australia
- 10. Helen Keen Melbourne, Australia
- 11. Katy Leung Singapore
- 12. Alexa Meara Ohio, USA
- 13. Zahi Touma Toronto, Canada
- 14. Peter Tugwell, MSc, MD, FRCPC Ottawa, Canada

TAG Fellow Members:

- 1. Ioannis Parodis Stockholm, Sweden
- 2. Didem Saygin Chicago, USA

The TAG members and TAG fellows operate under the terms outlined in Appendix C



2.3.3. Patient Research Partner Support Team

The PRP Support Team ensures meaningful PRP engagement and promotes collaboration within OMERACT. The team, which consists of five members, including the Chair, works closely with the Management Group to ensure that PRP perspectives shape all aspects of OMERACT's work.

PRP Support Team Members:

- 1. Cathie Hofstetter Chair, Toronto, Canada
- 2. Mary Cowern Wales, UK
- 3. Ingrid de Groot Amsterdam, Netherlands
- 4. Maya Desai Toronto, Canada
- 5. Ben Horgan Perth, Australia

The PRP Support Team operates under the terms outlined in Appendix D.

The OMERACT PRP Network is a global community of PRPs, representing diverse experiences with rheumatic and musculoskeletal conditions. With members from over 41 countries, the network embodies OMERACT's commitment to inclusivity and comprehensive representation of patient perspectives. 168 PRPs have actively participated in conferences, contributing directly to the advancement of research methodologies and outcomes.

Members of the OMERACT PRP Network operate under the terms outlined in Appendix E.

2.3.4 Strategic Advisory Group

The OMERACT Strategic Advisory Group (SAG) serve as advisors to the OMERACT Management Group, providing strategic guidance and implementation advice on matters related to the overall direction of OMERACT.

The SAG is led by 3 Co-Chairs, including the Chair of Operations from the OMERACT Management Group.

SAG Co-Chairs:

- 1. Peter Tugwell, MSc, MD, FRCPC Ottawa, Canada
- 2. Lyn March Sydney, Australia
- 3. Maria Antonietta D'Agostino Rome, Italy

The SAG Co-Chairs operate under the terms outlined in Appendix F.

SAG Members:

- 1. Ben Horgan Perth, Australia
- 2. Bethan Richards Sydney, Australia
- 3. Catherine Hill Adelaide, Australia
- 4. Francis Guillemin Lorraine, France
- 5. Grayson Schultz Athens, USA
- 6. Heidi Siddle Leeds, UK
- 7. Ingrid de Groot (PRP Support Team Liaison) Amsterdam, Netherlands
- 8. Mikkel Ostergaard Copenhagen, Denmark
- 9. Peter Merkel Philadelphia, USA
- 10. Robin Christensen Copenhagen, Denmark
- 11. Vibeke Strand Portola Valley, USA

The SAG operates under the terms outlined in Appendix F.



2.3.5 Business Advisory Committee

The Business Advisory Committee (BAC) is a forum where the OMERACT Management Group exchanges ideas with pharmaceutical and biotechnology industry members. Members are invited to comment on the agenda of activities for OMERACT and can suggest items for consideration. Through its direct access to the Management Group, the BAC allows rapid and timely development of the agenda for OMERACT activities. It ensures sponsors have a voice in developing Core Outcome Sets in Rheumatology.

The BAC meets at least once a year during the American College of Rheumatology (ACR) annual meeting. The Co-Chairs regularly update members on the agenda for OMERACT meetings and any other developments.

The BAC has provided OMERACT with the opportunity to reach a consensus through the sharing of information on a global level, which in turn has led to the validation of instruments in rheumatologic clinical trials and furthered the efforts to develop consistent regulatory expectations for new products to treat rheumatic diseases. The supporting sponsor selects representatives for the BAC and OMERACT conference attendees, who need not be the same persons. However, participants must be clinical researchers and/or methodologists. All individuals are expected to be actively involved in OMERACT activities, bringing their expertise to the process.

The BAC is co-chaired by two members of the OMERACT community, including the Chair of Finance from the OMERACT Management Group.

BAC Co-Chairs:

- 1. Lee Simon MD, FACP, MACR Boston, USA, Chair OMERACT Finances
- 2. Vibeke Strand Portola Valley, USA

2.4. Succession Plan for Management Group and Advisory Committee Co-Chair Positions

OMERACT recognizes the importance of sustainable leadership in achieving its mission and advancing its vision for collaborative, patient-centered research in rheumatology and musculoskeletal health. This policy outlines a structured framework for the succession planning process for Management Group and Advisory Committee Co-Chair positions, ensuring alignment with OMERACT's core values, including equity, diversity, and inclusion (EDI). By defining clear processes for identifying, recruiting, and onboarding leaders, this policy aims to facilitate seamless leadership transitions, foster a culture of inclusivity and collaboration, and develop a pipeline of future leaders equipped to guide OMERACT's strategic direction and operational success.

Position Descriptions and Recruitment

Position Descriptions

Each Management Group and Advisory Committee Co-Chair position must have a comprehensive description that includes:

- Key responsibilities and expected deliverables.
- Core competencies and qualifications.

Posting of Position Descriptions

Position descriptions will be posted broadly within the OMERACT community through:

- The OMERACT website.
- Email newsletters to all members.
- Targeted outreach to individuals identified as potential candidates.

Information sessions may be hosted to explain the position and answer questions.

Encouragement of Nominations

Both self-nominations and peer recommendations will be accepted to ensure inclusivity and transparency.



Nominees must confirm their interest in the role to proceed to the next stage.

Candidate Identification and Screening

Maintain a database of potential leadership candidates identified through:

- Contributions to OMERACT working groups and Emerging Leaders programs.
- Demonstrated alignment with OMERACT's mission and values.

Require candidates to submit:

- A letter of interest describing their vision for OMERACT.
- A curriculum vitae or resume highlighting relevant experience.
- Responses to a structured questionnaire about leadership competencies.

Structured Selection Process

General Guidelines:

- The exact composition of the interview team will depend on the role being filled, ensuring relevant expertise is available to evaluate the candidate's qualifications comprehensively.
- External advisors may be included to provide specialized expertise (e.g., financial management or patient engagement).

