Pan-American Manifesto for Rheumatic Diseases: The patients' view

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Background and aims

Rheumatic and musculoskeletal diseases (RMDs for its acronym in English), are chronic pathologies of high morbidity with a great impact in quality of life, which generate disability and increase the costs of care. In Latin America there are multiple barriers to patient care.

The objective of the study was to identify the care needs and difficulties that patients with RMDs face in the region.

Methods

The information gathering technique was the socalled citizen jury, which involved the participation of 30 leaders of patient organizations in 13 countries evaluating the needs and preferences of patients with RMDs, as well as experts in the scientific area. The analysis process followed three phases: coding, description, and identification.



Group of expert patients and authors



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Results

The jury determined 12 recommendations that were categorized into different groups: prevention, detection, timely diagnosis, and comprehensive care by a multidisciplinary team in specialized centers, the role of patient organizations and their participation in health policies.

Conclusion

Pan American RMDs patient's organizations, are aware of the urgent needs of the people they represent. Their contribution is essential to design strategies to improve the detection, access and monitoring of a better quality of life. The Pan American manifesto of RMDs constitutes a call to action to include the perspective of patients in the design of public policies.



