

Lupus Quality Measurement

WHAT IS THE PROJECT?

Systemic Lupus Erythematosus (SLE) is a complex autoimmune disease that can involve many organs and systems, including the skin, joints, lungs, kidneys, brain, and blood-forming system. Lupus affects an estimated 1.5 million Americans and mostly strikes women of childbearing age. People with lupus can experience significant symptoms, such as pain, extreme fatigue, and physical impairments that impact every facet of their lives. Right now, there is no cure for lupus, but high-quality appropriate care and chronic disease management can help mitigate disease activity, prevent organ damage accrual, and improve quality of life. This National Quality Forum (NQF) Measure Incubator® project brought together a multistakeholder Expert Panel to share input, expertise, and strategic thinking around quality of care in lupus and identify measure concepts that address gaps in quality measurement.

This Measure Incubator® project is the first step toward facilitating the development of measures to fill critical gaps in quality measurement and lay the groundwork for outcome measurement in lupus care.

STRATEGY SESSION

NQF convened a Measure Incubator® Strategy Session with a multistakeholder Expert Panel comprised of a patient partner, clinicians, researchers, payers, policymakers, data experts, and measure developers in February 2020. At this meeting, panelists discussed the quality issues that affect patients with lupus, including misdiagnosis and timely referral, specialty care access and retention, appropriate medication use, preventing negative health outcomes, contraception and pregnancy in lupus, and patient-reported outcomes. Panelists emphasized that improving health outcomes and patient quality of life is the ultimate goal of lupus care. They noted that the quality measurement landscape for lupus care is emerging and evolving, and that there are opportunities to address critical care processes that help move the field towards measuring outcomes that matter for lupus patients and their families.

High-priority measure concepts address hydroxychloroquine use, proper prednisone dosing and harm reduction, access to specialty care, evaluation for active lupus nephritis, and patient-reported outcomes.

The Expert Panel identified and prioritized five measure concepts, based on potential impact and feasibility, that could be developed into quality measures for lupus care. These concepts focus on promoting hydroxychloroquine use, proper prednisone dosing and harm reduction, access to specialty care, evaluation for active lupus nephritis, and patient-reported outcomes. Panelists recommended that these measures concepts be moved forward into development and testing. Panelists noted similarities in some facets of rheumatoid arthritis care and suggested using rheumatoid arthritis quality measurement approaches as an exemplar and path to accelerate measure development for lupus.

WHAT IS THE ENVISIONED OUTCOME?

NQF seeks to facilitate the development of one or more measure concepts into fully specified and tested performance measures, as well as work to advance patient-reported outcome measurement in lupus care. NQF will explore funding to support these efforts beginning in fall 2020.

NQF is delivering this project through the Measure Incubator® with financial support from Johnson and Johnson Health Care Systems, Inc (JJHCS). In accordance with the **NQF Measure Incubator Conflict of Interest Principles**, JJHCS has not influenced the outcomes and activities associated with this project.