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# Optimizing care for patients with rheumatic disease worldwide: a concept of global rheumatology

**Barbara B Mittleman and Peter E Lipsky**

Many clinical trials of novel and expensive therapies for rheumatic diseases are currently being carried out in Eastern Europe, South and Central America, and Asia. The principal investigators and sponsors of almost all these trials reside in Western Europe or the US, the results of the studies are usually published in western journals, and the largest and most lucrative markets for these therapies are in the more developed countries. As trial participants, subjects in the less developed regions mentioned have access to accurate diagnosis, regular and competent follow-up, and potentially effective, safe therapeutic agents. After the study is complete, however, very few participants will continue to have access to these therapies because of cost; even fewer will receive comparable ongoing rheumatologic care, because it is simply not available in many parts of the world. The ethical concerns raised here are comparable to those surrounding HIV and AIDS trials carried out in the developing world a few years ago.

It has become clear that optimum rheumatologic care involves early and accurate diagnosis, regular and appropriate follow-up, availability of a wide range of modalities for assessing clinical status, disease activity and progression, and unfettered access to all the various approved therapeutic options. It is unacceptable that so few can expect to receive optimum care. This is even true in the US and Europe, where the limited availability of rheumatologists to make diagnoses and provide follow-up assessments and care, inequities in health coverage, and lack of funding for recommended therapies all contribute to substandard care for many patients. These limitations are only magnified in the developing world.

With increasing divergence between optimum care and available care for patients with rheumatic diseases in most of the world, it is incumbent on us as members of the rheumatology community to ask what is our responsibility to establish minimal standards for rheumatologic care globally? This is especially urgent when so many clinical trials are being carried out in regions in which optimum rheumatologic care is not available. An objective of the Bone and Joint Decade is "to continually seek and promote cost effective prevention and treatment of musculoskeletal injuries and disorders" (www.boneandjointdecade.org). In a world teeming with unmet medical needs, providing adequate care for chronic rheumatic diseases that often affect people in midlife does not seem to be a high priority.

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Perhaps the time has come for all members of the rheumatology community—including the health-care providers, the pharmaceutical companies, the private and public insurers, the various professional and patient organizations, and all those people affected by rheumatic disease—to come together and demand an acceptable minimal standard of care for all rheumatic disease patients as a human right.

Only broad-based proactive advocacy will bring about timely change. Rheumatology has become a global community, at least as regards the generation of new information from clinical trials. We need to work together to ensure that exploitation of patients in clinical trials neither occurs, nor seems to occur, and that the results generated are useful and available to all. Currently, only those who already have good access to rheumatology care and therapies benefit from the results of clinical trials carried out in the developing world. One way to improve the balance of the risk-to-benefit ratio for participants in these clinical trials would be for the global rheumatology community to embrace its ethical responsibility to improve the care of all patients with rheumatic disease, wherever they are.

*BB Mittleman is the Director of the Program on Public-Private Partnerships, Office of Science Policy, NIH, Bethesda, MD, USA, and PE Lipsky is the Editor-in-Chief of Nature Clinical Practice Rheumatology.*

**Competing interests**
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