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Initial Benchmarking of the Quality of Medical Care of Childhood-Onset Systemic Lupus Erythematosus

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Abstract

Objective—To assess the quality of medical care in childhood-onset systemic lupus erythematosus (cSLE) at tertiary pediatric rheumatology centers as measured by observance cSLE quality indicators (cSLE-QI).

Methods—International consensus has been achieved for cSLE-QI (Hollander et al. Arthritis Care & Research, 2013) capturing medical care provision in nine domains: diagnostic testing, education of cardiovascular (CV) risk and lifestyles, lupus nephritis (LN), medication management, bone health, ophthalmological surveillance, transition, pregnancy and vaccination. Using medical record information, the level of performance these cSLE-QI was assessed in cSLE populations treated at four tertiary pediatric rheumatology centers in the U.S, two in Brazil, and one center in India.

Results—A total of 483 cSLE patients were assessed. Care for the 310 U.S. patients differed markedly for cSLE-QI addressing LN, bone health, vaccinations, education on CV risk, and transition planning. Performance of safety blood testing for medications was high at all centers. Despite often similar performance on the cSLE-QI, access to kidney biopsies was lower in Brazil

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than in the U.S. Irrespective of country of practice, larger centers tended to meet the cSLE-QI more often than smaller centers.

Conclusions—The cSLE-QI, evidence based minimum standards of medical care, are not consistently met in the U.S. or some other countries outside the U.S. This has the potential to contribute to suboptimal cSLE outcomes.

Keywords

Childhood-onset SLE; Quality Indicator; quality of care; lupus; children

Introduction

The Institute of Medicine defined quality as “the step to which health services for individuals and populations increase the probability of desired health consequences and are reliable with current specialized knowledge” (1). Monitoring health care quality is virtually impossible without the use of so-called quality indicators (QI), i.e. minimum standards of medical care in support of optimal disease outcomes (2, 3).

Considering current medical knowledge and expert opinions, an international consensus has been reached for a set of 26 QI to be used for children and adolescents with childhood-onset systemic lupus erythematous (cSLE-QI) (4). The cSLE-QI address laboratory testing at the time of cSLE diagnosis, general prevention, LN management, medication safety, bone health, ophthalmologic surveillance, education about cardiovascular risk factors, pregnancy, and neuropsychiatric manifestations (4).

It has been shown in the past for many diseases that treatment at large centers may support the provision of medical care more reliably. Additionally, health disparity exists in pediatric rheumatology care. It has been suggested that this affects medical care for adult-onset SLE (5, 6) but it is unknown to which degree this affects basic cSLE medical care as can be defined by the cSLE-QI. As a next step towards focusing research and quality improvement efforts, benchmarking may help identify areas of health care that would benefit from added attention in an effort to improve patient outcomes.

Hence, the objective of this study was to measure the performance of the cSLE-QI in different regions of the world under consideration of differences in pediatric rheumatology center size. Furthermore, only for the U.S sites we aimed at delineating the effects of public and private insurance on the recommended medical care.

Materials and Methods

With the approval of institutional review boards of participating centers, cross-sectional population-based data pertaining to the cSLE-QI were acquired based on information provided in the medical records. A standardized data collection form (see supplemental table online) with detailed completion instructions were used to ensure consistent recording of events that only occur in quarterly or longer time intervals. The time frame for data collection was October 2011 through June 2014.

Patients and Participating Sites

Each center provided data on every cSLE patient seen more than once for cSLE care in the 12-month period preceding the data extraction. To be included in the study, patients had to fulfill Classification Criteria for SLE prior to the age of 18 years (7). Pediatric rheumatology care at these centers was provided by physicians experienced and specifically trained in the care of children with rheumatic diseases. The seven centers participating in this study were self-selected.

