# 2022 Year End Report





### WORDS FROM THE MANAGEMENT TEAM

As we begin the new year, we want to take a moment to reflect on the changes that have occurred within our organization over the past year. The past 12 months have been a time of reflection for OMERACT.

As we look towards the future of our organization, we wanted to ensure that we are meeting the needs of our community and achieving our mission. To do this, we needed input and feedback. We had over 200 OMERACTers complete a survey to gather thoughts and opinions on the current state of our organization and ideas for how we can improve and grow in the future. The feedback provided us the information we need to build a roadmap for OMERACT's future success. We look forward to sharing these plans in the coming months.

We are excited about the opportunities that lie ahead and are committed to continuing to evolve as an organization and improve outcomes for patients with autoimmune and musculoskeletal diseases.



We look forward to hosting our inperson meeting May 1st - 5th 2023 at the Cheyenne Mountain Resort in Colorado Springs and hope to see you there.

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





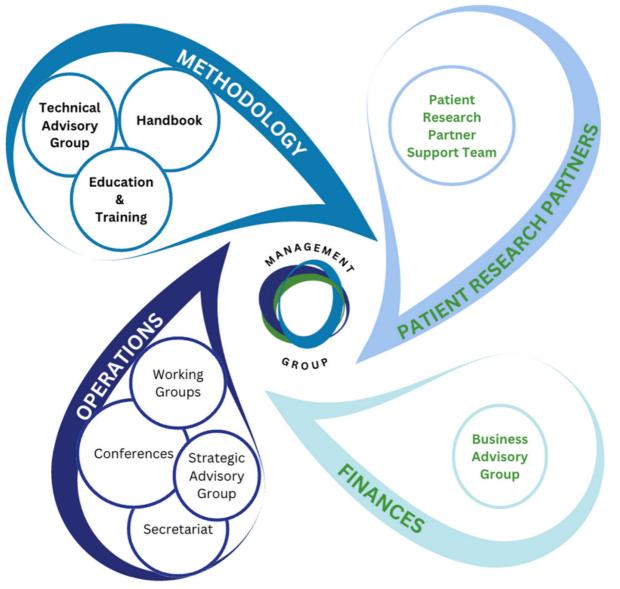








# **OMERACT STRUCTURE**



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 40 active Working Groups in OMERACT.

OMERACT has 3 staff (1 administrator and 2 senior methodologists)



### MEET the MANAGEMENT TEAM







Peter Tugwell MSc, MD, FRCPC Chair - OMERACT Ottawa, Canada

Dorcas Beaton BScOT, PhD Chair - OMERACT Methods Toronto, Canada Philip Conaghan MBBS,PhD,FRACP,FRCP Deputy Chair - OMERACT Leeds, UK



Catherine Hofstetter Chair - OMERACT Patient Research Partners Toronto, Canada



Lee Simon MD, FACP, MACR Chair - OMERACT Finances Boston, USA

OMERACT is led by our Management Team, they work together to make OMERACT successful.

- Each member has two hats: that of a member of the management team, and a leader of their sector of OMERACT
- Members support and challenge one another.
- The team works continuously on strategy, direction and finding ways to best support the work of our Working Groups



## OUR TECHNICAL ADVISORY GROUP



### **OMERACT TECHNICAL ADVISORY GROUP**

**Dorcas Beaton - Co-Chair** 

Annelies Boonen Ernest Choy Robin Christensen Andrea Doria Catherine Hill **George Wells - Co-Chair** 

Cathie Hofstetter Ben Horgan Féline Kroon Katy Leung

#### **Bing Bingham - Co-Chair**

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Sarah Mackie Alexa Meara Zahi Touma Peter Tugwell

#### Lara Maxwell - Sr. Methods Advisor



### TECHNICAL ADVISORY GROUP (TAG) ROLE & THE OMERACT HANDBOOK

THE OMERACT HANDBOOK

FOR ESTABLISHING AND IMPLEMENTING CORE OUTCOMES IN CLINICAL TRIALS ACROSS THE SPECTRUM OF RHEUMATOLOGIC CONDITIONS

VERSION 2.1 | April 1st 2021

OMERACT HAS DEVELOPED A MORE EXPLICIT PROCESS FOR DETERMINING WHEN AN INSTRUMENT MEETS THE OMERACT FILTER OF 'TRUTH', 'DISCRIMINATION', AND 'FEASIBILITY'. WE HAVE CREATED GUIDANCE IN THE FORM OF A HANDBOOK FOUND HERE: HTTPS://OMERACTHANDBOOK.ORG/ AND DOMAIN AND INSTRUMENT SELECTION WORKBOOKS TO HELP OMERACT WORKING GROUPS MOVE THROUGH THE FILTER 2.2 PROCESS.

