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BRIEF REPORT

Factors Associated With Variation in Pediatric Systemic Lupus Erythematosus Care Delivery

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Objective. Patients with pediatric systemic lupus erythematosus (pSLE) and mixed connective tissue disease (MCTD) receive only a fraction of recommended care. Using published quality indicators and guidelines, we developed a 13-item pediatric lupus care index (p-LuCI) to quantify the proportion of recommended clinical evaluations and comorbidity prevention interventions completed and the timeliness of follow-up. Our objective was to assess baseline index performance and identify sources of p-LuCI variation.

Methods. We performed a cross-sectional study in patients with pSLE or MCTD and analyzed the performance of individual p-LuCI process metrics and calculated the overall p-LuCI score. We identified factors associated with the p-LuCI using multivariable linear regression with clustering by provider.

Results. For 110 patients (99 with pSLE and 11 with MCTD), the median p-LuCI was 65.2% (interquartile range: 9.1-92.3%). Component performance ranged from 27.3% (on-time scheduling) to 95.4% (steroid-sparing treatment). Patients with p-LuCI scores above the median had higher scores across all 13 components. Higher p-LuCI scores were independently associated with disease-modifying antirheumatic drug use (β = 14.3 [95% confidence interval (CI), 1.5-27.2]), nephritis (β = 10.4 [95% CI, 5.1-15.8]), higher provider pSLE/MCTD volume (β = 3.1 [95% CI, 1.9-4.2] per patient), assignment to rheumatology fellow trainee (β = 36.3 [95% CI, 17.3-55.2]), and disease duration of less than 1 year (β = 12.6 [95% CI, 0.7-24.5]). Differences by race, ethnicity, and/or insurance were not observed.

Conclusion. Using an index of recommended pSLE care metrics, we identified significant variation in performance by disease, treatment, and provider characteristics. The p-LuCI may be useful to assess care quality at the patient, provider, and practice levels and to identify areas in need of greater standardization.

INTRODUCTION

There is a profound need to improve care and outcomes for children with pediatric systemic lupus erythematosus (pSLE). Children with pSLE experience greater disease activity and damage than adults, require more immunosuppression (1), and have a greater risk of early death (2). Effective pSLE care requires complex medication and comorbidity management to prevent life-threatening complications. However, children with pSLE receive only a fraction of recommended care (3), and pervasive health care disparities exist (4).

Consensus-driven efforts have been published in recent years to help close the pSLE quality gap. The pSLE quality indicators and Single Hub and Access Point for Paediatric Rheumatology in Europe (SHARE) guidelines help define a minimum level of recommended care around diagnostic testing, disease monitoring, and medical management (5,6). In addition, adults with systemic lupus erythematosus (SLE) who achieve a "low disease activity state" accrue less SLE-related damage (7). An international task force recommended reducing disease activity to the lowest possible level in a treat-to-target approach in which the "treatment… should aim at ensuring long-term survival, preventing organ damage, and optimizing health-related quality-of-life, by controlling disease activity and minimising comorbidities and drug toxicity" (8). These consensus statements focus on sets of critical activities that providers caring for patients should consider. In adults

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SIGNIFICANCE & INNOVATIONS

- We developed and assessed a composite index of 13 process measures for use in youth with pediatric systemic lupus erythematosus (pSLE) and mixed connective tissue disease.
- We demonstrated that patients received a median of 65% of the recommended care, with index variation distributed across all 13 measures.
- Independent predictors of higher index scores were disease-modifying antirheumatic drug use, nephritis, provider pSLE volume, care by a fellow trainee, and shorter disease duration.
- The pediatric lupus care index may be used to assess the quality of care at the patient, provider, or practice level to drive quality improvement activities.

enrolled in the Lupus Outcomes Study, those who received higher-quality care achieved better outcomes. Receiving greater than 85% of the recommended care was associated with significantly less disease damage accumulation (9).

In an effort to improve patient outcomes at our center, we defined 13 metrics to standardize pSLE clinical assessment, optimize comorbidity management, and ensure timely follow-up. We then operationalized a pediatric lupus care index (p-LuCI) to represent a summary of performance across all 13 measures. In this study, we aimed to assess baseline p-LuCI and component performance at a single center and identify demographic, disease-specific, and provider-level determinants of index variation.

