

2023 Year End Report



OMERACT[®]

Outcome Measures in Rheumatology

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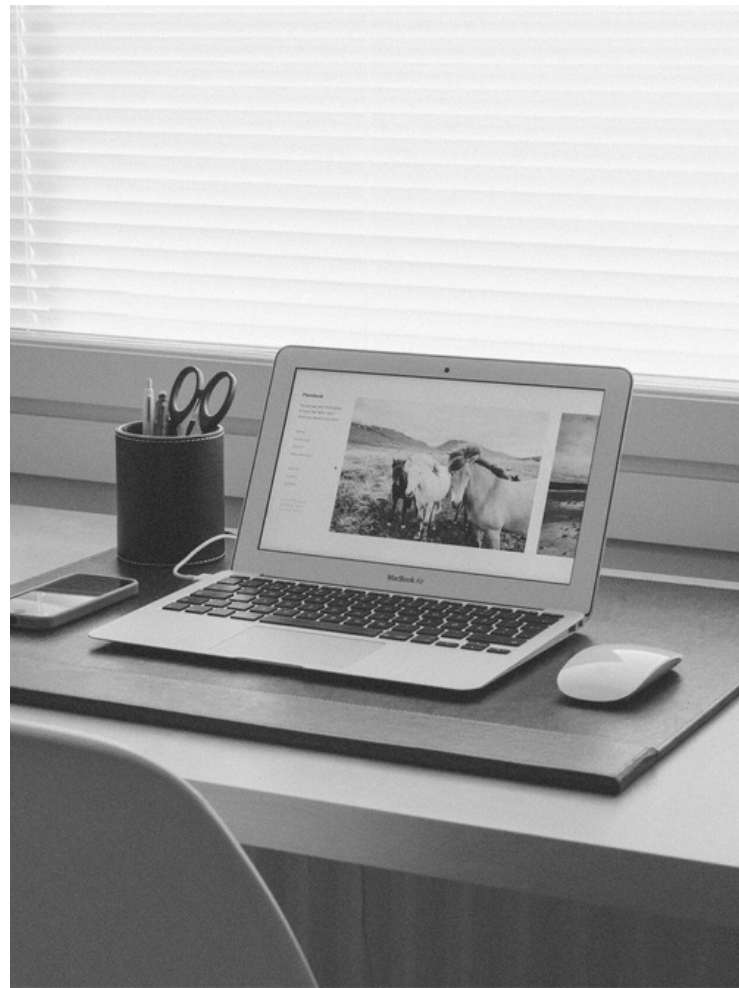
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WORDS FROM THE MANAGEMENT TEAM

As the year draws to a close, it's a moment for OMERACT to look back on the past 12 months.

A cornerstone of this year's success was the OMERACT 2023 Conference in Colorado Springs. This event brought together a diverse group of collaborators from the OMERACT community, creating a forum for exchange and advancement. Throughout the meeting, we engaged in a series of interactive workshops, working group meetings and strategic discussions. These sessions were invaluable for sharing knowledge, fostering innovative thinking, and setting the stage for future initiatives in autoimmune and musculoskeletal disease core outcome set research. The enthusiasm and active participation of all attendees amplified the impact of the meeting, making it not only a professional success but also a testament to the strong community spirit within OMERACT.

As we approach the upcoming year, we are filled with optimism about the new possibilities and challenges that lie ahead. Our commitment remains steadfast: to continuously evolve as an organization and to enhance the lives of those affected by autoimmune and musculoskeletal diseases through the development of core outcome sets.



