

Patients included in OMERACT working groups and biennial meetings

The *Patients Included* charter enables conference organizers to demonstrate that their events are committed to incorporating the experience of patients as experts living with their condition, while ensuring they are neither excluded nor exploited. *Patients Included* status is self-assessed. A conference successfully meeting all five of the charter's clauses may accredit itself as a *Patients Included* event. The **OMERACT 2020 biennial Conference Colorado Springs** fulfills the five *Patients Included* charter clauses as follows:

1. Patients or caregivers with experience relevant to the conference's central theme actively participate in the design and planning of the event, including the selection of themes, topics and speakers.

Capturing the patient perspective is an important part of research because the objective of OMERACT is to improve clinical outcomes for patients. In order to effectively capture the patient perspective during the research phase, active collaboration between researchers and patients is essential. OMERACT has been involving patients in research as patient research partners (PRPs) since 2002. This has enabled efficient inclusion of the patient perspective in the development of clinical outcome measures^{1 2}. OMERACT's Executive Committee has 1 patient representative on the board who is part of the selection of themes included in the biennial meeting program. The Local Organizing Committee also has 1 patient member to be a part of all discussions leading up to the conference.

2. Patients or caregivers with experience of the issues addressed by the event participate in its delivery, and appear in its physical audience.

All OMERACT Working Groups are required to involve at least one patient, preferably 2, in their steering committee and in their ongoing work in preparation of OMERACT 2020. As a principle, 10% of the meeting participants need to be PRPs which means that 20 PRPs are invited to the meeting. Each Working Group has to nominate at least 1 patient to attend the conference.

¹ De Wit M, Abma T, Koelewijn-van Loon M, Collins S, Kirwan J. Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences. *BMJ Open* 2013;3(5). Doi:10.1136/bmjopen-2012-002241

² De Wit M, Kirwan JR, e.a. Successful Stepwise Development of Patient Research Partnership: 14 Years' Experience of Actions and Consequences in Outcome Measures in Rheumatology (OMERACT). *Patient*. 2017 Apr;10(2):141-152. Doi: 10.1007/s40271-016-0198-4.

- 3. Travel and accommodation expenses for patients or carers participating in the advertised programme are paid in full, in advance. Scholarships are provided by the conference organisers to allow patients or carers affected by the relevant issues to attend as delegates.**

OMERACT and OMERACT Working Groups fully fund all patients that attend the meeting. This includes all travel, accommodation and registration costs.

- 4. The disability requirements of participants are accommodated. All applicable sessions, breakouts, ancillary meetings, and other programme elements are open to patient delegates.**

The 2020 OMERACT Conference will be held at the Cheyenne Mountain Colorado Springs hotel. All scientific programme sessions will be open to all delegates wishing to attend and the Cheyenne Mountain Resort is ADA compliant.

Guide Dogs are permitted throughout the hotel. There are escalators and elevators in the conference centre along with accessible washrooms. The accessible washrooms on the main floor of the conference centre also have open assist buttons. The hotel has accessible guest rooms as well and can offer roll in showers, shower seats, elevated toilet seats, handrails, visual or vibration alarms and lowered peep holes, closet hangers, etc.

The Cheyenne Mountain Resort & OMERACT are committed to ensuring that all disability requirements of participants are accommodated and that all session spaces and programme elements are accessible to all. The local resort staff are trained to provide assistance to visitors with limited mobility as well as other disabilities or needs.

- 5. Access for virtual participants is facilitated with free streaming video provided online wherever possible.**

New for OMERACT 2020 we will be offering virtual participation to selected attendees. Due to the format of an OMERACT conference and the number of concurrent sessions we are limited in providing streaming of all sessions. The sessions that are streamed will be available to members who may not be able to attend the conference. After the event, access to the PowerPoint presentations and breakout group discussions will be available to all OMERACT Members and delegates of the conference. Those that are unable to attend will be able to participate in conference discussions using the hashtag #OMERACT2020.

For additional information on Patients Included Charters visit the **Patients Included** website.

For additional information on the OMERACT PRP policy, see the OMERACT recommendations for PRP-researcher collaboration.³

³ Cheung PP, de Wit M, Bingham CO, 3rd, Kirwan JR, Leong A, March LM, et al. Recommendations for the Involvement of Patient Research Partners (PRP) in OMERACT Working Groups. A Report from the OMERACT 2014 Working Group on PRP. *The Journal of rheumatology* 2016;43(1):187-93.