Position-Specific Interview Teams

a. Chair - Operations

- Outgoing Chair of Operations To assess leadership alignment and strategic vision.
- Deputy Chair of Operations To assess leadership alignment and strategic vision.
- Chair of Methodology To evaluate understanding of OMERACT methodologies.
- Senior PRP Representative To assess inclusivity and collaboration with diverse collaborators.
- OMERACT Secretariat Member To evaluate the understanding of organizational operations.

b. Chair - Finance

- Outgoing Chair of Finance To assess technical financial expertise.
- Current Chair of Operations To ensure alignment with organizational priorities.
- OMERACT Secretariat Member To evaluate the understanding of organizational operations.
- Member of the OMERACT Business Advisory Group To evaluate the understanding of fundraising and resource allocation.

c. Chair - Methodology

- Outgoing Chair of Methodology To evaluate methodological expertise.
- Co-chairs of TAG To assess alignment with OMERACT's research goals.
- Chair of PRPs To assess commitment to inclusivity in methodology.
- OMERACT Secretariat Member To evaluate the understanding of organizational operations.

d. Chair - Patient Research Partners (PRPs)

- Outgoing Chair of PRPs To assess experience in patient engagement and advocacy.
- Senior PRP Representative To evaluate commitment to patient-centered research.
- Chair of Methodology To assess the ability to integrate patient perspectives into methodologies.
- OMERACT Secretariat Member To evaluate the understanding of organizational operations.

e. Deputy Chair of Operations

- Current Chair To assess leadership alignment and readiness to assume Chair responsibilities.
- Chair of Finance To evaluate the ability to support financial initiatives.
- Chair of PRPs To ensure commitment to inclusivity and collaboration.



OMERACT Secretariat Member – To assess operational understanding and adaptability.

f. Technical Advisory Group, Strategic Advisory Group, and Business Advisory Committee Co-Chairs (exclusive of Management Group members who hold dual roles)

- Current Co-Chairs To assess alignment and readiness to assume Co-Chair responsibilities.
- Deputy Chair of Operations To assess leadership alignment and strategic vision.
- External advisors may be included to provide specialized expertise (e.g., financial management or patient engagement).

Standardized Interview Guide

- Interviews will follow a structured guide to evaluate candidates on:
 - o Their commitment to OMERACT's mission, vision, and EDI principles.
 - o Leadership skills, including strategic thinking, collaboration, and mentorship.
 - o Technical expertise and alignment with the specific position.
 - Vision for advancing OMERACT's initiatives and goals.

Evaluation and Decision-Making

- A consensus-driven approach will be used to evaluate and rank candidates based on:
 - o Alignment with OMERACT's mission, vision, and EDI principles.
 - o Demonstrated leadership skills and relevant technical expertise.
 - o Strength of responses in interviews and application materials.
 - Vision for advancing OMERACT's strategic goals.

Decision Process:

- o Each interview team member will provide individual scores and qualitative feedback for discussion.
- o A composite score will be generated from the evaluation criteria.
- Final decisions will be made by consensus. If consensus cannot be reached, the Chair of Operations will
 cast the deciding vote.

Candidate Communication

- All candidates will receive timely updates regarding the status of their application.
- Feedback will be provided to unsuccessful candidates to support future opportunities.

Onboarding and Integration

Onboarding Package

New members will receive a comprehensive onboarding package, including:

- Terms of Reference and strategic plans.
- Background on ongoing initiatives and key deliverables.
- Access to relevant OMERACT policies and governance documents.

Mentorship Assignment

- Each new member will be paired with a mentor from the current Management Group or Advisory Committee Co-Chair to:
 - o Facilitate their integration into the role.
 - Provide ongoing guidance and support during the transition.

Review Period for New Members

• New members will be subject to a 6-month review period, during which:



- Their progress will be evaluated based on role-specific deliverables and adherence to OMERACT's values.
- Feedback will be collected from peers, mentors, and collaborators.
- o Any necessary adjustments or additional support will be provided to ensure successful integration.
- A formal performance review will be conducted at the end of the 6-month period, and findings will be documented and shared with the new member.

2.5. Emeritus Chair Status for Past Management Group Chairs

OMERACT values the expertise and institutional knowledge of outgoing Management Group Chairs and recognizes their role in supporting the continuity and success of organizational leadership. This section outlines the process by which past Management Group Chairs transition to emeritus chair status and contribute to the onboarding and support of new leaders.

Eligibility for Emeritus Chair Status:

- Outgoing Chairs of Management Group positions are eligible to serve in an Emeritus Chair capacity immediately following the conclusion of their term.
- Emeritus Chair members are non-voting participants in the Management Group but retain the right to provide input and guidance during discussions.

Duration of Emeritus Chair Status:

- The standard term for emeritus chair status is 1 year, beginning at the conclusion of the outgoing Chair's term.
- o Extensions may be considered on a case-by-case basis, based on organizational needs and mutual agreement.

Roles and Responsibilities of Emeritus Chair Members

Emeritus Chair members are expected to:

Support Leadership Transition:

- o Provide mentorship and advice to the incoming Chair, sharing institutional knowledge and best practices.
- Assist with the onboarding process, including familiarizing the new Chair with ongoing projects, key collaborators, and strategic goals.

Maintain Organizational Continuity:

- o Offer historical perspectives and insights to inform decision-making and strategic planning.
- Act as a resource for resolving challenges that may arise during the transition period.

Facilitate Knowledge Transfer:

- Ensure comprehensive documentation and handover of role-specific responsibilities, including access to relevant files, policies, and contacts.
- o Provide clarity on unresolved matters or ongoing initiatives requiring follow-up.

Participate in Advisory Capacity:

 Attend Management Group meetings as needed, offering input on relevant issues and supporting the leadership team's work.

Conclusion of Emeritus Chair Term

At the conclusion of the Emeritus Chair term, the outgoing Chair will:

- o Receive formal acknowledgment and appreciation for their contributions.
- Be invited to remain involved in OMERACT activities in other capacities, such as advisory roles, working group membership, or mentoring Emerging Leaders.



2.6. Working Groups

Working Groups are the foundation of OMERACT's mission, implementing the organization's methodology to develop Core Outcome Sets and related research. Each group includes international collaborators from diverse fields, ensuring well-rounded perspectives and impactful research.

2.6.1. Guidelines for Working Groups

Forming the Working Group Team

It is important to incorporate a variety of perspectives from the start and throughout the research process. Identifying the necessary expertise, considering the intended use settings and populations, and engaging a broad range of collaborators will enhance the research impact and facilitate dissemination.