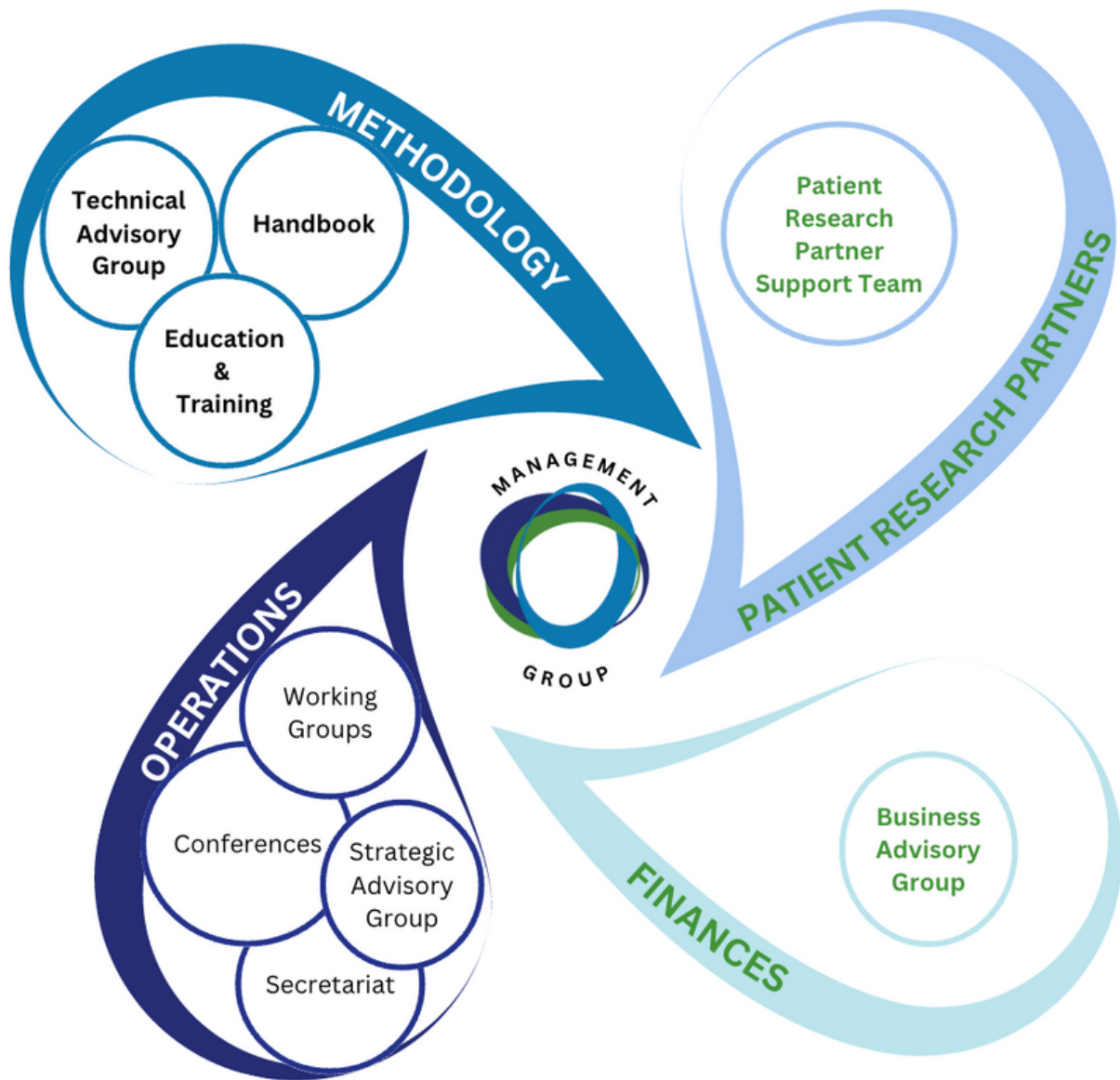
We look forward to hosting our in-person meeting May 14th-18th 2025 in Antalya, Turkey.

We eagerly anticipate sharing our progress and plans with you in the months to come.

Dorcas Beaton, Phil Conaghan, Catherine Hofstetter, Lee Simon and Peter Tugwell
OMERACT Management Team



OMERACT STRUCTURE



The hub of OMERACT activity takes place in the Working Groups, defined by a disease or intervention they are focused on. We currently have over 35 active Working Groups in OMERACT.

OMERACT has 3 staff (1 Administrator and 2 Senior Methodologists)

MANAGEMENT GROUP



The OMERACT Management Group provide oversight of all OMERACT activities and operations. They are responsible for making key decisions, guiding the organization's policies & procedures, and ensuring its overall effectiveness. Each member wears two hats within OMERACT: one as a valuable member of the management team and another as a dedicated leader responsible for coordinating activities within their respective organizational sector to advance OMERACT's mission statement. The Management Group is comprised of 5 members who possess expertise and experience in areas crucial to OMERACT.

TECHNICAL ADVISORY GROUP



Dorcas Beaton
Co-Chair

George Wells
Co-Chair

Bing Bingham
Co-Chair

Annelies Boonen
Ernest Choy
Robin Christensen
Andrea Doria

Catherine Hill
Cathie Hofstetter
Ben Horgan
Katy Leung

Alexa Meara
Zahi Touma
Peter Tugwell

TECHNICAL ADVISORY GROUP (TAG) ROLE

OMERACT is committed to empowering Working Groups with a robust framework to develop Core Outcome Sets effectively. To facilitate this, we've enhanced our process to guide Working Groups through the process. Our comprehensive Handbook, along with Domain and Instrument Selection Workbooks, are designed to support Working Groups through the Core Outcome Set process, ensuring clarity and efficiency in achieving their goals.

The OMERACT Technical Advisory Group (TAG) operates as an integral part of the Methods sector of OMERACT, offering its specialized expertise in methodology for Core Outcome Set Development. Comprising a team of skilled collaborators, TAG members bring a wealth of knowledge in patient-centered research, measurement science, psychometrics, and statistical analysis. Their primary mission is to provide expert methods advice, rigorously review measurement methodologies, and contribute to the advancement of OMERACT's methodological approaches. This ensures the application of robust and reliable technical practices within the OMERACT community.

A key function of the TAG is to support OMERACT Working Groups. This includes thorough reviews of working group materials, offering constructive feedback, and ensuring their alignment with OMERACT's Master checklist for Domain Development and Instrument Selection.

Central to OMERACT's vision, the TAG is instrumental in upholding the integrity and quality of outcome measurement in rheumatology, thereby significantly contributing to OMERACT's overarching mission of enhancing outcome measurement in rheumatic diseases.