THE ROLE OF THE TAG IS TO CRITICALLY APPRAISE SUBMITTED DOCUMENTATION FROM OMERACT WORKING GROUPS FOR ADHERENCE TO FILTER 2.2 CHECKLIST REQUIREMENTS AND TO ADVANCE THE METHODS USED IN THE OMERACT FILTER. AFTER REVIEWING THE DOCUMENTATION, THE TECHNICAL ADVISORY GROUP WILL MEET TO AGREE ON WHETHER THE PROCESSES WERE FOLLOWED AND JUSTIFICATIONS IN PLACE TO SUPPORT THE DECISIONS BEING PROPOSED BY THE WORKING GROUP.



## OUR PATIENT RESEARCH PARTNER SUPPORT TEAM

### MEET the PRP SUPPORT TEAM



Catherine Hofstetter Chair Toronto, Canada



Tom Buttel Sydney, Australia



George Casey Colorado, USA



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/





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The Business Advisory Committee (BAC) is a forum in which OMERACT 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 OMERACT community, 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.

#### **BAC Co-Chairs**



Lee S. Simon MD, FACP, MACR



Vibeke Strand MD, MACR, FACP



ADULT STILL'S DISEASE ANCA-ASSOCIATED VASCULITIS (RESPONSE CRITERIA) AXIAL SPONDYLOARTHRITIS (CORE DOMAIN SET) BEHÇET'S SYNDROME (CORE DOMAIN SET) CALCIUM PYROPHOSPHATE DEPOSITION (CPPD) CHRONIC NONBACTERIAL OSTEOMYELITIS (CNO) CTD-ILD (CORE DOMAIN SET) FLARES IN OA (CORE DOMAIN SET) FOOT & ANKLE DISORDERS GLUCOCORTICOID-RELATED ADVERSE EVENTS (CORE DOMAIN SET) GOUT (CORE SET) HAND OA (CORE DOMAIN SET) HIP & KNEE OSTEOARTHRITIS (CORE DOMAIN SET) JUVENILE IDIOPATHIC ARTHRITIS (CORE DOMAIN SET) LARGE VESSEL VASCULITIS (CORE DOMAIN SET) LATE STAGE KNEE & HIP OA COMPOSITE MEASURE MYOSITIS (CORE DOMAIN SET) OSTFOPOROSIS PATIENT OUTCOMES IN LONGITUDINAL OBSERVATIONAL STUDIES (POLOS) POLYMYALGIA RHEUMATICA (PMR) (CORE DOMAIN SET) **PSORIATIC ARTHRITIS (CORE DOMAIN SET)** RHEUMATOID ARTHRITIS (CORE SET) SCLERODERMA VASCULAR DISEASE SHOULDER PAIN OUTCOME MEASURES (CORE DOMAIN SET) SYSTEMIC LUPUS ERYTHEMATOSUS



# OMERACT WORKING GROUPS CONT.

#### **INSTRUMENTATION ACROSS DISEASE**

ADHERENCE

PAIN

SHARED DECISION MAKING (CORE DOMAIN SET)

WORKER PRODUCTIVITY

#### METHODOLOGY STREAM

COMPOSITE OUTCOMES

CONTEXTUAL FACTORS

EQUITY

IMMUNE RELATED ADVERSE EVENTS

PATIENT PREFERENCES TO VALUE HEALTH OUTCOMES FOR RCT'S

**REMISSION IN RA-PATIENT PERSPECTIVE** 

SAFETY

#### **IMAGING & BIOMARKERS STREAM**

JUVENILE IDIOPATHIC ARTHRITIS MRI (JAMRI)

MRI TASKFORCE

SURROGATE OUTCOMES

SYNOVIAL TISSUES IN RCT

ULTRASOUND



### **KEY ACHIEVEMENTS 2022**

- Running monthly town halls for our working group members, to provide an open space for discussion and feedback of our methods process for domain generation and instrument selection.
- Development of OMERACT eLearning Modules
- Update of the OMERACT Domain Workbook
- Monthly newsletter to provide frequent updates on both methods advancements and activities.