2.6.2. Structure of Working Groups:

Co-Chairs: The OMERACT Working Group Co-Chairs steer the group's research initiatives and are tasked with leadership and coordination. They comprise OMERACTers, including researchers, clinicians, methodologists, fellows, emerging leaders and PRPs.

Each Working Group should have a minimum of three co-chairs representing at least three continents.

The Working Group co-chairs operate under the terms outlined in Appendix G.

2.6.3. Working Group Transparent Communication and Reporting

Working Groups are asked to maintain open lines of communication with the OMERACT community by providing periodic updates through their websites, checklists, supporting documentation, presenting at town halls, attending the biennial conference and publications. This ensures transparency in methodologies, activities, and outcomes.

2.7. Overview Of Decision-Making Responsibilities

Group	Primary Role	Scope of Decision-Making Authority	Escalation Role	
Management Group (MG)	Central decision-making body that provides oversight and strategic direction for all activities.	Final approval of policies, strategies, budgets, and key organizational changes.	Final arbiter for conflicts and escalated issues.	
Strategic Advisory Group (SAG)	Provides strategic guidance on long-term goals, partnerships, and alignment with OMERACT's mission.	ong-term goals, partnerships, and lignment with OMERACT's Recommends strategic initiatives.		
Technical Advisory Group (TAG)	Ensures scientific rigor and methodological quality in OMERACT's work, particularly in Core Outcome Sets (COS).	Recommends standards and provides technical feedback on COS methodology	Escalate methodological issues to MG for resolution.	
Business Advisory Group (BAC)	Engages with OMERACT to align OMERACT's activities with relevant market needs.	Provides input on agenda items and industry-relevant developments.	Escalate unresolved industry-related issues to MG.	
PRP Support Team	Promotes and facilitates meaningful Patient Research Partner (PRP) engagement within all OMERACT activities.	Develops policies for PRP involvement and supports PRP participation.	Escalate PRP-related issues to MG.	



Ad Hoc Committees / Delegated Authorities	Formed to address specific, temporary needs (e.g., task forces, working committees).	orary needs (e.g., task forces, the scope of their assigned	
Working Group Leaders	Implement specific research initiatives, COS development, and operational activities aligned with OMERACT's methodology.	Responsible for day-to-day operational decisions within their scope.	Escalate significant operational delays or conflicts to relevant advisory groups or MG.
OMERACTers (Members at Large)	Contribute to discussions, consultations, and decision-making through participation in surveys, meetings, and working groups.	Provide feedback and input on strategic, operational, and methodological decisions.	Report unresolved issues to relevant group chairs or MG.

This framework outlines key decision areas and responsibilities across OMERACT's governance structure to ensure clarity and efficient operations.

2.8. Escalation and Issue Management Policy

This policy outlines the process for documenting and managing escalated issues within OMERACT to ensure transparency, accountability, and effective resolution. It applies to all OMERACTers and groups involved in the escalation process.

Centralized Escalation Log

OMERACT will maintain a centralized escalation log to document all issues escalated to the Management Group. This log will serve as an official record and include the following details:

- Date of Escalation
- Nature of Issue (e.g., conflict, strategic disagreement, methodological concern, PRP-related issue)
- Summary of Context
- Actions Taken by Management Group (e.g., discussions, decisions, or delegated follow-ups)
- Outcome and Resolution
- Date of Resolution
- Responsible Management Group Member(s)

The log will be reviewed periodically to identify trends and improve OMERACT's decision-making and operational processes.

Escalation Submission Protocol

To ensure consistency, OMERACTers or groups escalating an issue must submit a standardized escalation form, which will include:

- A detailed description of the issue.
- Steps already taken to resolve it.
- Specific questions or decisions required from the Management Group.

Documentation of Deliberations and Decisions

During Management Group meetings, detailed minutes will be recorded for each escalated issue, including:

^{*}Note: While it covers significant decisions, not all organizational choices are included. Any unforeseen matters will follow OMERACT's principles of transparency and collaboration, with escalation to the Management Group as needed.



- Discussions held.
- Rationale for decisions made.
- Actions assigned, with deadlines and responsible individuals/groups.

Escalation Status Tracker

The Management Group will maintain a live escalation tracker to monitor the progress and resolution of escalated issues. This tracker will include:

- Issue Status (e.g., "Pending Review," "Under Discussion," "Resolved")
- Priority Level (e.g., High, Medium, Low)
- Assigned Management Group Member(s) for resolution.

Updates will be provided during MG meetings to ensure progress is monitored and communicated effectively.

Communication of Resolutions

Once an escalated issue is resolved, the Management Group will communicate the outcome to the originating group and other relevant OMERACTers. This communication will include:

- The final decision and rationale.
- Implementation steps (if applicable).
- A contact point for follow-up questions.

Encouraging Proactive Reporting

OMERACT encourages all groups, including Working Group Leaders and OMERACTers, to report potential issues early to avoid escalation when possible.

2.9. Exit Strategy And Contingency Planning

To ensure the sustainability and continuity of OMERACT's mission, this section outlines the procedures and strategies for managing organizational transitions, including planned wind-downs, leadership changes, or unforeseen disruptions. Proper preparation helps maintain integrity, minimize risks, and support smooth transitions for collaborators.

2.9.1. Wind-Down Procedure for OMERACT

If OMERACT faces closure or a major restructuring, a phased exit strategy will be implemented to ensure that critical functions are adequately concluded, and collaborator expectations are managed. The following steps outline the procedure:

- Step 1: Identify essential activities, projects, and commitments requiring completion before closure.
- **Step 2:** Notify sponsors, working groups, patient research partners (PRPs), and collaborators about the timeline and key milestones of the wind-down.
- Step 3: Reassign or transition ongoing initiatives to appropriate external organizations where feasible.
- **Step 4:** Develop a detailed communication plan to ensure transparency.

2.9.2. Knowledge Transfer

Preserving OMERACT's institutional knowledge is essential to ensure future access to data, tools, and insights. A systematic knowledge transfer process includes:

- Compile, organize, and archive all essential documents, including governance policies, project reports, meeting minutes, and research data.
- Ensure that essential collaborators (e.g., OMERACT leadership, working group leaders, and sponsors) retain appropriate access to the archived content through secured platforms.
- Develop a knowledge repository to support new leadership or successor organizations in continuing relevant initiatives.