PATIENT RESEARCH PARTNER SUPPORT TEAM



MEET *the* PRP SUPPORT TEAM



Catherine Hofstetter, Chair
Toronto, Canada



Mary Cowern
South Wales, UK



Ingrid de Groot
The Netherlands



Maya Desai
Toronto, Canada



Ben Horgan
Australia

Five individuals comprise the PRP Support Team who have responsibility for all aspects of engaging and preparing interested rheumatology patients to become effective Patient Research Partners in OMERACT.

This team has prepared numerous resources for omeract patient research partners including the website with training videos and FAQ's found here: <https://omeractprpnetwork.org/>

STRATEGIC ADVISORY GROUP



Lyn March
Co-Chair

MADA
Co-Chair

Peter Tugwell
Co-Chair

Ben Horgan
Bethan Richards
Catherine Hill
Francis Guillemin

Grayson Schultz
Heidi Siddle
Ingrid de Groot
Mikkel Ostergaard

Peter Merkel
Robin Christensen
Vibeke Strand

To support OMERACT in our evolution we have developed The OMERACT Strategic Advisory Group (SAG). The OMERACT Strategic Advisory Group is responsible for providing strategic recommendations to the OMERACT Management Group. Their primary role is to ensure that OMERACT's activities align with its mission and objectives. The SAG comprises experts from various disciplines within rheumatology, including clinicians, researchers, methodologists, and patient research partners. They are going through the Future of OMERACT survey results to develop a set of recommendations to be delivered to the OMERACT Management Group early 2024.

BUSINESS ADVISORY COMMITTEE

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The Business Advisory Committee (BAC) is a forum in which the OMERACT Management Group exchanges ideas with members of the pharmaceutical and biotechnology industry. Members are invited to comment on the agenda of activities for OMERACT meetings, and can suggest items for consideration. The BAC, through its direct access to the Management Group, allows more rapid and timely development of the agenda for OMERACT activities. It ensures that sponsors have a voice in the development of consensus in outcome measures in rheumatology.

The BAC is co-chaired by two members of OMERACT. The BAC meets at least once a year at the annual meeting of the American College of Rheumatology (ACR). Members of the BAC are regularly updated by Co-Chairs on the agenda for OMERACT meetings and any other developments.



LEE SIMON
MD, FACP, MACR



VIBEKE STRAND
MD, FACP, MACR

BAC CO-CHAIRS

WORKING GROUPS

OMERACT organizes its working groups into six thematic areas. Beyond these thematic categories, we also track their advancements through the stages of Core Outcome Set or related Methodological development.

1. **Disease Theme:** focuses on specific health conditions, often within the realm of rheumatology but potentially extending to related fields. These groups aim to establish and refine Core Outcome Sets specific to the disease.

Adult Still's Disease

Calcium Pyrophosphate Deposition (CPPD)

Chronic Nonbacterial Osteomyelitis (CNO)

Foot & Ankle Disorders

Gout

Juvenile Idiopathic Arthritis

Myositis

Patient Outcomes in Longitudinal Observational Studies (POLOS)

Polymyalgia Rheumatica (PMR)

Rheumatoid Arthritis

Scleroderma Vascular Disease

Shoulder Disorders

Sjögren's Disease

Systemic Lupus Erythematosus

2. **Bolt-On:** a supplemental measure or set of measures (such as a questionnaire or a set of clinical indicators) that can be added to a Core Outcome Set to make it more comprehensive or applicable to a particular population or context.

Adherence

Shared Decision Making

WORKING GROUPS CONTINUED

3. Imaging & Biomarkers: concentrates on the evaluation and endorsement of imaging techniques and biomarkers as reliable outcome measures in rheumatological research and clinical trials. These specialized working groups aim to integrate modern imaging technologies like MRI, ultrasound, X-ray, or CT scans, as well as biochemical markers detectable in blood, urine, or tissue samples, into the Core Outcome Sets developed for specific diseases or conditions.

Juvenile Idiopathic Arthritis MRI (JAMRI)

MRI Taskforce

Synovial Tissues in RCT

Ultrasound

4. Methodology: primarily focused on the methodological aspects of developing, validating, and implementing COS.

Composite Outcomes

Contextual Factors

Equity, Diversity & Inclusivity (EDI)

Immune Related Adverse Events

Patient preferences to value health outcomes for RCT's (PPRCT)

Surrogate Outcomes

WORKING GROUPS CONTINUED

5. Domain Specific: focuses on the in-depth exploration and understanding of specific domains, or areas of concern, that are critical for assessing patient outcomes in the field of rheumatology. These domains could include factors like pain, physical function, mental well-being, or other relevant domains that help to gauge the effectiveness of treatments and interventions.

Glucocorticoid-Related Adverse Events

Pain

Remission in RA-patient perspective

Safety

Worker Productivity

6. Composites: focuses on the development, validation, and refinement of a composite. A composite measure is a single score or index that combines multiple individual instruments or domains, offering a more holistic view of patient status.