PATIENTS AND METHODS

Patient population and setting. This cross-sectional study was conducted among patients with pSLE cared for in outpatient clinics at a tertiary care pediatric hospital using electronic health record (EHR) data extracted on a single reference date in October 2020. Study inclusion was based on a two-step process. Patients were first identified by the presence of an International Classification of Diseases, tenth revision (ICD-10), diagnostic code for SLE or mixed connective tissue disease (MCTD) associated with an ambulatory visit in the rheumatology, nephrology, or combined pSLE nephritis clinic within the last 15 months. Patients were included if there was also a physician diagnosis of pSLE or MCTD in the EHR using a specific pSLE documentation template. Patients were excluded if the visit was for a second opinion, if the patient transferred care to another center, or if the patient was deceased prior to the data extraction date. The institutional review board determined that this research was exempt.

p-LuCI metric selection, definition, and documentation. The p-LuCI was developed by the study team in collaboration with faculty and trainees at our center. The study team reviewed relevant literature (5,6,8) and obtained input from clinicians at quarterly division-wide quality improvement conferences between 2017 and 2019. We developed 13 priority measures based on feasibility and potential impact. Using key driver diagrams the study team created to conceptualize how to improve disease control and comorbidity management, we classified the measures in the following three domains: clinical assessment, comorbidity assessment and prevention, and population management. The measures were mainly drawn from the pSLE quality indicators (5), the SHARE project (6), and recommendations from an international SLE treat-to-target task force (8). Of note, we included clinical assessment components required to assess a "Lupus Low Disease Activity State," given its association with lower damage progression (7). Comorbidity assessment and prevention measures aligned with quality improvements at other pediatric rheumatology centers to increase generalizability. After the p-LuCI development process, the majority of the pediatric rheumatology faculty at our center (10/11; 91%) assessed the p-LuCI as appropriate, acceptable, and feasible (10). We prioritized measure selection focused on our center; we did not include measures that were consistently implemented (eg, hydroxychloroquine prescribing) or were the subject of anticipated future quality improvement activities (eg, mental health screening). The measure specifications and data sources are detailed in Table 1.

The p-LuCI was scored based on the percentage of eligible metrics completed at the last clinical encounter preceding the reference (data extraction) date or within prespecified time windows preceding the reference date (Table 1). If a patient had MCTD, then the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI, 2K version) and Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI, pediatric version) metrics were excluded. Similarly, if a patient was not exposed to chronic glucocorticoid therapy (11), stress-dose steroid planning and steroid-sparing agent metrics were excluded. Therefore, each patient had a denominator ranging from 9 to 13. Metrics were calculated electronically using data from standardized pSLE clinical templates, glucocorticoid prescription data (11), laboratory results, immunization tables, and appointment schedules through an EHR data extract.

Assessment of demographic, disease, and practice characteristics. Demographic, pSLE diagnosis and manifestations (such as nephritis), previous treatments, primary language, and insurance type were collected through chart abstraction and automated extraction of structured, pSLE-specific EHR data. Because this was a study of health care delivery, pSLE and MCTD classification was based on physician diagnosis. Current medication exposures included assessments of nonbiologic and biologic disease-modifying antirheumatic drug (DMARD) therapies as well as glucocorticoid, antimalarial (hydroxychloroquine), and cyclophosphamide exposures at the last visit preceding the reference date. Patients were classified as currently exposed to rituximab or ofatumumab if the last treatment occurred within the 6 months

