

Online supplement to Measuring Disease Activity and Damage with Validated Metrics: A Systematic Review on Mortality and Damage in Systemic Lupus Erythematosus, *The Journal of Rheumatology*. doi:10.3899/jrheum.171310

ONLINE SUPPLEMENTARY DATA

Supplementary Data 1. Search Strategy.

Database(s): **Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present.**

#	Searches
1	lupus.mp.
2	libman sack*.ti,ab.
3	exp Lupus Vulgaris/ or exp Lupus Erythematosus, Cutaneous/ or exp Lupus Nephritis/ or exp Lupus Erythematosus, Systemic/ or exp Panniculitis, Lupus Erythematosus/ or exp Lupus Erythematosus, Discoid/ or exp Lupus Vasculitis, Central Nervous System/
4	1 or 2 or 3
5	(British Isles Lupus Assessment Group or BILAG).mp.
6	(European Consensus Lupus Activity Measurement or ECLAM).mp.
7	(systemic lupus activity measure or systemic lupus erythematosus activity measure or SLAM or slam-2 or slam-R).mp.
8	(systemic lupus activity questionnaire or systemic lupus erythematosus activity questionnaire or SLAQ).mp.
9	(Systemic Lupus Erythematosus Disease Activity Index or sledai* or mex-sledai or SELENA-SLE).mp.
10	(American College of Rheumatology Damage Index or SDI).mp.
11	(american college of rheumatology criteria or american college of rheumatology classification or ACR criteria or ACR classification).mp.
12	(Systemic Lupus International Collaborating Clinics or SLICC).mp.
13	(Lupus Activity Index or LAI or lupus activity scoring tool).mp.
14	(Lupus Damage Index Questionnaire or LDIQ).mp.
15	(Brief Index of Lupus Damage or BILD).mp.
16	LupusQoL.mp.
17	(SLEQoL or LQoL or L-QoL).mp.
18	(Systemic Lupus Erythematosus Symptom Checklist or SSC).mp.
19	(Systemic Lupus Erythematosus Responder Index or SLE Responder Index).mp.
20	(LupusPRO or Lupus Patient-Reported Outcome).mp.
21	physician global assessment.mp.

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22	(health assessment questionnaire or HAQ).mp.
23	(short-form 36 or SF36 or SF-36).mp.
24	((frequency or "length of time" or time or interval* or monthly or bimontly or weekly or yearly) adj3 (monitor* or test* or evaluat* or assess* or exam* or follow-up or visit*)).mp.
25	or/5-24
26	4 and 25
27	exp "Sensitivity and Specificity"/
28	Feasibility Studies/
29	exp "reproducibility of results"/
30	validation studies/
31	evaluation studies/
32	evaluation studies as topic/ or validation studies as topic/
33	"analysis of variance"/
34	(sensitivity or specificity or feasibility or viability or valid* or accuracy or responsiveness or reproducib* or reliab* or consistency).ti,ab.
35	(cronbach adj2 coefficient).mp.
36	correlation coefficient.mp.
37	kappa.ti,ab.
38	comparison.ti.
39	exp Prognosis/
40	exp survival analysis/
41	survival/
42	(predict* or prognost*).ti,ab.
43	((treatment or patient* or disease) adj2 outcome*).mp.
44	"Outcome Assessment (Health Care)"/
45	probability/ or bayes theorem/ or likelihood functions/ or propensity score/
46	exp Regression Analysis/
47	kaplan meier.mp.
48	cox regression.mp.
49	charlson comorbidity.mp.

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50	khan index.mp.
51	davies index.mp.
52	exp morbidity/ or exp mortality/
53	(morbidity or mortality or death* or surviv*).mp.
54	mo.fs.
55	(flare* or remission*).mp.
56	or/27-55
57	26 and 56
58	Humans/
59	Animals/
60	59 not (58 and 59)
61	57 not 60

Supplementary Table 1. Instruments used in the assessment of disease activity and damage in systemic lupus erythematosus (63, 64).