ANCA-Associated Vasculitis

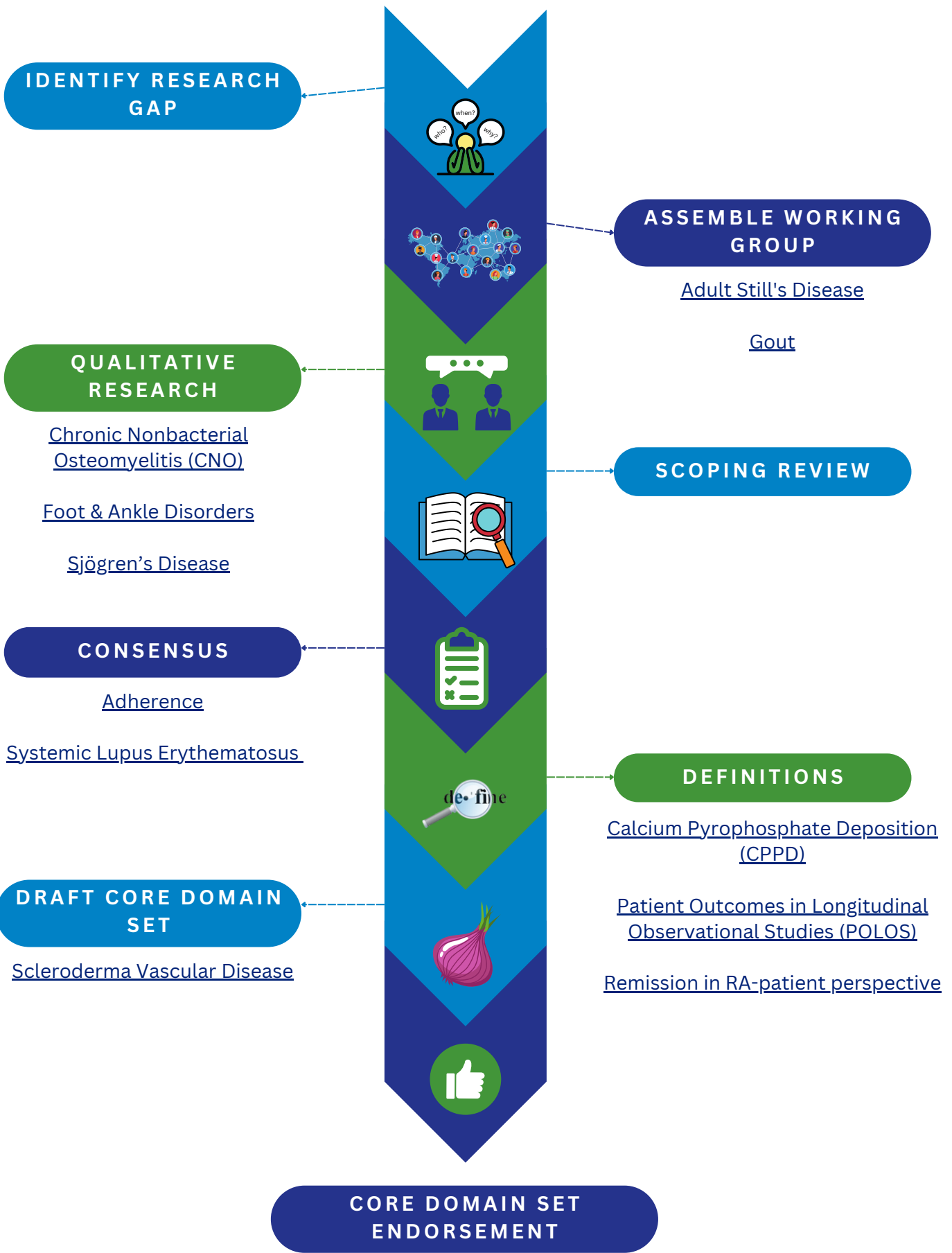
Behçet's Syndrome

Flares in OA

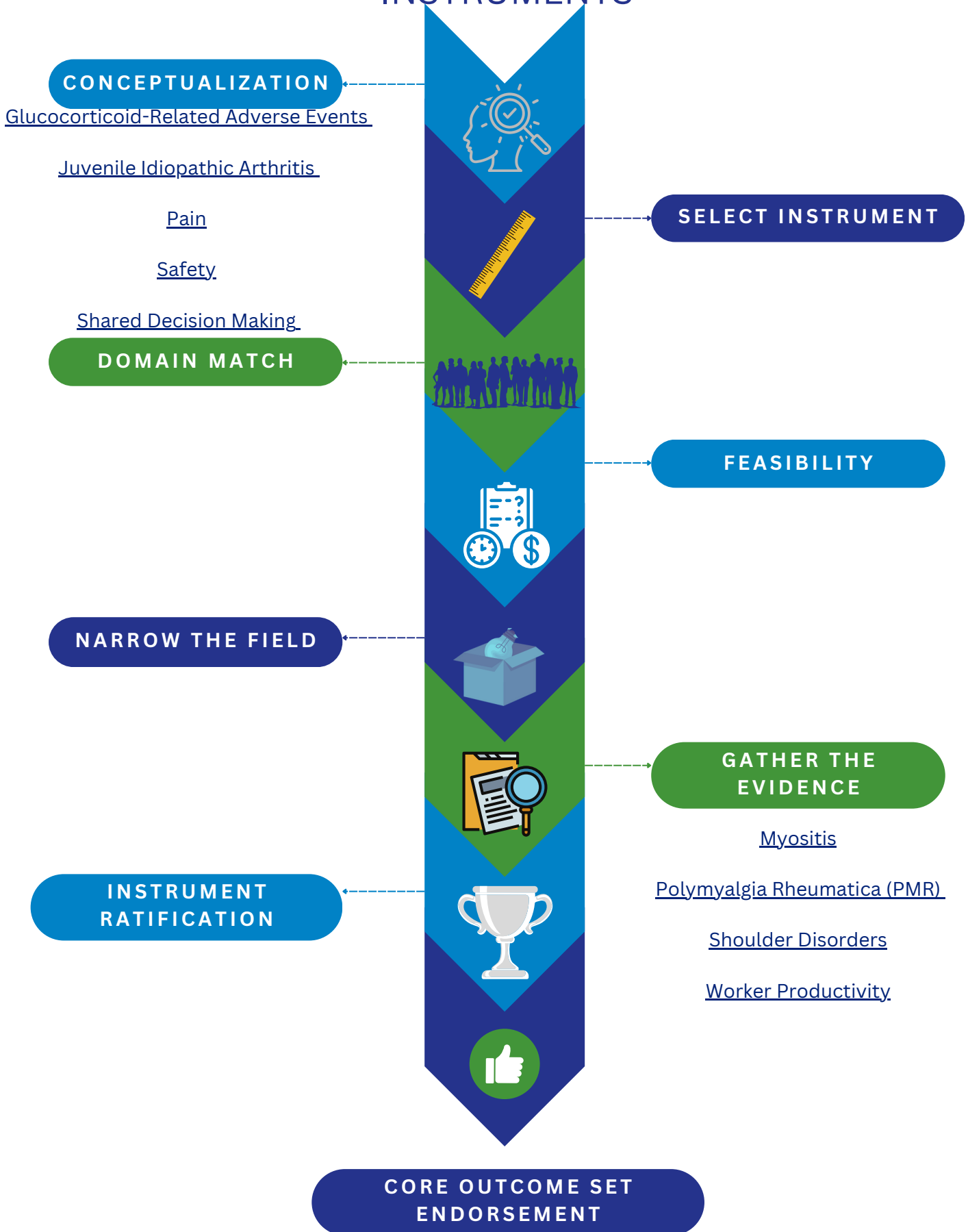
Large Vessel Vasculitis