Medical Record Review

Demographic information and insurance status were recorded. A QI item was only considered to be met if there was written documentation that a certain education or test had been performed. Information pertaining to cSLE-QI relevant to cSLE diagnosis was only obtained for patients diagnosed within 18 months of data collection. Furthermore, to have performed the cSLE-QI, any testing recommended at the time of cSLE diagnosis or that of LN diagnosis had to be documented in the medical record within two clinic visits of the index visit. LN flare was defined as worsening glomerular filtration rate or ongoing proteinuria. For performance of safety laboratory evaluations, we focused on glucocorticoid steroids (GCC) and hydroxychloroquine (HCQ). For the purpose of vaccination compliance, we only assessed performance of influenza vaccination. For life-style modification QI, we focused on smoking cessation (QI 24). Given the methodological approach taken, information about the diagnostic approach to suspected cSLE could not be assessed, as is considered in the first of the cSLE-QI.

Statistics

We performed descriptive analysis and calculated percent of QI implementation per center. We then assessed differences in cSLE-QI performance among U.S. centers, using Cochran-Mantel-Haenzel test. Arbitrarily, centers treating at least 100 cSLE patients were considered as large and those following fewer cSLE patients as small, respectively. Differences between centers or categories of interest (large vs. small centers, U.S. private vs. public insurance) was assessed using contingency table analysis with a continuity-corrected Chi-square or a Fisher exact test, if appropriate. Two-sided probabilities were assessed and p-values < 0.05 were considered statistically significant. Analyses were done with SAS 9.3 statistical software, published by SAS Institute Inc., Cary, NC, USA.

Results

Patients

A total of 483 patients followed at seven centers were included in this study (Table 1). All seven sites were at academic centers, with three considered as large sites and four as small sites. All participating centers are at urban areas and all US sites have electronic medical record. There were 2-5 providers in the small centers and about 4-15 providers in large centers. Most patients were female. Notably, 178 patients from all of the sites were 18 years or older. Renal involvement in the cohorts ranged from 30% to 71%. Pregnancies were rare, and insurance status varied widely between sites, even in the same country.

Observance of the cSLE-QI by QI domain

Performance of the cSLE-QI is presented in the sequence previously published by Hollander et al. (4).

Laboratory Testing at Diagnosis—The cSLE-QI (QI 2) recommended standard laboratory evaluation for children who newly carry the diagnosis of cSLE was documented for almost all patients (Table 2).

General Prevention—The majority of the cSLE patients received the annual influenza vaccination (QI 3). However, there was a considerable variability among sites. This was also true for other cSLE-QI in this domain, namely education on sun avoidance, photoprotection, and transition planning (QI 4 -5).

Lupus Nephritis and Hypertension Management—Most of the sites followed the diagnostic procedures suggested for LN (QI 7 + 9). Exceptions were sites in Brazil with apparent problems with access to kidney biopsies. Regular laboratory surveillance for LN flares was performed inconsistently (QI 6 + 10), but immunosuppression for severe LN was started promptly at the majority of the sites (QI 8).

Medication Management—Explaining the risks and benefits of new medications for cSLE was regularly performed and documented (QI 13). Conversely, HCQ prescription varied between 75% to 100% at the participating sites (QI 14). Both GCC tapering efforts (QI 15) and high-dose GCC usage differed widely among the participating sites (Table 1). Introduction of immunosuppressive medications after failed GCC tapering (QI 16) was also highly variable (25 to 100%) but the number of patients per site available to assess the performance of this cSLE-QI was often small. However, sites generally performed the recommend safety laboratory testing with medication usage (QI 17).

Bone Health—Assessment of bone mineral density at least once in every patient with cSLE exposed to GCC differed widely among sites, ranging from 90% to 7% (QI 18). Lack of repetition of dual-energy x-ray absorptiometry (DEXA), when warranted, was congruent with the frequency of baseline DEXAs (QI 19). Calcium and Vitamin D supplementation with chronic GCC use also differed widely among sites (QI 20).

Ophthalmological Surveillance—Documentation of regular eye examination in the setting of HCQ and GCC use ranged from 96% to 72% of the patients at the participating sites (QI 21+ 22).

Education on Cardiovascular Risk Factors—The largest variability among sites was observed for education on cardiovascular risk factors and life style modification (QI 23+24).