2.9.3. Contingency Plans

OMERACT must be prepared to address unforeseen challenges, such as leadership changes or disruptions in funding. The following contingency measures will ensure continuity during critical situations:

- Maintain a leadership succession plan that identifies interim leaders and provides clear protocols for onboarding new leadership.
- Develop emergency operating procedures to address unexpected events that could disrupt ongoing activities or events.

These measures form a comprehensive approach to managing organizational risks and ensuring the long-term impact of OMERACT's work, even in scenarios of transition or closure. With clear planning, OMERACT can maintain transparency and stability, preserving its legacy while minimizing disruption for collaborators.



ETHICAL CONSIDERATIONS

3.1. Code of Ethics and Transparency

OMERACT upholds the highest ethical standards in all activities. Members of the Management Group, Committee Chairs, Working Group Leaders, and participants commit to these principles, ensuring their actions reflect the values and mission of the organization.

Accountability

- Follow OMERACT's governing policies and procedures.
- Exercise diligence, good faith, and reasonable care in managing organizational affairs.
- Promptly disclose actual or potential conflicts of interest.
- Ensure transparency in all decision-making processes by sharing relevant information at the earliest opportunity.

Professional Integrity

- Maintain courtesy, respect, and objectivity in all interactions.
- Promote high standards of professional conduct in every aspect of OMERACT's work.

Collaboration and Respect

- Respect differing opinions and encourage open dialogue across all OMERACT groups and committees.
- Register formal dissent when appropriate, ensuring all perspectives are acknowledged.

Violations

Any breach of these ethical standards may result in disciplinary action, as outlined in OMERACT's governing documents, including possible removal from positions of responsibility.

3.2. Transparency and Disclosure Policy

OMERACT aims to minimize the risk of personal interests interfering with organizational decision-making. This policy seeks to identify, manage, and address potential conflicts of interest to help protect the integrity of the organization's work.

Identification and Disclosure:

- Members must disclose any personal interests that may conflict with their roles in OMERACT before assuming leadership positions or engaging in decision-making.
- The Management Group will review all disclosures to determine potential conflicts.

Recusal:

Members with conflicts of interest must recuse themselves from related discussions, decisions, or votes. The
meeting minutes must document these recusals.

Final Determination:

• The Chair of OMERACT will assess the conflict and, if necessary, ensure the involved member refrains from further participation in relevant committee activities.

3.2.1. Online Transparency and Disclosure Form

OMERACT uses an online Transparency and Disclosure Form to ensure all members declare relevant interests and maintain organizational integrity. The form can be found here

The Management Group or relevant advisory body will review all submitted disclosures to ensure compliance with OMERACT's transparency standards.



3.3. Privacy Policy

Our Commitment to Your Privacy

OMERACT is committed to protecting your personal data by ensuring it is accurate, confidential, secure, and used responsibly. This policy outlines how OMERACT collects, uses, shares, and protects personal information in compliance with the General Data Protection Regulation (GDPR) and other relevant privacy laws, including the Canadian Freedom of Information and Protection of Privacy Act (FIPPA).

This privacy policy applies to OMERACT participants, sponsors, employees, and visitors to our website or events.

3.3.1. What Data Do We Collect?

OMERACT collects the following data:

- **Identification & Contact Details**: Name, address, phone number, email (used for event registration, communications, and feedback).
- **Demographic Information**: Gender, affiliation, or professional role (to assess participation and improve services).
- Accessibility & Dietary Requirements (if voluntarily provided for event planning).
- Payment Information: Billing address and transaction details (for registration payments).
- Technical Information: Cookies and IP addresses (to improve website functionality).
- Photographs/Videos: With your consent, for event documentation and promotion.

3.3.2. How do we collect your data?

You directly provide OMERACT with the data we collect. We collect data and process data when you:

- Register online for any of our mailing lists or events.
- Voluntarily complete a survey or provide feedback on any of our message boards or via email.
- Use or view our website via your browser's cookies.

3.3.3. How will we use your data?

OMERACT collects your data to:

- Process your conference registration and manage your account.
- Send you monthly newsletters and keep you informed about updates and events.
- Share relevant information with the co-chairs of the working groups you wish to participate in.

OMERACT may share your information with credit reference agencies when processing your registration to verify your details and help prevent fraudulent transactions.

3.3.4. How do we store your data?

Your data is stored with Mailchimp. Mailchimp and its affiliates own and operate servers in world-class data centers located in the United States.

Mailchimp takes the protection and security of your personal information seriously. You can find more details on their Mailchimp Data Security and Privacy page.

3.3.5. How long do we keep your data?

OMERACT retains personal data only as long as necessary to fulfill the purposes for which it was collected or to meet legal, regulatory, or business requirements. Our data retention periods are determined based on the following criteria:

Conference and Event Registration Data: Personal data collected for event registration, such as contact
information and payment details, is retained for up to two years after the event for administrative purposes,
feedback, and reporting. After this period, it will be securely deleted or anonymized unless further retention is
required by law.



- Mailing List and Communication Data: Contact information used for newsletters and updates will be retained as
 long as you remain subscribed. You may unsubscribe at any time, and your data will be removed from our
 mailing list promptly.
- Working Group Participation Data: Information shared with working group co-chairs is retained for the duration of your participation in the group. If you leave the group, your data will be removed promptly.
- **Legal Compliance**: Some data may need to be retained for specific legal or regulatory reasons, such as tax obligations, which may require retention for up to six years after collection.
- **Retention Review and Deletion**: OMERACT conducts regular reviews to ensure personal data is not retained longer than necessary. When data is no longer required, we securely delete, anonymize, or archive it in compliance with GDPR requirements.

You have the right to request the deletion of your personal data in certain circumstances, such as when it is no longer necessary for the purpose it was collected or if you withdraw consent (where consent was the basis for processing). To request, please contact

Shawna Grosskleg, Privacy Officer

OMERACT, 501 Smyth Rd. Room L1258 P.O. Box 201B Ottawa, ON K1N 5C7 Canada

Phone: (613) 794-1355; Email: admin@omeract.org

3.3.6. Marketing

OMERACT would like to send you information about our events and information that we think you might like. If you have agreed to receive marketing, you may always opt-out at a later date.

You have the right at any time to stop OMERACT from contacting you for marketing purposes.

Please click <u>here</u> if you no longer wish to be contacted for marketing purposes.