Late Stage Knee & Hip OA

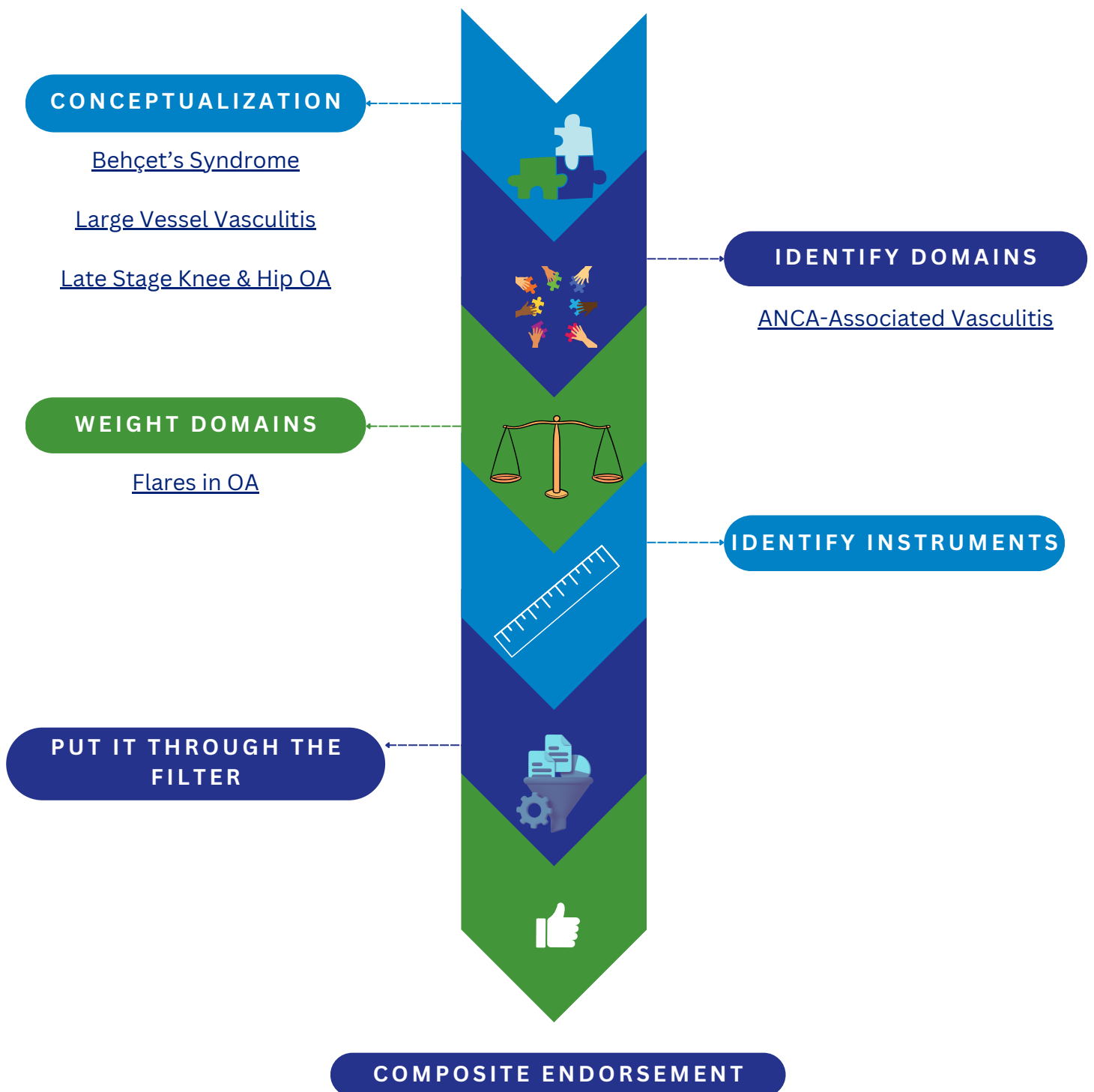
WORKING GROUPS' PROGRESS TOWARDS THE DEVELOPMENT OF A CORE OUTCOME SET - DOMAINS



