

# Patient reported outcome measurement system (PROMIS) valid in assessing patient experience

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A study at Hospital for Special Surgery (HSS) evaluating the Patient Reported Outcomes Measurement Information System (PROMIS) in patients with lupus finds that the questionnaire is valid in assessing subjective patient experience. Researchers also observed a disconnect between the patient perspective and objective signs and symptoms, underscoring the need to integrate patient-reported outcomes into clinical care to ensure optimal disease management.

The HSS study, "Feasibility and Validity of Patient Reported Outcome Measurement Information System (PROMIS) in SLE," will be presented at the American College of Rheumatology/Association of Rheumatology Health Professionals annual meeting on November 8 in San Francisco.

The National Institutes of Health assessment tool known as PROMIS seeks to measure the impact of disease on quality of life. The patient questionnaire evaluates physical, psychological and social well-being.

"Accurate measurement of patient-reported outcomes is particularly important in [systemic lupus erythematosus](#) (SLE), a heterogeneous disease in which similar symptoms can affect patients in different ways," explains Shanthini Kasturi, MD, a rheumatology fellow at Hospital for Special Surgery and lead investigator. "PROMIS offers dynamic computer adaptive tests (CATs) to assess the subjective patient experience in a variety of relevant domains."

PROMIS surveys ask patients questions to measure pain, fatigue, physical function, depression, anxiety, social function and other quality of life indicators. The online questionnaire administered by Hospital for Special Surgery investigators uses computerized adaptive testing (CAT), an interactive method to streamline surveys by selecting questions based on patients' previous responses.

"In order to provide patient-centered care, we need to have an idea of what the patient is really experiencing," Dr. Kasturi said. "Having additional information about patients' quality of life will help us to see how well our treatments are working and whether we should be pursuing different treatments. To our knowledge, this is the first study to assess the feasibility and validity of administering PROMIS CATs to adult SLE outpatients."

Researchers aimed to correlate PROMIS CATs with traditional patient reported outcome measures, lupus [disease activity](#) and organ damage. They also assessed the retest reliability of the PROMIS questionnaire.

Adult patients with lupus were recruited from the Lupus Center of Excellence at Hospital for Special Surgery. They completed the SF-36 and LupusQoL-US, which are considered gold-standard quality of life questionnaires, and PROMIS CATs to assess how lupus affected their health-related quality of life. Disease activity, flares, and damage were evaluated with the SELENA-SLEDAI and SLICC-ACR indices.

Patient answers in PROMIS domains were compared with similar domains in the gold-standard surveys, and also with disease activity and damage. Retest reliability was evaluated among subjects reporting stable lupus activity at two assessments one week apart.

Of 198 patients approached, 163 (82%) completed at least one assessment. One hundred thirty-eight patients completed a retest. "The

data show that PROMIS CATs can be successfully administered to a diverse group of SLE [patients](#) at the point of care or remotely, and are valid, reliable and responsive for many lupus-relevant domains," Dr. Kasturi said.

Most PROMIS domains showed moderate to strong correlations with similar domains in the established questionnaires, although social function and fatigue CAT categories showed poor correlations. "The weak correlations of social function and fatigue CATs with corresponding SF-36 domains point to a knowledge gap and the need for further study," Dr. Kasturi said.

Another important finding was that PROMIS scores did not correlate well with physician- derived lupus disease activity or damage measures, according to Dr. Kasturi. "This disconnect between the subjective patient experience and objective signs and symptoms underscores the need to integrate patient reported outcomes into clinical care to ensure optimal disease management," she noted.

**More information:** Study Title: "Feasibility and Validity of Patient Reported Outcome Measurement Information System (PROMIS) in SLE"

Provided by Hospital for Special Surgery

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