Pregnancy and Neuropsychiatric cSLE—There were a few pregnancies, making the assessment of the observance of QI 25 difficult in this study. Immunosuppressive medication usage in the setting of major Neuropsychiatric Systemic Lupus Erythematosus (NPSLE) events was commonly done (QI 26).

Differences in Performance of the cSLE- QI in the U.S

Table 3 presents cSLE-QI for which statistically significant differences in observance among the participating U.S. sites were observed. Among the 25 QIs assessed, there were 14 (14/25 = 56%) with important differences among the four U.S. sites. The largest variability was noted for QIs that address education on cardiovascular risks (QI 23 + 24) and calcium/ vitamin D supplementation with GCC use (QI 20).

Larger sites more consistently provide the recommended medical care to cSLE patients

As is summarized in Table 4, for 13 of the 25 QIs (13/25 = 52%) assessed there were statistical significant differences in observance between large (N=3) and smaller (N=4) sites. Generally, larger sites performed the QIs more frequently than smaller sites, with the exception of the recommended work-up at the time of LN diagnosis (QI 7).

Public vs. private health insurance in the U.S

Given known differences in the health insurance systems between countries, we only assessed whether there were differences in the quality of medical care by insurance status in the U.S. Besides rare patients without insurance, there were cSLE patients whose care was covered by private (n=189) and public insurance (n=112). There were no statistically significant differences in any of the cSLE-QI when compared by insurance groups.

Discussion

QI can be considered minimum standards of recommended medical care. In order to guide quality improvement efforts, benchmarking is required to delineate areas of greatest need for intervention. In a study of cSLE patients followed at tertiary rheumatology centers in the U.S., Brazil and India, we found statistically significant differences in the observance to cSLE- QI within the U.S. and also between larger and smaller centers.

Physicians across centers consistently ordered laboratory tests necessary in accordance to the two cSLE-QI addressing drug safety surveillance. Conversely, there was marked variation in the frequency patients of influenza vaccination. Given the increased risk of infections with cSLE, vaccinations are highly relevant for patient safety and disease control. Notably, there are documented suboptimal responses to at least some vaccinations with cSLE (8). Therefore, cSLE patients should likely follow vaccination schedules that are recommended for immunocompromised populations. Potential barriers to vaccinations are a lack of affordability or reimbursement and potential deleterious effects of vaccine on disease itself. No severe vaccine or disease-specific adverse events have been observed in cSLE patients who have been vaccinated with non-live agents in a recent narrative review, reinforcing the vaccine safety for this population (9). Possible approaches to improve vaccination rates include training of pediatricians and pediatric rheumatology providers about optimal vaccination practices. Additionally, education of families of children and young adults with cSLE about the benefits of vaccinations seems warranted.

It is well known that sun and other light exposure is associated with SLE disease flares (10). Hence, photo protection education should be a critical part of care, but it was not consistently done at many of the participating centers.

Due to differences in the needs of children and adults with SLE, patients are transferred to adult providers generally after their 18th birthday, although the exact age when the adult rheumatology commences care is influenced by many factors. Difficulties with transfer of care are supported by the findings of our study that a considerable proportion of cSLE patients age 18 or even 21 years and older continued to receive treatment at pediatric facilities. Transition planning seemed to constitute a challenge across all of the participating U.S. centers. Best transition practices are an intense focus of research and are influenced by not only patient factors but also health system factors (11). The former comprise patient self-management skills and disease activity while the latter include access to adult providers, medications and required social support. Not all the sites have transition program in place. Both Brazilian centers have dedicated transition clinics for cSLE patients age 18 years or older with proven self-management skills.

The recommended work-up for LN, including a kidney biopsy, was well established across U.S. centers. Conversely, kidney biopsies were more difficult to obtain at the participating Brazilian sites. Time intervals at which patients with LN were assessed at the U.S. pediatric rheumatology centers were often longer than recommended, possibly suggesting problems with access to care.