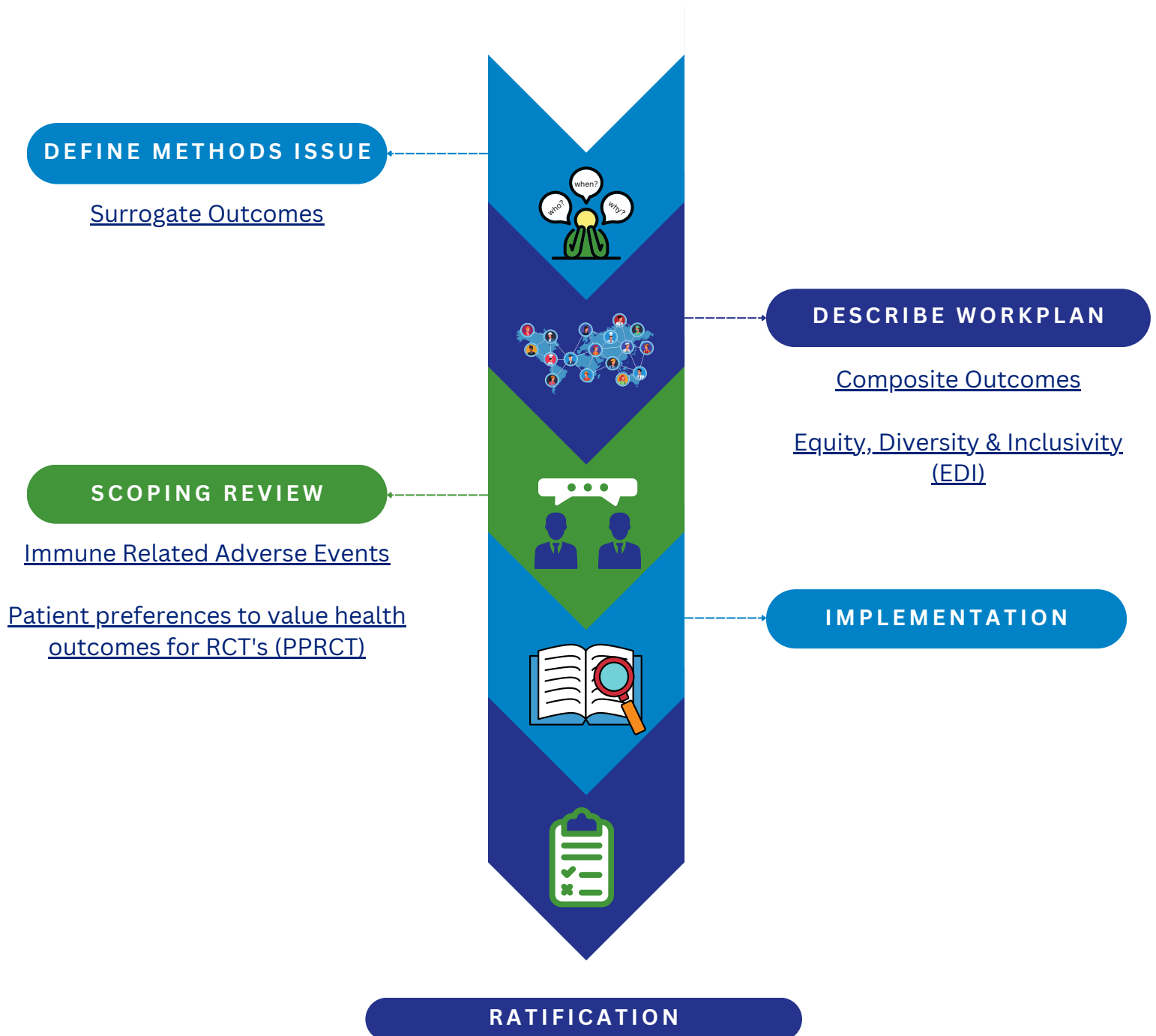
WORKING GROUPS' PROGRESS TOWARDS THE DEVELOPMENT OF A CORE OUTCOME SET - INSTRUMENTS