3.3.7. What are your data protection rights?

OMERACT would like to ensure you are fully aware of your data protection rights. Every user is entitled to the following:

- The right to access You have the right to request OMERACT for copies of your personal data.
- The right to rectification You have the right to request that OMERACT correct any information you believe is inaccurate. You also have the right to request OMERACT to complete the information you believe is incomplete.
- The right to erasure You have the right to request that OMERACT erase your personal data under certain conditions.
- The right to restrict processing You have the right to request that OMERACT restrict the processing of your personal data under certain conditions.
- The right to object to processing You have the right to object to OMERACT's processing of your personal data under certain conditions.
- The right to data portability You have the right to request that OMERACT transfer the data we have collected to another organization or directly to you under certain conditions.

If you make a request, we have one month to respond to you. If you would like to exercise any of these rights, please contact us at our email: admin@omeract.org.

3.3.8. Cookies

Cookies are text files placed on your computer to collect standard Internet log information and visitor behaviour information. When you visit our websites, we may collect information from you automatically through cookies or similar technology

For further information, visit allaboutcookies.org



How do we use cookies?

We use cookies to help you navigate efficiently and perform certain functions. You will find detailed information about all cookies under each consent category below.

The cookies that are categorized as "Necessary" are stored on your browser as they are essential for enabling the basic functionalities of the site.

We also use third-party cookies that help us analyze how you use this website, store your preferences, and provide the content and advertisements that are relevant to you. These cookies will only be stored in your browser with your prior consent.

You can choose to enable or disable some or all of these cookies but disabling some of them may affect your browsing experience.

What types of cookies do we use?

There are a number of different types of cookies. However, our website uses:

- Necessary: Necessary cookies are required to enable the basic features of this site, such as providing secure log-in or adjusting your consent preferences. These cookies do not store any personally identifiable data.
- Functional: Functional cookies help perform certain functionalities like sharing the content of the website on social media platforms, collecting feedback, and other third-party features.
- Analytics: Analytical cookies are used to understand how visitors interact with the website. These cookies help provide information on metrics such as the number of visitors, bounce rate, traffic source, etc.
- Performance: Performance cookies are used to understand and analyze the key performance indexes of the website which helps in delivering a better user experience for the visitors.
- Advertisement: Advertisement cookies are used to provide visitors with customized advertisements based on the pages you visited previously and to analyze the effectiveness of the ad campaigns.

How to manage cookies

You can choose to enable or disable some or all of these cookies but disabling some of them may affect your browsing experience.

3.3.9. Privacy policies of other websites

The OMERACT website contains links to other websites. Our privacy policy applies only to our website, so if you click a link to another website, you should read their privacy policy.

3.3.10. Changes to our privacy policy

OMERACT keeps its privacy policy under regular review and places any updates on this web page. This privacy policy was last updated on 1 November 2024

3.3.11. How to contact us

If you have any questions about OMERACT's privacy policy or the data we hold on you, or you would like to exercise one of your data protection rights, please do not hesitate to contact us.

Email us at: admin@omeract.org

Call us: (613) 794-1355

Or write to us at: OMERACT 501 Smyth Rd. Room L1258 P.O. Box 201B Ottawa, ON K1N 5C7 Canada



4. COMMUNICATION

4.1. Perceived Authority

OMERACT requires that all official communication originates from authorized representatives to maintain consistency and professionalism. Only the Chair or the Management Group may issue communications on behalf of OMERACT. Leaders and members must avoid making verbal or written statements that conflict with OMERACT's official policies or positions.

- Working group co-chairs, sub-committee members, or task forces must not use OMERACT letterhead for personal communication.
- The Secretariat manages the preparation and distribution of official letters, maintaining copies for organizational records.
- Any exceptions to this policy require prior approval from the Chair, with a copy of the communication submitted to the Secretariat within 24 hours.

4.2. OMERACT Mailing List

Mailing List Records: OMERACT maintains an active list of working group members through Mailchimp that is shared quarterly with groups. This is used to keep a current record of OMERACTers, detailing each member's contact details and collaborator type. This facilitates active engagement and recognizes the contributions of all OMERACTers. Co-chairs regularly review and update the membership list to accurately reflect active and contributing participants. Working groups must comply with the OMERACT privacy policy in all communications with members and in the management of their contact information.

4.3. Communication Standards

4.3.1. Written Communication

Spell out "Outcome Measures in Rheumatology (OMERACT)" on first reference. Use "OMERACT" in subsequent mentions.

4.3.2. Organizational Identity and Strategy

Mission: OMERACT is a global, volunteer-driven, not-for-profit organization committed to improving outcomes for patients with autoimmune and musculoskeletal diseases through advancing the design and quality of clinical studies.

Through rigorous methodology and our global Working Groups, OMERACT supports the development of Core Outcome Sets (COS), identifying patient and disease-relevant areas to be measured (domains) and the corresponding measurement instruments for use in clinical trials, including those for regulatory approval of new treatments.

Core Values: At the heart of OMERACT's mission lies a commitment to excellence, inclusivity, and integrity. These core values known as the Spirit of OMERACT serve as guiding principles that shape how we work together and achieve meaningful progress in outcomes research. Spirit of OMERACT: Consensus, Communication, Collaboration, Critical Thinking, Careful Work, Concrete Outcomes, Continuous Learning, Continuity.

Positioning: Global leader in outcome measurement science, distinct for multi-collaborator engagement, especially with patients.

4.3.3. Logos

Logos, Typography, and Typesetting: All written documents featuring the OMERACT name or logo should follow OMERACT's Brand Standards.





Colors:

#0182c6 (Light Blue) #429539 (Green) #25338c (Dark Blue)

Font: Calibri

Logo Placement Considerations: Careful consideration is required when placing the logo to ensure it does not imply unauthorized endorsement of companies or products.

External Use of the OMERACT Brand

Third-party use of the OMERACT logo requires prior approval from the Secretariat and must comply with OMERACT's branding policies.

Generally, the logo's use by an outside entity may not:

- Discredit or diminish the reputation and goodwill of OMERACT.
- Imply endorsement or alignment with a product/company.
- Be false or misleading.
- Violate any law or regulation.

OMERACT reserves the right to revoke permission for logo use if it harms the organization's reputation or conflicts with its policies. Logos provided to external entities remain the property of OMERACT and may only be used for the specified project or event duration.