In support of effective patient self-management, detailed discussion of risks and benefits of new medications is important and was generally provided by the physicians. The same held true for ordering the recommended laboratory testing for surveillance of drug safety. Antimalarial usage was provided to the vast majority of cSLE patients, with larger variability at non-U.S. sites. This may reflect difficulties in paying for such medications out of pocket. Likewise, tapering of high-dose GCC generally was attempted but, if unsuccessful, did not always result in prescribing GCC-sparing treatments. Reasons may be cost or lack of viable therapeutic alternatives.

Monitoring of bone health with chronic use of GCC varied widely across centers and was generally low in the U.S. and the participating site in India. This may expose patients to long-term risks associated with osteoporosis. This is a special concern as sites with low percentages of patients receiving monitoring of bone mineral density were also often not prescribing the recommended calcium/vitamin D prophylaxis. Further, even closer surveillance of patients with known low bone mineral density seems tenuous at best.

Often education on cardiovascular risk factors was not performed consistently. Reasons might include that cardiovascular events rarely occur while patients are under the care of pediatric rheumatologists. Education for cardiovascular risk factors and observance of some other cSLE-QI possibly may be better than the results we reported in our study since this is based strictly on information recorded in the medical records. In line with this, several centers indicated that the education referenced in these QI was provided but not systematically documented in the record.

We believe that inconsistent documentation is closely associated with inconsistent care across patient populations. Indeed, when we evaluated the QI 4 (education on sun-exposure) and considered education that was performed by physicians– to the best of their knowledge - but had not been documented in the medical record (data not shown), the observance of QI 4 increased up to 46% at some sites. Dedicated recording space in the electronic medical records improved documentation of all educational efforts. Lack of routine documentation of QI 4 was twice as common in small as compared to larger sites (23% vs. 12%) with marked variability at some sites.

As has been reported from other areas of medicine, we observed that larger centers more often reliably followed QI recommendations as compared to smaller centers. As such there were statistically significant differences in frequency at which 14 of the 25 QI examined in this study were followed, with smaller sites consistently showing lower endorsements. There was one exemption (QI 7) where larger sites performed worse than the smaller ones and this was due to limited access to kidney biopsies at the Brazilian sites.

While we found marked difference in QI performance among the tertiary U.S. pediatric rheumatology centers that participated in this study, similar standards of care were provided to patients with public as compared to private insurance. Thus health insurance status in the U.S. does not seem to influence minimum standards of care as is defined by the set of cSLE-QIs.

Salient to the concept of quality indicators is the assumption that observance results in improved disease control and long-term prognosis. Our study did not collect information on disease activity or disease damage. Further no data are yet available in support of the notion that consistent observance of the cSLE-QI is associated with improved cSLE outcomes. Another limitation of the study is that there is a possibility of “volunteer” bias for the centers that participated or that the centers that participated may not be representative of all sites caring for cSLE patients. Among the seven participating sites in the study, two sites were involved in the initial development of the cSLE-QI. Nevertheless, our study remains the first to evaluate QI benchmarking among different international centers that care for cSLE patients, and can serve as the basis for further quality improvement work that has been largely lacking in cSLE.

Reasons for non-performance of QI is often multifactorial and the result of factors pertaining to patients and families, physicians and health care systems. Learning networks have been developed to address quality improvement approaches in complex, multi-center health care systems. An example from pediatric rheumatology may be PR-COIN (Pediatric Rheumatology Collaborative Improvement Network), a learning collaborative of 13 pediatric rheumatology sites, currently focused on juvenile arthritis care (12). Within PR-COIN, patient education combined with improved disease monitoring and standards for adjusting therapies have led to a measurable increase in the children with remission. Similar efforts in cSLE seem necessary and beneficial to ensure improved evidence-based care of children with cSLE.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Significance and Innovations

- This constitutes the first benchmarking effort for the observance of the recently proposed cSLE quality indicators.
- Performance of some quality indicators differs significantly among pediatric rheumatology sites in the United States.
- Smaller centers often have more difficulties in consistently adhering to the cSLE quality indicators.

