

History of patient involvement at OMERACT



OMERACT started in 1992 as an initiative to overcome the problem of widespread and inconsistent use of many different outcome measures in rheumatoid arthritis (RA) clinical trials. The objective was to improve “the accuracy and responsiveness to change of clinically relevant (to patient and clinician) endpoints.” Rheumatologists from many countries met in Maastricht and achieved consensus on a core set of outcomes for RA.

The RA core set was endorsed by the WHO. The initial stand-alone conference was sufficiently successful to be followed by conferences in alternate years continuing the discussion and consensus building about new core sets for other rheumatic diseases and new measurement instruments.

During the fifth OMERACT conference (2000), participants discussed the concept of a minimum clinically important difference (MCID). Based on methodological arguments, a growing interest in PROs emerged, culminating in a spontaneous proposal at the final session to invite patients to the next conference. All participants voted in favor of this proposal.²⁸ The chair of the conference felt confident about the proposal because it had been discussed previously in the organising committee, although no decisions had been taken. Participants of the MCID module argued that patient perspectives should be explored further²⁹ and took responsibility for identifying 11 patients to join OMERACT 6 and to review the RA core set.

Between 2002 and 2020, a total of almost 100 patients with different rheumatic diseases have participated as full delegates with equal voting rights. Their role and contributions have developed over time. At the first conference (2002), they formed an homogeneous group of people with RA with little or no experience in scientific research. The level of involvement in the conference in general was relatively low, support was not organized and the number of sessions patients attended was limited. Contributions centred on participation in the workshop discussions about the severity of fatigue and the definition of low disease activity, although there was a keynote speech at the opening ceremony.

In contrast, by OMERACT 14 (2018), a heterogeneous group of patient research partners participated representing a variety of rheumatic conditions and different levels of experience, competences and cultural backgrounds. They received a pre-conference information pack and were actively supported by a pre-conference dinner, a glossary, training sessions and a buddy system.

They carried out a variety of tasks similar to professionals such as giving plenary presentations, co-chairing breakout sessions, reporting back from breakout sessions and preparing consensus statements. Several partners became co-authors of peer-reviewed publications.