WORKING GROUPS' PROGRESS TOWARDS THE DEVELOPMENT OF CORE OUTCOME SET - COMPOSITES



WORKING GROUPS' PROGRESS TOWARDS THE DEVELOPMENT OF CORE OUTCOME SET METHODS



KEY ACHIEVEMENTS 2023 OMERACT 2023 CONFERENCE



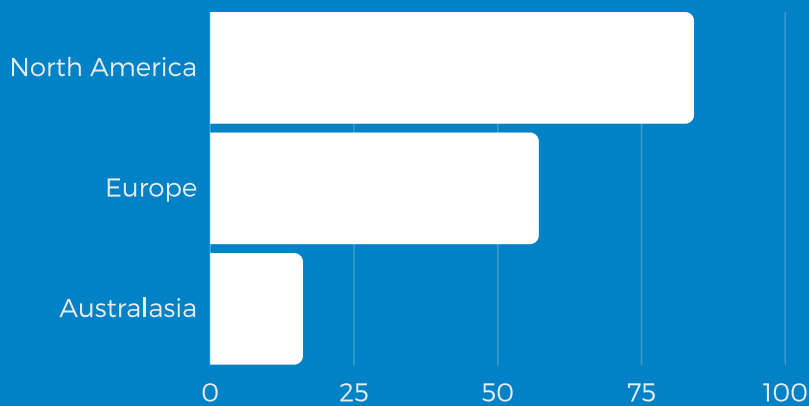
1. The OMERACT 2023 Conference, held in Colorado Springs after a three-year delay due to COVID-19, successfully brought together 157 international participants, emphasizing patient engagement and innovative in core outcome set research in rheumatology.
2. The event featured interactive workshops and Special Interest Group sessions, focusing on diverse topics like Equity, Diversity & Inclusivity, Pain, and Core Outcome Set methodology, fostering interdisciplinary collaboration and knowledge sharing.
3. Key initiatives like the OMERACT Emerging Leaders Program, Fellows Program, Patient Research Partner Program and Newcomers Program, along with the adoption of digital tools for a paperless conference, highlighted OMERACT's commitment to advancing rheumatology outcomes and its adaptability over 30 years.

OMERACT 2023

BY THE NUMBERS

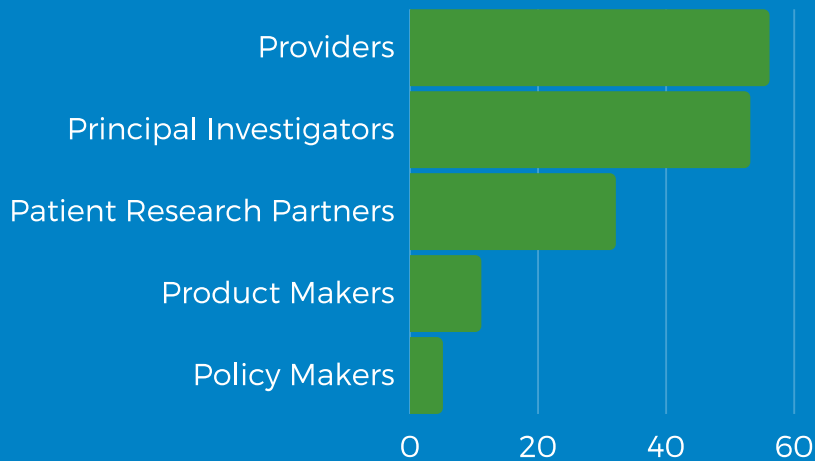
157

IN-PERSON & VIRTUAL PARTICIPANTS
ACROSS 9 PLENARY AND 20 SPECIAL
INTEREST GROUP SESSIONS



ATTENDEES BY CONTINENT

STAKEHOLDERS



SESSIONS

12

PLENARY
SESSIONS

20

WORKING GROUP
SESSIONS

KEY ACHIEVEMENTS 2023

OMERACT METHODOLOGY UPDATES

In 2023, OMERACT achieved significant milestones in advancing its methodology framework, underpinning its commitment to enhancing the quality and relevance of Core Outcome Set development. Here are some key achievements in our methodology updates:

Defining Foundational Domains

- Successfully defined foundational domains across various conditions. This initiative has provided a clear framework for researchers, facilitating a more standardized approach to domains definitions in Core Outcome Sets.

Domain Definition Repository

- Established a comprehensive repository for domain definitions, serving as a central resource. The repository promotes provide working groups with access to endorsed domain definitions for their use.

Knowledge Translation Tool – Updated SOMP

- Launched an updated version of the Summary of Measurement Properties (SOMP) table, serving as a knowledge translation tool. This tool assists working groups in effectively communicating their findings, ensuring that instruments are reported with clarity and transparency.