4.4. Media Interactions

OMERACT communicates with the media to provide timely, accurate, and transparent information while protecting participants' privacy. The OMERACT Secretariat manages media inquiries, ensuring alignment with organizational goals.

4.4.1. Spokespersons

Only the Chair or designated representatives may issue official statements.

4.4.2. Media Inquiries

OMERACTers must refer all media requests to the Secretariat, which will coordinate responses by:

- Clarifying the requested information with the reporter.
- Notifying designated spokespersons.
- Organizing interviews or issuing written responses on behalf of OMERACT.

OMERACT respects free speech and encourages scholarly activities, community engagement, and personal expression. However, individuals must distinguish their personal opinions from official OMERACT positions.

4.5. Social Media

OMERACT uses social media to connect with its community and promote research initiatives. All social media activities must align with OMERACT's mission and values.

- The Secretariat manages OMERACT's official social media accounts, ensuring consistent and accurate messaging. Specific members may be assigned roles on platforms for designated periods or purposes.
- Members should promptly report any concerns about social media activities to the Secretariat or Management Group for resolution.

4.5.1. Social Media Conduct

- OMERACT ensures content on social platforms reflects the organization's credibility and mission. Participants are expected to engage in respectful and constructive discourse.
- All users must respect copyright and trademark laws. OMERACT will address any alleged infringement immediately.
- OMERACT values diverse viewpoints. Discussions must remain professional, even during disagreements.



• Bullying, intimidation, threats, defamation, and obscene or inappropriate material are strictly prohibited.

OMERACT moderates its platforms to maintain a safe and professional environment. Violations may result in account restrictions or collaboration with law enforcement when necessary.



5. PUBLICATION

This section outlines OMERACT's policies on publishing materials generated by OMERACT Working Groups, task forces, and committees. All publications must align with OMERACT's mission, methodologies, and principles to ensure consistency and credibility. Authors are encouraged to seek OMERACT's endorsement and appropriately acknowledge the organization's role.

Key principles:

- Publications must adhere to OMERACT's methodologies and address relevant issues in rheumatology, Core
 Outcome Set Development and related methodologies and clinical trials.
- Authorship should reflect the diverse perspectives of OMERACT participants, ensuring broad and meaningful contributions.
- The term "OMERACT" should be included in the title or as a keyword to signify alignment with the organization.
- Full disclosure of conflicts of interest is required to maintain transparency.

5.1. Co-Authorship and Authorship Criteria

OMERACT values the contributions of all participants in its research efforts. Co-authorship is guided by the following principles:

- Co-authorship is reserved for individuals who actively contribute to the research, either through direct involvement in meetings or significant project contributions.
- The number of co-authors should remain reasonable and reflect those with the most substantial contributions.
- Priority for Significant Contributions: Those making substantial contributions should receive priority in authorship.

5.2. Authorship Process and Guidelines

- 1. **Draft Preparation:** The core group, typically the steering committee, prepares the initial draft to ensure a focused and coherent manuscript.
- 2. **Feedback and Criteria:** The draft is shared with the broader group for feedback. Co-authorship eligibility follows the International Committee of Medical Journal Editors (ICMJE) guidelines.
- 3. Tracking Contributions: Shared documents track individual contributions to ensure accurate credit.
- 4. **CRediT Author Statement:** Co-authors must complete the CRediT Author Statement in line with <u>Elsevier</u> guidelines.
- 5. **Acknowledgments:** Individuals who contribute to the project but do not meet authorship criteria will be recognized in the acknowledgments section, adhering to ICMJE guidelines.
- 6. **Communication and Deadlines:** All deadlines and requirements will be communicated transparently to participants via email. Any delays will be addressed promptly, with justifications provided where necessary.

5.3. AI Use in OMERACT Publications

OMERACT recognizes the growing role of artificial intelligence (AI) in research and supports the responsible use of AI tools in developing and publishing OMERACT-related materials. To ensure transparency, integrity, and adherence to OMERACT's standards, the following guidelines apply to the use of AI in OMERACT publications:

- Any use of AI tools in data analysis, manuscript drafting, editing, or figure generation must be disclosed in the Methods or Acknowledgments sections, as appropriate. The specific tool and purpose (e.g., data processing, language editing) should be clearly stated.
- Authors are responsible for verifying the accuracy of any AI-generated content. AI tools should complement, not replace, the expert input and review by OMERACT working group members.
- Al should not be used in ways that compromise data integrity, patient confidentiality, or ethical standards in research. This includes avoiding any Al-generated text or analyses that might misrepresent findings or methodologies.



• The use of AI in manuscript preparation does not qualify for authorship. However, any substantial reliance on AI tools must be appropriately acknowledged, and the role of AI in assisting with the manuscript should be documented transparently.

Failure to adhere to these AI guidelines may result in the following actions:

- Authors may be required to revise the manuscript to disclose or clarify AI usage before publication.
- OMERACT may withhold endorsement if Al use is not disclosed or Al tools are used in ways that compromise
 methodological integrity.
- In cases of significant non-compliance, OMERACT reserves the right to inform the journal of the authors' failure to adhere to OMERACT policies.
- Repeated or intentional non-compliance with AI guidelines may restrict future participation in OMERACT,
 OMERACT working groups, task forces, or committees.

5.4. Submitting Articles to Seminars

For working groups submitting articles to Seminars in Arthritis and Rheumatism for inclusion in the OMERACT collections, manuscripts must include substantive new content:

- If you include an 'update' paper detailing the working group's projects, processes, outcomes, and future research agenda, it is expected to summarize substantial work and include original research.
- Additional publication(s) will be considered if they are original research and contain appropriate robust results.
 If there are no new findings, for example, because results are being utilized in another manuscript, a manuscript will not be supported for publication. Decisions on additional manuscripts will be based on abstracts submitted to the OMERACT Secretariat that describe the content of all OMERACT proceedings manuscripts from that group.
- When asked about Free Preprint Service, please select NO; I don't want to share my research early and openly as a preprint.

5.5. Submitting Articles Outside Seminars

We ask that OMERACTers and OMERACT Working Groups wishing to publish OMERACT work outside Seminars referencing OMERACT in the title or manuscript abstract send the manuscript to the OMERACT Secretariat to ensure alignment with OMERACT principles and methods before submission. The Secretariat will provide a rapid turnaround of such manuscripts.