Table 1

Demographics of the cSLE patients[†]

	US 1	US 2	US 3	US 4	Brazil 1	Brazil 2	India
Number of patients	105	107	59	38	43	103	28
Newly-diagnosed patients in previous year	38	15	16	5	2	16	3
Patients ≥ 18 years	36 (34)	61 (57)	31 (53)	10 (26)	19 (44)	16 (18)	5 (18)
Patients≥ 21 years	4 (4)	26 (24)	6 (10)	3 (8)	0	10 (23)	2 (7)
Major organ involvement							
Major NPSLE features	5 (5)	15 (14)	3 (5)	0	6 (14)	19 (18)	1 (4)
Lupus nephritis	47 (45)	34 (32)	18 (31)	17 (45)	13 (30)	68 (66)	20 (71)
ISNPRS Class III or IV	34	17	11	12	5	17	12
Females	88 (84)	85 (79)	47 (80)	32 (84)	38 (88)	85 (83)	17 (61)
Pregnancies in previous year	2	2	1	0	0	0	0
Race							
White	84 (80)	57 (53)	30 (51)	20 (53)	26 (60)	85 (83)	
Black	16 (15)	42 (39)	19 (32)	14 (37)	6 (14)	8 (8)	
Asian	4 (4)	7 (7)	3 (5)	2 (5)	0	4 (4)	28 (100)
Other	1 (1)	1 (1)	7 (12)	2 (5)	11 (26)	5 (5)	
Hispanics	43	5	0	16	57	98	0
Medication							
Chronic GCC exposure	66 (63)	51 (48)	25 (42)	22 (58)	39 (91)	71 (69)	16 (57)
High-dose GCCs	10	39	3	2	25	68	3
Health Insurance							
Private Insurance	56 (53)	85 (79)	36 (61)	23 (61)		11 (11)	
Public insurance	45 (43)	20 (19)	22 (37)	14 (37)	43 (100)	91 (89)	
Uninsured/unknown	4 (4)	2 (2)	1 (2)	1 (3)			28 (100)

[†]Values are N or N (%) unless stated otherwise;

* mean ± standard deviation. GCC-glucocorticoids.

Table 2

QI observance by participating pediatric rheumatology site[†]

Quality Indicators by Domain	US 1	US 2	US 3	US 4	Brazil 1	Brazil 2	India
Domain 1: Laboratory testing around the time of diagnosis							
QI 1: IF a patient has suspected childhood-onset SLE, THEN then laboratory studies should be obtained.	N/A	N/A	N/A	N/A	N/A	N/A	N/A
QI 2: IF a patient has confirmed childhood-onset SLE, THEN the laboratory studies should be obtained	92	100	100	100	100	100	100
Domain 2: General prevention							
QI 3: IF a patient has childhood-onset SLE, THEN vaccination against influenza should be prescribed, unless there are contraindications.	100	89	95	73	57	97	0
QI 4: IF a patient has childhood-onset SLE, THEN education about sun avoidance should be documented at least once in the medical record (e.g., wearing protective clothing, applying sunscreens whenever outdoors, and avoiding sunbathing).	72	99	54	58	93	88	58
QI 5: IF an adolescent has childhood-onset SLE, THEN a transition plan should be carefully designed to facilitate transfer of care to the appropriate adult health care providers.	53	77	34	13	100	100	0
Domain 3: Lupus Nephritis & hypertension management							
QI 6: IF a patient has a flare after having achieved remission of kidney disease, THEN diligent follow-up of renal disease (kidney function, urine sediment, and proteinuria) every 3 months is needed.	75	88	100	50	100	98	0
QI 7: IF a patient has newly diagnosed LN, THEN renal biopsy, urine sediment analysis, proteinuria, and kidney function should all be assessed.	100	100	100	100	50	54	100
QI 8: IF a patient is diagnosed with proliferative childhood-onset SLE nephritis (WHO or ISN/RPS class III or IV), THEN therapy with corticosteroids combined with another immunosuppressive agent should be provided and documented within 1 month of this diagnosis, unless contraindicated[‡]	100	100	100	83	100	94	100
QI 9: IF a childhood-onset SLE patient without known LN has developed daily proteinuria of > 500 mg or clinically relevant worsening of GFR/urinary sediment, THEN a kidney biopsy should be performed.	100	100	100	100	50	54	100
QI 10: IF a patient has known LN, THEN a clinical assessment for childhood-onset SLE should occur at least every 3 months, regardless of disease activity.	98	97	94	76	100	100	100
QI 11: IF a childhood-onset SLE patient has LN plus evidence of ongoing proteinuria >500 mg/day, THEN an ACEI or ARB should be prescribed, unless there are contraindications.	100	100	100	100	88	94	80
QI 12: IF a patient has LN and/or hypertension, THEN disease co-management with a nephrologist should be considered.	96	61	67	76	54	68	67
Domain 4: Medication Management							
QI 13: IF a patient is prescribed a new medication for childhood-onset SLE (e.g., NSAIDs, DMARDs, or glucocorticoids), THEN a discussion with the patient about the risks versus benefits of the chosen therapy should be documented.	100 (31)	100 (14)	100 (8)	100 (5)	100 (2)	100 (15)	60 (5)
QI 14: IF a patient has childhood-onset SLE, THEN antimalarial therapy should be prescribed, unless there are contraindications.	93	94	85	92	75	95	100