FDA-OMERACT Comparison

- Conducted a comprehensive comparison between FDA guidelines and OMERACT methodologies, identifying synergies and areas for alignment. This comparison has paved the way for closer collaboration with regulatory bodies, ensuring that OMERACT methodologies align with regulatory expectations and contribute to the advancement of patient-centered research.

Through these accomplishments, OMERACT has strengthened its methodological foundation, promoting the development of robust, relevant, and patient-centered Core Outcome Sets. These achievements not only reflect OMERACT's dedication to methodological excellence but also its commitment to fostering collaboration and standardization in outcomes research.

KEY ACHIEVEMENTS 2023

PATIENT RESEARCH PARTNER SUPPORT TEAM

The Patient Research Partner (PRP) Support Team has made significant strides in 2023 towards enhancing patient involvement and representation in OMERACT's activities. Here's an overview of our initiatives and achievements:

Continued Education for PRPs

- **Expanded Educational Resources:** Provided PRPs with comprehensive educational materials focusing on Core Outcome Set development methodology.
- **Pre-Conference Training:** Implemented targeted training sessions for PRPs to engage effectively in the OMERACT conference.

Building PRP Support Team Capacity

- **Team Expansion:** Welcomed 2 new members from the OMERACT PRP Class of 2023 into the Support Team, emphasizing geographic and disease diversity.

Continuous Improvement

- **Feedback Implementation:** Actively addressed PRP feedback on SIG session preparedness and resource access, committing to continuous improvement.
- **Equity, Diversity, and Inclusivity (EDI):** Focused on EDI within the PRP program to attract and involve underrepresented populations more effectively.
- **Process Evaluation:** Regularly evaluated and adapted PRP support and selection processes to enhance the program's effectiveness and inclusivity.

Communication and Support

- **Maintaining Connections:** Utilized platforms like WhatsApp to maintain and foster ongoing connections among PRPs, ensuring a supportive community.
- **Post-Conference Support:** Provided continued support to PRPs after conferences, especially those facing health challenges, to ensure their ongoing engagement.

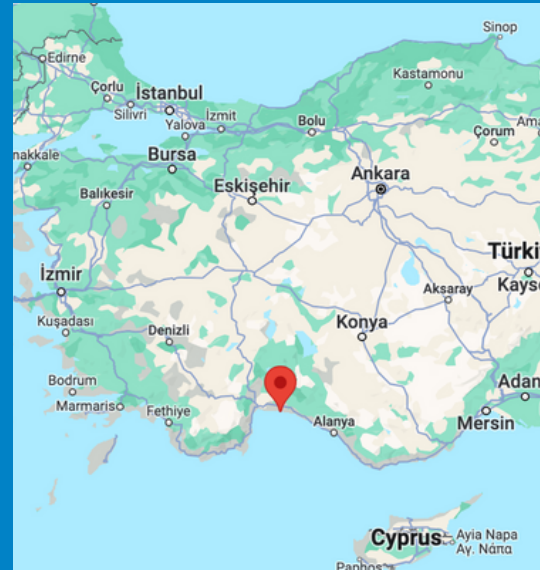
PRP Network Directory

- **Directory Participation:** Created the PRP Network Directory, aiming to strengthen the ties within the PRP community and facilitate collaboration.

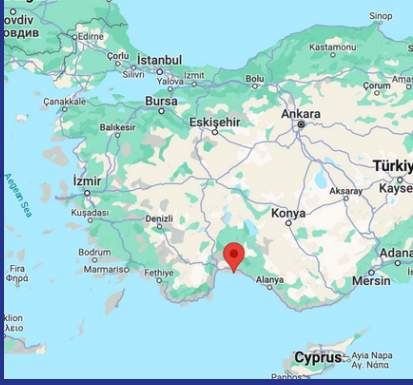
Through these initiatives, the PRP Support Team has not only contributed to the enrichment of OMERACT's research processes but also ensured that the patient voice remains a cornerstone of our work. Moving forward, we are committed to building on these successes to further enhance patient engagement and representation in all aspects of OMERACT's activities.

OUR GOALS FOR 2024

- Publication of the OMERACT Handbook in Seminars in Arthritis and Rheumatism
- Development of Validation of Composites through the OMERACT Filter Methodology
- Further OMERACT Methods Development
 - AI Integration into OMERACT Instrument Selection Process
 - Complete Instrument Selection for 4 PROMIS Instruments
- Continued Development & Endorsement of Core Outcome Sets
 - Development of a Virtual Endorsement Platform
 - Virtual Workshops and Consensus Meetings



OMERACT 2025 MAY 14- MAY 18



**SAVE
THE
DATE**

**ADVANCING
CORE OUTCOME
SETS IN
RHEUMATOLOGY
THROUGH
COLLABORATION**

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ANTALYA,
TURKEY**

**VISIT OUR WEBSITE FOR
MORE INFORMATION**



**FOR MORE INFORMATION, CONTACT OMERACT AT
ADMIN@OMERACT.ORG**

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We extend our gratitude to the numerous OMERACT participants, patient research partners, and members of the Business Advisory Committee for their invaluable contributions to OMERACT



Contact Us:

(613) 794-1355 ▪ admin@omeract.org

www.omeract.org ▪ [Twitter @omeract](https://twitter.com/omeract)