5.6. Dispute Resolution Process for Authorship Disagreements

OMERACT is committed to resolving authorship disagreements through a clear, fair, and transparent process. The following steps will be followed to handle disputes:

Step 1: Informal Resolution within the Group

- Disputes should first be discussed and resolved internally within the working group.
- A neutral facilitator, such as the group leader or chair, may mediate discussions to seek consensus.

Step 2: Escalation to OMERACT Management

- If a resolution is not achieved within the group, the issue will be escalated to OMERACT management.
- OMERACT management will review the dispute by consulting involved parties and relevant documentation (meeting notes, draft contributions, etc.).

Step 3: Formal Mediation

- If management intervention does not resolve the issue, an external mediator may be appointed to facilitate resolution.
- The mediator will recommend solutions, aiming for a fair outcome that accurately reflects contributions.

Step 4: Final Decision by OMERACT Leadership

 If mediation efforts fail, OMERACT leadership will make a binding decision based on all available evidence and mediation recommendations.



resolution.	cision will be n	otified to all p	arties, and t	ne manuscri	ot will proceed	a according to	o the agreed-t	pon



FUNDING AND SPONSORSHIP

OMERACT ensures that all financial activities align with its mission, maintaining transparency, integrity, and accountability. The organization carefully manages funding sources and sponsorships to uphold trust with collaborators and external partners.

6.1. Funding Sources

OMERACT relies on industry sponsorship to support its research initiatives, operations, and events. While industry partnerships provide essential financial support, OMERACT is committed to maintaining transparency, scientific independence, and alignment with its mission. All sponsorships are managed under strict guidelines (outlined in the Sponsorship Guidelines) to ensure they do not compromise the organization's integrity.

6.2. Sponsorship Guidelines

OMERACT welcomes partnerships with industry to promote the development of Core Outcome Sets and advance rheumatology research. The following principles govern these partnerships:

- Sponsors have no influence on OMERACT's governance or decision-making processes.
- All sponsorship agreements are reviewed by the Management Group to ensure alignment with OMERACT's mission and adherence to organizational policies.
- Sponsorships are publicly acknowledged, and the nature of each contribution is transparently disclosed in reports, event materials, and other communications.
- OMERACT avoids reliance on a single sponsor by maintaining a diverse range of industry partnerships to safeguard independence.
- OMERACT does not offer exclusive sponsorship rights to any single organization, ensuring independence and avoiding dependency.
- The Management Group reserves the right to decline sponsorships that conflict with OMERACT's mission or research objectives.
- Sponsorship acknowledgments are made in accordance with OMERACT's policies and may appear in event materials, banners, and websites.
- Sponsorships may be accepted from pharmaceutical companies, medical device manufacturers, and other relevant industry partners. Organizations involved in lobbying efforts that conflict with OMERACT's mission are not eligible to sponsor.

6.3. Financial Management

OMERACT maintains strict financial oversight to ensure efficient use of resources and compliance with financial policies.

- The Finance Chair reviews annual budgets in collaboration with the Management Group. Budgets are aligned with OMERACT's strategic priorities and reflect anticipated revenues and expenditures.
- Financial reports, including statements of income and expenses, are prepared quarterly and shared with the Management Group.
- All expenditures are subject to approval by authorized personnel. Expense claims related to travel, meetings, and other operational activities are processed according to OMERACT's reimbursement policy.
- All funds received by OMERACT are allocated toward achieving the organization's objectives, including research, events, and activities. Funds are not used for lobbying or activities outside OMERACT's core mission.
- OMERACT publishes annual reports with a breakdown of industry sponsorships to maintain transparency.

6.4. Reimbursement Policies and Limitations

OMERACT mandates original receipts for all reimbursements and maintains the right to deny reimbursements without such receipts. OMERACT will not cover costs associated with early departure fees, service upgrades, hotel movie rentals, long-distance phone calls, meals for non-participants, transportation ticket change or cancellation fees, limousine or rental car services. Expenses beyond what is listed or amounts exceeding the approved budget must be approved by the OMERACT Chair of Finances.

6.4.1. Conference Reimbursement Policies

OMERACT provides financial support for selected participants at its biennial conferences:

1. Management Group Members: Receive complimentary registration and reimbursement for travel expenses.



- 2. **Fellows and Emerging Leaders:** Each active OMERACT working group may select one fellow or emerging leader to receive complimentary registration.
- 3. **Patient Research Partners (PRPs):** Successful PRP applicants receive complimentary registration and travel reimbursement.
- 4. **Speakers:** OMERACT may compensate speakers with complimentary registration and reimbursement for preapproved travel expenses, subject to recommendation by the Program Chair and approval by the Chair of Finance.

6.4.2. Meetings Outside of the Annual Conference

OMERACT organizes specialized meetings as needed. Reimbursement for these meetings will depend on the availability of funds and prior approval by the Management Group.

6.4.3. Management Group Meetings

The Management Group meets annually to align strategy and review progress. OMERACT supports the following expenses for these meetings:

- OMERACT will cover the room and tax for two nights
- OMERACT will reimburse for round-trip airfare.
- For Management Group members who opt not to fly, OMERACT will reimburse ground transportation costs.
- Meal expenses will be reimbursed upon presentation of original receipts.
- Other direct expenses related to the meeting, such as parking fees and tips, will also be covered by OMERACT.

Note: Reimbursement amounts are subject to change based on funding availability.

6.5. Risk Management

OMERACT proactively manages financial risks to ensure operational continuity and maintain trust with collaborators and partners.

OMERACT monitors potential risks, including:

- Reputational Risks: Conflicts of interest or public controversies.
- Operational Risks: Leadership transitions or funding gaps.
- Financial Risks: Misallocation of funds or sponsor withdrawals.



BIENNIAL CONFERENCES

OMERACT's biennial conferences are the cornerstone for advancing its mission of developing and improving outcome measures in rheumatology. This section outlines key policies and processes for planning, organizing, attending, and documenting these conferences.