Quality Indicators by Domain	US 1	US 2	US 3	US 4	Brazil 1	Brazil 2	India
QI 15: IF a childhood-onset SLE patient is receiving a dose of steroids not acceptable for long-term use, then an attempt should be made to taper steroids.	100	98	100	100	64	97	75
QI 16: IF a patient with childhood-onset SLE is unable to decrease the dose of GCC acceptable for long-term use, THEN the addition of a GCC-sparing agent or an increased dose of an existing GCC-sparing agent should be considered.	71 (5)	35 (6)	100 (3)	NA (NA)	42 (10)	38 (5)	25 (1)
QI 17: IF a childhood-onset SLE patient is treated with medications, THEN laboratory surveillance for medication safety should be done at regular intervals (complete blood count, renal and liver function test every 12 months)*HCQ*	99	100	98	83	97	100	89
GCC	100	100	100	86	97	100	100
Domain 5: Bone Health							
QI 18: IF a patient has received chronic systemic steroids, THEN the patient should have bone mineral density testing documented in the medical record.	79	63	44	18	90	86	7
QI 19: IF baseline bone mineral density testing is outside of the normal limits (Z scores of -2 or less), THEN bone mineral density should be re-measured after 1 year.	8	16	17	0	60	58	0
QI 20: IF a patient is receiving any steroid therapy, THEN calcium and vitamin D supplementation should be recommended after 3 months.	95	75	80	59	97	89	100
Domain 6: Ophthalmological Surveillance							
QI 21: IF a childhood-onset SLE patient is treated with corticosteroids, THEN eye screening should be done at least annually.	95	85	78	80	78	96	93
QI 22: IF a childhood-onset SLE patient is treated with antimalarial therapy, THEN eye screening should be done at least annually.	94	82	72	77	82	96	94
Domain 7: Education on Cardiovascular Risk Factors							
QI 23: IF a patient has childhood-onset SLE, THEN education about cardiovascular risk factors should occur in regular intervals with the parent and the patient age ≥13 years							
Every 1 year: Smoking, hypertension, high body mass index	72	97	38	21	100	100	0
Every 2 years: diabetes. hyperlipidemia	60	97	18	15	100	100	0
QI 24: IF a patient has childhood-onset SLE, THEN lifestyle modification (i.e. smoking cessation) is likely to be beneficial for patient outcomes and should be encouraged	2	78	10	82	94	95	10
Domain 8: Pregnancy							
QI 25: IF a patient with childhood-onset SLE is pregnant, THEN anti-SSA, anti-SSB, and antiphospholipid antibodies should be documented in the medical record.	50 (2)	100 (2)	100 (1)	-	-	-	-
Domain 9: Neuropsychiatric Manifestations							
QI 26: IF a patient with childhood-onset SLE has major neuropsychiatric manifestations (optic neuritis, acute confused state/coma, cranial or peripheral neuropathy, psychosis, and transverse myelitis/myelopathy), THEN immunosuppressive therapy should be considered.	80 (5)	100 (15)	100 (3)	-	100 (6)	89 (19)	100 (1)

† Values are % or % (N) unless stated otherwise. For a given QI, the number of patients are specifically mentioned if there are two at any of the sites.