Instruments	Score range	Time frame	Reliability (63, 64)	Validity (63, 64)	Responsiveness (63, 64)	Administrative burden (65)	Refs
DISEASE ACTIVITY							
<p>Original instrument: SLEDAI</p> <p>Derivations¹: SLEDAI-2K SLEDAI-2K 30 days SELENA-SLEDAI</p>	<p>0-105</p> <p>0-105</p> <p>0-105</p> <p>0-105</p>	<p>Last 10 days</p> <p>Last 10 days</p> <p>Last 30 days</p> <p>Last 10 days</p>	X	X	X	<p><u>Cost²</u> Time: 15 minutes <u>Requirements:</u> -Training⁴ -Laboratory test including hematology (white blood count, platelets), renal (24-hour proteinuria, urine sediment), serologic (Anti dsDNA, C3, C4, CH50), musculoskeletal (myositis: CK or aldolase) -Diagnostic tests and imaging as determined by physician (e.g. echocardiography, ECG for pericarditis)</p>	(66) (67) (68) (69) (70)
<p>Original instrument: BILAG</p> <p>Derivations: BILAG-2004</p>	<p><u>Categories:</u> A = Active, B = Beware, C = Contentment, D = Discount, E = No evidence <u>Response scale:</u> Each question is</p>	<p>Previous month</p>	X	X	X	<p><u>Cost³</u> Time: 50 minutes <u>Requirements:</u> -Training⁴ (glossary) -Laboratory tests including: hematology (hemoglobin, white blood count, neutrophils, lymphocytes, platelets), TTP, direct coomb, hemolysis studies, renal (urine albumin, urine protein, urine creatinine, 24-hours proteinuria) -Diagnostic tests and imaging as determined by physician -Computer</p>	(71) (72)

	answered as: 0 = not present, 1 = improving, 2 = same, 3 = worse, and 4 = new						
Original instrument: SLAM	0-86	Previous month	X	X	X	<u>Cost</u> ³ <u>Time:</u> 15 minutes <u>Requirements:</u> -Training ⁴ -Laboratory results including: hematology (hematocrit, white blood cell count, lymphocyte count, platelet count), Erythrocyte Sedimentation Rate, renal (serum creatinine, urine sediment, 24-hour proteinuria) -Diagnostic tests and imaging as determined by physician	(73) (74) (75)
Derivations ⁵ : SLAM-R	0-81						
DAMAGE							
SDI	0-49	Last year ⁶	X	X	X	<u>Cost</u> ² <u>Time:</u> 15 minutes <u>Requirements:</u> -Training ⁴ (glossary) -Laboratory and diagnostic tests as determined as physician	(76)

“X” Confirms that the psychometric properties (validity, reliability or responsiveness) for the instrument have been studied

SLEDAI = Systemic Lupus Erythematosus Disease Activity Index; **SLEDAI-2K** = Systemic Lupus Erythematosus Disease Activity Index 2000; **SELENA-SLEDAI** = Safety of Estrogens in Lupus Erythematosus-National Assessment Trial-SLEDAI; **BILAG** = British Isles Lupus Assessment Group; **SLAM** = Systemic Lupus Activity Measure; **SLAM-R** = Systemic Lupus Activity Measure-Revised; **SDI** = Systemic Lupus Collaborating Clinics (SLICC) - American College of Rheumatology (ACR) Damage Index.

NOTES

1. Adjusted Mean SLEDAI (AMS): AMS was developed to summarize disease activity over time (42). SLEDAI-2K Responder Index 50 (SRI-50): It was developed to identify partial improvement, $\geq 50\%$ in each of the 24 descriptors of the SLEDAI-2K (43).
2. Cost related to the use of the instrument: There is no cost for using the instrument.
3. Cost related to the use of the instrument: There is no cost for using the instruments unless the computerized version is needed; the cost of this version depends on the use of the instrument (academic vs. commercial)(33).
4. Training: Physicians must be trained on the use of the instrument.
5. The Systemic Lupus Activity Questionnaire (SLAQ) was developed based on the SLAM. The SLAQ purpose is to follow on SLE patients who may be at a distance from a center. The SLAQ is filled by the patients as a screening tool for flares requiring further assessment (44).
6. SDI: Damage occurring since diagnosis of lupus, ascertained by clinical assessment and present for at least 6 months unless otherwise stated.

References for Supplementary Table 1:

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76. Gladman D, Ginzler E, Goldsmith C, Fortin P, Liang M, Urowitz M, et al. The development and initial validation of the Systemic Lupus International Collaborating Clinics/American College of Rheumatology damage index for systemic lupus erythematosus. *Arthritis Rheum* 1996;39:363-9