Table 1. Pediatric lupus care index metric specifications

Measure	Calculation	Source
Clinical assessment		
SLEDAI score	Numerator: SLEDAI score documented within the previous 12 months Denominator: number of patients in the cohort diagnosed with pSLE (excluding MCTD)	Outpatient EHR template
SDI score	Numerator: SDI score documented within the previous 12 months Denominator: number of patients in the cohort diagnosed with pSLE (excluding MCTD)	Outpatient EHR template
PGA score	Numerator: PGA score documented at the last visit Denominator: number of patients in the cohort	Outpatient EHR template
Disease activity reconciled	Numerator: number of patients with standard disease activity reconciliation at last visit[a] Denominator: number of patients in the cohort	Outpatient EHR template
Disease characteristics review	Numerator: number of patients with disease characteristics reviewed in previous 12 months Denominator: number of patients in the cohort	Outpatient EHR template
Comorbidity assessment and prevention		
Pneumococcal vaccination	Numerator: number of patients appropriately vaccinated for PCV13 and PPV23 based on age Denominator: number of patients in the cohort	Outpatient EHR template and immunization table
Influenza vaccination	Numerator: number of patients who received influenza vaccination after August 1 of calendar year of the last visit Denominator: number of patients in the cohort 6 months of age or older	Immunization table
Blood pressure assessment	Numerator: number of patients with blood pressure reconciliation completed at last visit Denominator: number of patients in the cohort	Outpatient EHR template
Lipid testing	Numerator: number of patients with lipid profile assessed within prior 2 years Denominator: number of patients in the cohort	Outpatient EHR template and laboratory tables
Vitamin D testing	Numerator: number of patients with 25-hydroxyvitamin D assessed within the prior year Denominator: number of patients in the cohort	Outpatient EHR template and laboratory tables
Stress-dose steroid plan	Numerator: number of patients with secondary adrenal insufficiency entered into the EHR problem list[b] Denominator: number of patients in the cohort with a prescription for chronic steroids within the past 18 months	EHR problem list
Steroid-sparing agent prescribed	Numerator: number of patients with cytotoxic, DMARD, or biologic medication treatment documented Denominator: number of patients in the cohort with a prescription for chronic steroids within the past 18 months	Outpatient EHR template
Population management		
Visit scheduling	Numerator: number of patients with an active scheduled appointment within recommended time frame plus 30 days or within 180 days if time frame not documented Denominator: number of patients in the cohort	EHR follow-up recommendation

Abbreviation: EHR, electronic health record; MCTD, mixed connective tissue disease; PCV13, pneumococcal conjugate vaccine (13-valent); PGA, Physician Global Assessment; PPV23, pneumococcal polysaccharide vaccine (23-valent); pSLE, pediatric systemic lupus erythematosus; SDI, Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; SLEDAI, Systemic Lupus Erythematosus Disease Activity Score (2K version).
[a] Refers to documentation of disease activity status in the clinical note using a standard format with the following choices: *1*) no clinical active disease (at target), *2*) minimal clinical active disease (at target), and *3*) active disease.
[b] Problem list entry was used as a proxy for stress-dose steroid planning. We developed a standard problem list documentation process in which stress-dose steroid plans based on the patient's body surface area are entered into the problem list overview.

preceding the reference date. We classified the rheumatology provider as the individual with whom the last appointment was scheduled, which was either a fellow trainee or an attending physician. We assigned each patient a provider volume value representing the total number of individuals in the pSLE cohort under the care of the patient's rheumatology provider.

Statistical analysis. The performance of individual measures was calculated along with the median p-LuCI score across patients. We divided patients into those with p-LuCI scores above the median and those with scores at or below the median. Differences in group means and medians in individual measures were assessed using t tests and the Wilcoxon signed-rank tests,

respectively. Differences in proportions were assessed using χ^2 tests. We used two-sided tests of hypotheses, and *P* values of less than 0.05 were considered statistically significant. Univariate and multivariate linear regression was performed to assess the relationship between the p-LuCI and demographic, disease-specific, and practice-based predictors. Covariates with *P* values of less than 0.2 in univariate analyses were included in the multivariate linear regression analyses. Backward elimination was used to select covariates to include in the final model. Cluster robust standard errors were used in all regression models to account for the clustering of patients seen by the same rheumatology provider. Time since the last visit was not included in the analysis of factors associated with the p-LuCI because multiple metrics were time dependent. Statistical analyses were performed using Stata 16 (StataCorp).

RESULTS

Demographic, disease, and practice characteristics. We identified 110 patients with a diagnosis of pSLE or MCTD. Demographic characteristics are shown in Table 2. The mean age was 18 years (interquartile range [IQR]: 15-18 years); 89 (80.9%) were female, 38 (34.6%) were Black, 14 (12.7%) were Hispanic, and 12 (10.9%) were non-English speaking. The primary insurer was public in 50 patients (45.5%), and four (3.6%) were uninsured. Rheumatology providers included 10 attending physicians and five fellow trainees assigned a minimum of one patient and a maximum of 19 patients.