7.1. Planning and Organization

The success of OMERACT's biennial conferences depends on comprehensive planning and coordination across multiple collaborators. The following policies govern the planning and organization process:

- The Conference Planning Committee (CPC) is responsible for creating the conference agenda, coordinating logistics, and ensuring alignment with OMERACT's goals. Membership includes representatives from the Management Group, working group leaders, PRPs (Patient Research Partners), and event organizers.
- Each conference must align with OMERACT's strategic priorities and address topics in Core Outcome Set
 Development. Each session should have clear objectives, focusing on consensus-building, knowledge exchange,
 and strategic decisions.
- The CPC coordinates with working group leaders to plan SIG sessions and workshops. Guidelines ensure these sessions are interactive and focus on developing or updating Core Outcome Sets or their related methodology.
- Budget and Funding: The CPC oversees the budgeting process, including registration fees, sponsorships, and grants, ensuring financial sustainability.

7.1.1. Venue and Accessibility

Venue selection ensures accessibility for all participants, including accommodations for PRPs and individuals with disabilities. Virtual attendance options should be incorporated when feasible to promote inclusivity. Conduct venue walk-throughs to ensure:

- Availability of ramps, elevators, and wide doorways.
- Automatic doors for event spaces and restrooms.
- Adequate space for wheelchair access and freedom of movement.
- Seating arrangements that can be easily adjusted for various needs.
- Quiet spaces for attendees who may feel overwhelmed by noise or crowds.
- Adequate sound systems with microphones, hearing loops, and accessible slides for attendees with dyslexia or other needs.
- Clear, visible signage (e.g., dark text on light backgrounds, large fonts, a mix of capitals and lowercase letters).

7.1.2. Choosing Dates

OMERACT takes multiple factors into account when selecting dates for its biennial conferences to ensure inclusivity and accessibility for all participants. These considerations include:.

- Avoid scheduling events on key religious or national holidays.
- Ensure there are no conflicts with other related conferences or major events in rheumatology and outcome research.

7.1.3. Scheduling and Time Management

- Share predictable and clear schedules in advance and ensure they are adhered to during the event.
- Avoid overloading the agenda; prioritize quality over quantity to ensure meaningful engagement and leave attendees feeling energized.

7.1.4. Ensuring a Diverse Line-Up

• Ensure diversity in speakers, panelists, and session leads to represent a range of experiences and perspectives. This enhances the event's relevance, reach, and impact.



7.1.5. Participant Needs and Communication

- When sending invitations, ask participants about accessibility needs, dietary requirements, and other considerations.
- Ensure the venue can meet these needs and share accessibility information well in advance.
- Provide various meal options, including:
 - Vegetarian, vegan, halal, kosher, gluten-free, lactose-free, and allergy-sensitive choices.
 - Healthy options such as salads, grain bowls, and fruit trays.
 - Sustainable practices like sourcing locally, reducing food waste, and minimizing plastic use.
 - Offer water and grab-and-go snack stations to keep attendees fueled throughout the day.

7.1.6. Reliable Wi-Fi

• Ensure reliable Wi-Fi for attendees to stay connected throughout the event.

7.2. Attendance and Participation

Participation at OMERACT biennial conferences is open to researchers, clinicians, PRPs, policymakers, and other collaborators involved in outcome measurement. Policies are in place to ensure a productive and inclusive environment.

- Participants include working group members, industry representatives, regulators, fellows, emerging leaders, PRPs, observers, and keynote speakers. Efforts are made to include diverse participants, with representation from different regions and disciplines.
- OMERACT ensures meaningful engagement of PRPs by covering travel costs, providing pre-conference training, and assigning buddies for new PRPs.
- Registration deadlines, discounts, and funding opportunities are communicated well in advance. Attendance is mandatory for working group leads to present progress and receive feedback during SIG sessions.
- All participants must adhere to OMERACT's Code of Conduct, promoting respectful communication and collaboration. A designated conference ombudsperson handles complaints or incidents.

7.3. Documentation and Reporting

Accurate documentation of conference activities is essential for transparency, accountability, and knowledge dissemination. The following policies govern conference documentation and reporting:

- Session leads are responsible for summarizing key points, decisions, and action items from their sessions. Dedicated rapporteurs ensure that all relevant discussions are captured in real time.
- Formal voting results from sessions are documented, with detailed breakdowns of consensus achieved. Any disagreements and their resolutions are also recorded.
- A comprehensive conference report is prepared within 3 months, covering session summaries, decisions, and next steps.
- Conference materials, including slides, recordings (where applicable), and reports, are archived and accessible to participants.

7.4. Seeking Feedback

- Collect feedback via surveys, focus groups, or interviews to improve future events.
- Share improvements with attendees to demonstrate a commitment to continuous enhancement.



8. AMENDMENTS AND REVISIONS PROCESS

OMERACT's policies must remain current, clear, and aligned with evolving practices. To ensure transparency, consistency, and accountability, this section outlines the process for amending and revising policies within the OMERACT Policy Manual.

8.1. Process for Policy Revision

- Any member of the OMERACT Management Group, working groups, or relevant committees may propose revisions.
- Recommendations for revisions may arise from internal reviews, feedback from collaborators, or changes in external guidelines.
- The relevant committees (e.g., Management Group, Technical Advisory Group) must review and endorse proposed changes before implementation.
- Major revisions require approval from the OMERACT Management Group.
- Policies affecting patient research partners (PRPs), working groups, or external collaborators will involve consultation with relevant collaborators before finalizing changes.

8.2. Updating Procedures

- Designated committees are responsible for drafting and justifying the proposed revisions.
- A structured feedback process ensures revisions align with OMERACT principles and best practices.
- All revisions will be communicated promptly to relevant parties and incorporated into the policy manual.

8.3. Version Control

Accurate versioning ensures consistency, traceability, and accountability for policy changes.

8.3.1. Policy Versioning:

- Assign unique version numbers (e.g., v1.0, v1.1) to each policy update.
- Significant changes increment the primary version number (e.g., v2.0), while minor updates increment the secondary number (e.g., v1.1).

8.3.2. Change Log:

- Maintain a detailed change log summarizing each revision, including the version number, change date, and a brief description of the updates.
- The change log will be included as part of the document history at the end of the manual.

8.3.3. Review Frequency:

- Policies will undergo annual reviews to reflect the latest best practices, regulatory requirements, and organizational needs.
- Interim revisions may be conducted as necessary based on urgent needs or significant external changes.



9. APPENDICES

Terms of Reference

- A. Management Group
- B. TAG Co-Chairs
- C. <u>TAG Members</u> and <u>TAG Fellows</u>
- D. PRP Support Team
- E. PRP Network Members
- F. SAG Co-Chairs
- G. SAG Members
- H. Working Group Co-Chairs
- I. Working Group Members