

# Challenges and Opportunities in Using Patient-reported Outcomes in Quality Measurement in Rheumatology



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## KEYWORDS

- Patient-reported outcomes • Quality measures • Performance measures
- Outcome measures • Health care quality • Rheumatology

## KEY POINTS

- The health care landscape in the United States is likely shifting to a model in which health systems will be reimbursed for the quality of care they provide, and developing valid, responsive, and meaningful patient-centered measures is key.
- How best to incorporate patient-reported outcome measures (PROs) in assessments of health care quality in rheumatology is underexplored.
- Experiences with widespread use of PROs in Sweden and the United Kingdom, and in smaller health systems within the United States, provide valuable lessons about challenges and opportunities in using PROs to assess quality.
- Major challenges include developing sufficient information technology infrastructure to collect data from diverse medical records and diverse patients; need for better understanding of PRO reliability, validity, and responsiveness; determining that PROs are responsive to changes in the health care environment; clarifying the role of case-mix adjustment; and understanding how measures should be summarized and reported to stakeholders.

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## INTRODUCTION

Quality measures provide important insight into variability or problems within structures of care, processes of care, or outcomes of care.<sup>1-3</sup> Patient-reported outcomes (PROs) provide valuable information on patients' health-related quality of life, and can be used to facilitate shared decision making in the clinical setting, for comparative effectiveness research, for adverse event reporting, and in quality assessment.<sup>1,2,4-6</sup> However, use of PRO measures as indicators of health care quality and accountability is a new, and growing, area in the United States.

Following passage of the Patient Protection and Affordable Care Act in 2010, there has been a growing emphasis on improving performance and accountability of health care systems and individuals.<sup>7-9</sup> Recent legislation, the Medicare Access and CHIP (Children's Health Insurance Program) Reauthorization Act of 2015, supports a shift in physician reimbursement via a merit-based incentive payment system (MIPS), in which physicians and systems will be judged and reimbursed partly based on the quality of care they provide. Appropriate selection of measures that define quality, particularly measures that matter to beneficiaries of care, will be critical to the success of MIPS.<sup>8,10</sup>

Given increased recognition that patient engagement and inclusion of the patient's voice are critical to the success of a high-quality, affordable health system,<sup>4,7,8,11</sup> incorporating measures that reflect the patient's direct report about how they feel and function into measures that evaluate quality of care is essential. However, there are several challenges to using PRO measures to assess performance and accountability,<sup>7,12-16</sup> and how best to do this in rheumatology has yet to be defined.

This article discusses the role of structure, process, and outcome measures of health care quality using PROs, reviews European countries' experiences collecting and evaluating national PRO data to assess quality of care, describes the current use of PROs as quality measures in rheumatology, and frames an agenda for future work supporting the development of meaningful quality measures based on PROs.

## STRUCTURE, PROCESS, AND OUTCOME: PATIENT-REPORTED OUTCOME MEASURES AS INDICATORS OF HEALTH CARE QUALITY

The ability to understand the quality of health care, defined by the Institute of Medicine as "the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge,<sup>17</sup>" is fundamentally linked to how quality is defined and measured. Quality measures that use PROs can address health care structures, processes, and outcomes, and there are important strengths and limitations to measuring each of these categories.

PRO outcome measures attempt to evaluate the ultimate impact of care provided, and thus are sought-after metrics of health care quality.<sup>1,18</sup> Outcomes can be measured at the individual level or aggregated by provider, practice, institution, organization, or region. Aggregating PRO outcomes data at the level of the health care system could theoretically identify poor performers and makes it possible for individuals to compare performance between health systems, driving accountability. However, with each level of aggregation, information about the processes and environments of care that contributed to a high or low score may become more difficult to identify.

Although outcome-based quality measures are preferred by the Centers for Medicare and Medicaid Services, they provide limited information about the processes of care that lead to an outcome. PRO outcome measures might therefore show what needs to be improved, not how to do so. By contrast, process measures using PROs (eg, whether a PRO was completed and scored, or shared with a patient) may be more actionable, and, as such, more conducive to iterative quality improvement

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