‡Based on patients who received kidney biopsy to confirm presence of proliferative LN.

LN- lupus nephritis; GFR- glomerular filtration rate; Angiotensin receptor blocker-ARB; Angiotensin converting enzyme inhibitor- ACEI;HCQ-hydroxychloroquine; DEXA-Dual-energy X-ray absorptiometry.

Table 3

Differences in observance of the cSLE-QI between four US sites*

	US sites	
	Range of Differences (%)	P-value‡
General prevention		
QI 3: Influenza vaccination	27	<.0001
QI 4: Photo protection	46	0.0039
QI 5: Transfer of care Planning	64	<.0001
Lupus Nephritis and Hypertension Management		
QI 8: Treatment with immunosuppressive and GCC within 1 month of kidney biopsy	17	0.0151
QI 10: Clinical assessment of LN at least every 3 months regardless of disease activity	21	0.0151
QI 12: Nephrology co-management	33	0.0015
Medication Management		
QI 16: Addition of a GCC-sparing agent or an increased dose of an existing GCC-sparing agent when unable to decrease GCC dose	35	0.049
QI 17: Safety labs with GCC/HCQ use**	14/17	0.0002/<.0001
Bone Health		
QI 18: DEXA for patients on chronic GCC.	61	<.0001
QI 20: Calcium and vitamin D supplementation when on GCC therapy for >3 months	67	0.0005
Ophthalmological Surveillance		
QI 21: Eye exams with GCC use	22	0.0345
QI 22: Eye exam with HCQ use	14	0.0158
Education on Cardiovascular Risk Factors		
QI 23: Education of Patient/Parent on CV risk factor, if patient ≥13 years		
Every 1 year: Smoking, hypertension, high body mass index	77	<.0001
Every 2 years: diabetes. hyperlipidemia	82	<.0001
QI 24: Discussed smoking cessation, irrespective of patient age	80	<.0001

*Excluded were QI with fewer than 2 events;

**every 3 months or less;

‡Cochran- Mantel Haenzel test

Table 4
Observance of cSLE-QI based on size of patient population

	Large vs. small sites*	
	Difference (%)	**P-value**
General prevention		
QI 3: Influenza vaccination	95 vs. 64	<.0001
QI 4: Photo protection	64 vs. 36	0.0218
QI 5: Transfer of care Planning	76 vs. 41	<.0001
Lupus Nephritis and Hypertension Management		
QI 6: Laboratory evaluations at least quarterly	94 vs. 46	<.0001
QI 7: Evaluations at diagnosis of LN	75 vs. 90	0.0152
QI 12: Nephrology co-management	76 vs. 49	0.0002
Medication Management		
QI 14: HCQ use	94 vs. 86	0.0044
QI 15: Attempt to taper GCC	78 vs. 69	<.0001
QI 17: Safety labs with GCC/HCQ use	100/100 vs. 97/94	< 0.04
Bone Health		
QI 18: DEXA for patients on chronic GCC	54 vs. 26	<.0001
Ophthalmological Surveillance		
QI 21: Eye exams with GCC use	92 vs. 80	0.0108
QI 22: Eye exam with HCQ use	91 vs. 81	0.0010
Education on Cardiovascular Risk Factors		
QI 23: Education of Patient/Parent on CV risk factor, if patient >13 years	89/85 vs. 45/36	<.0001

* Large sites treating ≥ 100 cSLE patients, otherwise considered small sites