The majority of patients had pSLE (n = 99; 90%), with a median disease duration of 3.3 years (IQR:1.7-6.2) and 92 (84%) were diagnosed more than 1 year earlier. The median time since the previous outpatient visit was 62.5 days (IQR: 38-145). pSLE nephritis was common, occurring in 38 patients (34.5%). The majority of patients received ongoing treatment with DMARDs (n = 84; 76.4%), most commonly mycophenolate mofetil or mycophenolic acid. Although no patient was currently receiving cyclophosphamide, 18 (16.9%) had received it previously. A minority of patients were currently prescribed glucocorticoid therapy (n = 34; 30.9%) at a median dose of 0.09 mg/kg/day. The majority of patients were prescribed hydroxychloroquine (n = 106; 96.4%).

p-LuCI and component performance. The median p-LuCI performance was 65.2% (IQR: 9.1-92.3%). Values for specific index measures are shown in Table 3. Within the clinical assessment domain, processes performed at the lowest and highest frequency, respectively, were SDI scores (38.4%) and physician global assessments (75.5%). Within the comorbidity assessment and prevention domain, influenza vaccination was performed at the lowest frequency (41.8%, noted in October of flu season) and steroid-sparing therapy was performed at the highest frequency (95.4%). Appropriate appointment scheduling was performed in 27.3% of patients.

We assessed whether specific processes were driving the difference between higher and lower p-LuCI performance.

Table 2. Demographics, disease characteristics, and treatments

Variable	Value
Age, years, mean ± SD	17.1 ± 2.9
Female, sex, n (%)	89 (80.9)
Race, n (%)	
Black	38 (34.6)
Asian	15 (13.6)
Caucasian	33 (30)
Other	24 (21.8)
Hispanic ethnicity, n (%)	14 (12.7)
Non-English speaking, n (%)	12 (10.9)
Insurance status, n (%)	
Commercial	56 (50.9)
Public	50 (45.5)
Uninsured	4 (3.6)
Diagnosis, n (%)	
pSLE	99 (90)
MCTD	11 (10)
Disease duration, years, median (IQR)	3.3 (1.7-6.2)
Renal disease, n (%)[a]	38 (34.5)
II	2 (5.4)
III	10 (27.0)
IV	18 (48.7)
V	7 (18.9)
Glucocorticoids, n (%)[b]	
Current prednisone or prednisolone	34 (30.9)
Current dose, mg/kg/day, median (IQR)[c]	0.09 (0.07-0.36)
Hydroxychloroquine, n (%)[b]	106 (96.4)
Nonbiologic DMARD, n (%)[b]	84 (76.4)
Mycophenolate mofetil or mycophenolic acid	70 (83.3)
Azathioprine	6 (7.1)
Methotrexate	11 (10)
Tacrolimus	3 (2.7)
Sirolimus	1 (0.9)
Biologic DMARD, n (%)[b,d]	11 (10)
Cyclophosphamide, n (%)[e]	18 (16.9)

Abbreviation: DMARD, disease-modifying antirheumatic drug; IQR, interquartile range; MCTD, mixed connective tissue disease; pSLE, pediatric systemic lupus erythematosus.
[a] Biopsy deferred in one participant. The maximum International Society of Nephrology/Renal Pathology Society class is reported such that classes III and IV are reported if mesangial or membranous patterns are also present. Membranous pattern is reported if mesangial pattern is also present.
[b] Indicates current therapy; 7 of 110 participants (6.4%) took more than one nonbiologic DMARD.
[c] If on prednisone or prednisolone.
[d] Included six patients currently exposed to rituximab and one each exposed to ofatumumab, belimumab, canakinumab, adalimumab, and tocilizumab.
[e] No participants were actively receiving cyclophosphamide at the time of the study. Patients included in this measure were previously exposed.

As shown in Table 3, individuals with p-LuCI values above the median had significantly higher performance across all 13 processes measured.

Predictors of p-LuCI performance. As shown in Table 4, in univariate models clustered by rheumatology provider, significant predictors of higher p-LuCI values included current MCTD diagnosis, glucocorticoid use, disease duration of less than 1 year, nephritis, and provider volume. In the final adjusted multivariable model, the significant predictors of higher p-LuCI values