### **2022 BY THE NUMBERS**

22

peer reviewed publications

41

active working groups 1400+

OMERACT community members



### TAG/HANDBOOK GROUP HIGHLIGHTS 2022

RESOURCES CREATED & UPDATED BY HANDBOOK GROUP: HTTPS://OMERACT.ORG/RESOURCES/

- OMERACT HANDBOOK & WORKBOOKS
- VIDEOS
- INFOGRAPHICS
- PUBLICATIONS
- WHITEBOARDS
- FAQ

CREATED A SET OF TRAINING VIDEOS PROVIDING DETAILS AND SUPPORT ON KEY AREAS DURING INSTRUMENT SELECTION. THEY COVER: BUILDING A SUMMARY OF MEASUREMENT PROPERTIES TABLE, DOMAIN MATCH & FEASIBILITY, TESTING SOURCES OF VARIABILITY, CRITICAL APPRAISAL, ADEQUACY OF RESULTS, AND SYNTHESIS OF EVIDENCE. HTTPS://OMERACT.ORG/INSTRUMENT-SELECTION/

OMERACT SENIOR METHODOLOGIST LARA MAXWELL & HANDBOOK CHAIR DORCAS BEATON MENTORING 19 WORKING GROUPS VALIDATING INSTRUMENTS USING THE OMERACT FILTER. SOME WORKING GROUPS ARE CONDUCTING MEASUREMENT PROPERTY STUDIES TO ADDRESS A LACK OF EXISTING EVIDENCE.

HOST MONTHLY OPEN TOWN HALL SESSIONS TO EXCHANGE IDEAS AND CLARIFY QUESTIONS ABOUT THE DOMAIN AND INSTRUMENT SELECTION PROCESSES. OFFERS WORKING GROUPS THE CHANCE TO LEARN FROM EACH OTHER.



#### OMERACT 2022 PATIENT RESEARCH PARTNER SUPPORT TEAM SUMMARY

The PRP Support Team is busy ramping up for OMERACT 2023! Here are some of our highlights from 2022...

In the spring of 2022, the Team was recruited to support the INTEGRATE - Pain Consortium which is part of the NIH's 'HEAL initiative'. It involved participation in a few meetings and 4 different Delphi surveys, each one on a different aspect of pain. We recruited from our larger PRP group to provide the patient voice to the Delphi rounds. To date there have been two rounds of the Delphi completed.

 In November we had an opportunity to address the Working Groups who held meetings in Philadelphia during ACR to extend an offer of support and to help connect the WG's with new and additional PRP's. We are calling this our "Right Patient Involvement Initiative". We were also able to address the Business Advisory Committee who are many of our industry partners to let them know just how the PRP's add value to the work of OMERACT.

·We have 20 PRP's coming to OMERACT in May 2023!

a)Eight PRP's that are new to OMERACT conferences, and they will be "Buddied up" with an experienced PRP to help them navigate the OMERACT experience. b)We have also planned 3 "Happy Hour" Zoom calls with the newbies to get to know

them and provide them with support so that they are able to provide meaningful participations in the planned sessions and that it will be a rich and rewarding experience for everyone.

c)We have also planned a meet and greet with the OMERACT Fellows in the form of a "Speed Dating Session"! It will be an hour of fun and information for the Fellows and PRP's to get to know one another a little better. We hope to foster that relationship as there is much that we can learn from one another.

#### LOOKING AHEAD...

•We are excited introduce the PEIRs Framework, Workbook and Evaluation tools during an opening day session at OMERACT. The tools will allow us to measure and document OMERACT's engagement with PRPs which has been integral to their success over the last 20 years. It's a roadmap to effective and meaningful Patient Engagement In Research (PEIR).

•We will continue to develop resources for the PRP's to support their continuing contributions to OMERACT.



#### OUR GOALS FOR 2023

- Successful OMERACT 2023 in person conference
- Continued Development & Endorsement of
  Core Outcome Sets
- Further OMERACT Methods Development
  - Creation of standard definitions for common domains
  - Standards for adequacy of performance
  - OMERR Database for facilitating tracking of the literature and storage of the extracted results, creation of reports
- Increasing Engagement & Promoting Uptake of Core Sets
- Establishment of a new Strategic Advisory Group. This committee will be dedicated to providing strategic guidance and support to the OMERACT Management Team. The Strategic Advisory Group will bring together a diverse group of individuals with a shared commitment to OMERACT.









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# OMERACT 2023 MAY 1-MAY 5



INTERACTIVE SESSIONS INCORPORATING PATIENT AND CLINICIAN/ RESEARCHER PERSPECTIVES

CHEYENNE MOUNTAIN RESORT | COLORADO SPRINGS, COLORADO, USA VISIT OUR WEBSITE FOR

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

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WITH THANKS TO THE MANY OMERACT PARTICIPANTS, PATIENTS AND BUSINESS ADVISORY COMMITTEE MEMBERS WHO CONTRIBUTE TO OMERACT



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