Table 3. Pediatric lupus care index metric performance

Metric	Performance, N (%)	Index Value Above Median, N (%)	Index Value at or Below Median, N (%)	*P* Value
Clinical assessment				
SLEDAI score documented	58/99 (58.6)	48/53 (90.6)	10/46 (21.7)	<0.001
SDI score documented	38/99 (38.4)	36/53 (67.9)	2/46 (4.4)	<0.001
PGA score documented	83/110 (75.5)	52/55 (94.6)	31/55 (56.4)	<0.001
Disease activity reconciled	80/110 (72.7)	53/55 (96.4)	27/55 (49.1)	<0.001
Disease characteristics review	70/110 (63.6)	53/55 (96.4)	17/55 (30.9)	<0.001
Comorbidity assessment and prevention				
Pneumococcal vaccination	83/110 (75.5)	46/55 (83.6)	37/55 (67.3)	0.046
Influenza vaccination	46/110 (41.8)	30/55 (54.6)	16/55 (29.1)	0.007
Blood pressure assessment	74/110 (67.3)	52/55 (94.6)	22/55 (40.0)	<0.001
Lipid testing	91/110 (82.7)	52/55 (94.6)	39/55 (70.9)	0.001
Vitamin D testing	58/110 (52.7)	46/55 (83.6)	12/55 (21.8)	<0.001
Stress-dose steroid plan	34/43 (79.1)	28/31 (90.3)	6/12 (50.0)	0.004
Steroid-sparing agent prescribed	41/43 (95.4)	31/31 (100)	10/12 (83.4)	0.02
Population management				
Visit scheduling	30/110 (27.3)	21/55 (38.2)	9/55 (16.4)	0.01

Abbreviation: PGA, Physician Global Assessment; SDI, Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; SLEDAI, Systemic Lupus Erythematosus Disease Activity Score, 2K version.

included current DMARD use, disease duration of less than 1 year, nephritis, higher provider volume, rheumatology fellow trainee assignment (R^2 = 0.56). In a sensitivity analysis, there were no differences in the adjusted model when calculating the p-LuCI score using the nine components applicable to all patients. Of note, race, ethnicity, primary language, and insurance status were not associated with the p-LuCI score in univariate or adjusted models.

DISCUSSION

In this study, we assessed care delivery across clinical assessment, comorbidity assessment and prevention, and population management domains. We showed that approximately 65% of selected evidence-based measures were performed and varied mainly according to disease characteristics, treatment intensity, provider characteristics, and patient follow-up. Specifically, patients on DMARD therapy, patients with nephritis, and patients earlier in their disease course had higher p-LuCI values. In addition, provider characteristics were important. Patients cared for by providers with a higher volume of patients with pSLE and by rheumatology fellows had higher index values (12).

There were several factors that facilitated pSLE care delivery. Similar to recently published quality improvement studies,

Table 4. Predictors of pediatric lupus care index performance

Variable	Unadjusted		Adjusted (R^2 = 0.56)	
	β (95% CI)	*P* Value	β (95% CI)	*P* Value
Age, years	0.83 (−3.18 to 1.52)	0.46	-	-
Female sex	−3.86 (−17.54 to 9.82)	0.56	-	-
Black race	4.17 (−7.90 to 16.23)	0.47	-	-
Hispanic ethnicity	7.90 (−6.12 to 21.91)	0.25	-	-
Commercial insurance	−6.35 (−13.3 to 0.68)	0.07	-	-
English as primary language	−9.59 (−22.88 to 3.70)	0.14	-	-
MCTD diagnosis	−25.47 (−44.48 to 6.46)	0.012	-	-
Nonbiologic DMARD (current use)	16.76 (−2.96 to 36.47)	0.09	14.3 (1.5 to 27.2)	0.03
Biologic (current use)	0.78 (−20.97 to 22.53)	0.94	-	-
Chronic steroid exposure	18.57 (5.63-31.50)	0.008	-	-
Prior cyclophosphamide use[a]	13.03 (−1.38 to 27.47)	0.07	-	-
Disease duration <1 year	20.7 (4.3 to 37.0)	0.02	12.6 (0.7 to 24.5)	0.04
Nephritis	21.41 (9.65 to 33.17)	0.002	10.4 (5.1 to 15.8)	0.001
Provider volume (per patient)	1.81 (0.20 to 3.43)	0.03	3.1 (1.9 to 4.2)	<0.001
Fellow trainee assigned	16.89 (−3.83 to 37.62)	0.10	36.3 (17.3 to 55.2)	0.001

Abbreviation: CI, confidence interval; DMARD, disease-modifying antirheumatic drug; MCTD, mixed connective tissue disease.
Linear regression with clustering according to provider was performed for all models.
[a] No patients were currently receiving cyclophosphamide.

we achieved consistent performance across several measures after specific efforts to projects within our division (13,14). Prior to developing the p-LuCI, we devised previsit planning processes to improve pneumococcal vaccination in patients with pSLE and stress-dose steroid counseling in all pediatric rheumatology patients exposed to chronic glucocorticoid therapy (12). These two measures were included in the index and were performed consistently in a high proportion of patients. In addition, we developed standardized documentation templates with embedded discrete data elements designed to fit the clinical workflow of an outpatient pSLE visit. For example, there are data elements embedded to document lipid screening, which was performed in the majority of patients. In addition, approximately half of the patients with nephritis receive care in a dedicated multidisciplinary clinic staffed by the two highest-volume providers. A sensitivity analysis excluding those two providers demonstrated that nephritis remained independently associated with higher p-LuCI values (data not shown). Finally, a rheumatology coordinator was responsible for reviewing an automated appointment report to find patients overdue for follow-up. Though there was substantial room for improvement, prior efforts to standardize high-priority processes and the clinical workflow likely enhanced our clinical effectiveness.

Our finding that patients assigned to providers with a higher volume of patients with pSLE had higher p-LuCI scores is consistent with previous reports (12). In a study of adults with SLE, patients treated in a dedicated clinic received a significantly higher proportion of recommended care (85.8% versus 70.2%). There was a significant correlation between the volume of patients with SLE and the receipt of care, explaining approximately 20% of the variance in the measure.

We found that patients under the care of a fellow trainee received a higher proportion of recommended care. This finding is consistent with a study performed using the National Hospital Ambulatory Medical Care Survey, in which medical residents provided a higher quality of care than staff physicians across processes such as angiotensin-converting enzyme inhibitor prescriptions for congestive heart failure and statin use for hyperlipidemia (15). Similar to our study, the authors focused on care processes. The relation between fellow trainee care and the p-LuCI may be confounded by clinical supervision, which was not measured. Finally, fellow trainees may be more likely to adhere to standard documentation templates, which were aligned with care delivery goals.

Interestingly, we did not identify disparities by race, ethnicity, primary language, or insurance status. Previous studies in adults and children with SLE have documented differences in health care delivery and outcomes according to demographic and socioeconomic factors (4,16). Although our study did not address whether differences in outcomes were observed, the lack of disparities in prespecified processes is encouraging and highlights the importance of previous efforts to improve care at our center. For example, a scheduling coordinator and social worker monitor a standard report to identify patients overdue for appointments. Similarly, it is possible the lower burden of glucocorticoid therapy observed in our cohort relative to the Childhood Arthritis and Rheumatology Research Alliance Cohort (31% versus 69%) (17), despite similar disease duration, is the consequence of continuous process improvement activities. Reviewing local data stratified by demographic and socioeconomic indicators may be a foundational method to identify and mitigate health care disparities in both processes and outcomes.

There are several limitations to consider. First, we did not assess the relationship between the p-LuCI and patient outcomes. In adults with SLE in a large, longitudinal, community-based cohort study, receiving greater than 85% of recommended care was strongly associated with lower damage accrual (9). We plan to perform longitudinal studies to assess the relationship between the p-LuCI, disease activity, and damage. Second, we designed the p-LuCI to assess measures that we could define, operationalize, and potentially improve. We have not yet developed measures of transition preparation and transfer, mental health screening, or reproductive health counseling. In addition, we did not include antimalarial therapy as a p-LuCI component, given that 96% of patients had active prescriptions. Antimalarial therapy, if not contraindicated, would likely represent a minimum therapeutic standard across most care settings. Future iterations of the p-LuCI will likely include a more comprehensive set of quality measures. Third, we assessed measures determined by the clinicians to be important on the basis of evidence-based recommendations. As we develop a system of high-quality pSLE care, it will be critical to engage youth and their caregivers as design partners because they may prioritize different components of care and symptom assessment. Fourth, developing accurate measures of appropriate stress-dose steroid planning may be challenging at other centers. We developed an automated registry to accurately identify patients with chronic steroid prescriptions, which allowed us to assess patients exposed to chronic steroids within the previous 18 months.

In conclusion, creating an index of high-priority care delivery metrics may be a feasible way to promote quality care at the clinician and practice level. At our center, clinicians may obtain Maintenance of Certification credits for participating in group learning, self-directed evaluation, and goal-setting activities to improve p-LuCI performance using automated reports and previsit planning tools. Common metric definitions will be critical to promote improvement across centers in a planned pSLE learning health system. Finally, future longitudinal studies are needed to determine whether improving processes assessed in the p-LuCI is associated with improved outcomes and health care use.

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Burnham had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Burnham, Cecere, Ukaigwe, Knight, Peterson, Chang.

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