

APPENDIX 1. SLEDAI-2K DATA COLLECTION SHEET (Check weight in SLEDAI-2K score column if descriptor is present at the time of the visit or in the preceding 10 days.)

Weight (check)	Descriptor	Definition
8 <input type="checkbox"/>	Seizure	Recent onset, exclude metabolic, infectious, or drug causes.
8 <input type="checkbox"/>	Psychosis	Altered ability to function in normal activity due to severe disturbance in the perception of reality. Include hallucinations, incoherence, marked loose associations, impoverished thought content, marked illogical thinking, bizarre, disorganized, or catatonic behavior. Exclude uremia and drug causes.
8 <input type="checkbox"/>	Organic brain syndrome	Altered mental function with impaired orientation, memory, or other intellectual function, with rapid onset and fluctuating clinical features, inability to sustain attention to environment, plus at least two of the following: perceptual disturbance, incoherent speech, insomnia or daytime drowsiness, increased or decreased psychomotor activity. Exclude metabolic, infectious, or drug causes.
8 <input type="checkbox"/>	Visual disturbance	Retinal changes of SLE. Include cytoid bodies, retinal hemorrhages, serous exudates or hemorrhages in the choroids, or optic neuritis. Exclude hypertension, infectious, or drug causes.
8 <input type="checkbox"/>	Cranial nerve disorder	New onset of sensory or motor neuropathy involving cranial nerves.
8 <input type="checkbox"/>	Lupus headache	Severe, persistent headache: may be migrainous but must be nonresponsive to narcotic analgesia.
8 <input type="checkbox"/>	Cerebrovascular accident	New onset of cerebrovascular accident(s); exclude arteriosclerosis.
8 <input type="checkbox"/>	Vasculitis	Ulceration, gangrene, tender finger nodules, periungual infraction, splinter hemorrhages, or biopsy or angiogram proof of vasculitis.
4 <input type="checkbox"/>	Arthritis	Two or more joints with pain and signs of inflammation (i.e., tenderness, swelling, or effusion).
4 <input type="checkbox"/>	Myositis	Proximal muscle aching/weakness, associated with elevated creatine phosphokinase/aldolase or electromyogram changes or a biopsy showing myositis.
4 <input type="checkbox"/>	Urinary casts	Heme granular or red blood cell casts
4 <input type="checkbox"/>	Hematuria	More than five red blood cells/high power field; exclude infection, or other cause.
4 <input type="checkbox"/>	Proteinuria	>0.5g/24 hr.
4 <input type="checkbox"/>	Pyuria	More than five white blood cells/high power field; exclude infection.
2 <input type="checkbox"/>	Rash	Inflammatory type rash
2 <input type="checkbox"/>	Alopecia	Abnormal, patchy, or diffuse loss of hair
2 <input type="checkbox"/>	Mucosal ulcers	Oral or nasal ulcerations
2 <input type="checkbox"/>	Pleurisy	Pleuritic chest pain with pleural rub or effusion or pleural thickening.
2 <input type="checkbox"/>	Pericarditis	Pericardial pain with at least one of the following: rub, effusion, or electrocardiogram or echocardiogram confirmation.
2 <input type="checkbox"/>	Low complement	Decrease in the complement proteins C3 and C4 or in total complement activity (CH50), below the lower limit of normal of testing laboratory.
2 <input type="checkbox"/>	Increased DNA binding	Increased DNA binding by Farr assay above normal range for testing laboratory.
1 <input type="checkbox"/>	Fever	>38°C; exclude infectious cause.
1 <input type="checkbox"/>	Thrombocytopenia	<100,000 platelets/x10 ⁹ /L; exclude drug causes
1 <input type="checkbox"/>	Leukopenia	<3,000 white blood cells/x10 ⁹ /L; exclude drug causes.
Total score		

**APPENDIX 2. SYSTEMIC LUPUS INTERNATIONAL COLLABORATING CLINIC/AMERICAN COLLEGE OF RHEUMATOLOGY
DAMAGE INDEX FOR SYSTEMIC LUPUS ERYTHEMATOSUS***

Item	Score
Ocular (either eye, by clinical assessment)	
Any cataract ever	1
Retinal change or optic atrophy	1
Neuropsychiatric	
Cognitive impairment (e.g., memory deficit, difficulty with calculation, poor concentration, difficulty in spoken or written language, impaired performance level) or major psychosis	1
Seizures requiring therapy for 6 months	1
Cerebrovascular accident ever (score 2 if >1)	1 (2)
Cranial or peripheral neuropathy (excluding optic)	1
Transverse myelitis	1
Renal	
Estimated or measured glomerular filtration rate <50%	1
Proteinuria ≥ 3.5 gm/24 hours	1
Or	
End-stage renal disease (regardless of dialysis or transplantation)	3
Pulmonary	
Pulmonary hypertension (right ventricular prominence, or loud P2)	1
Pulmonary fibrosis (physical and radiograph)	1
Shrinking lung (radiograph)	1
Pleural fibrosis (radiograph)	1
Pulmonary infarction (radiograph)	1
Cardiovascular	
Angina or coronary artery bypass	1
Myocardial infarction ever (score 2 if >1)	1 (2)
Cardiomyopathy (ventricular dysfunction)	1
Valvular disease (diastolic, murmur, or systolic murmur > 3/6)	1
Pericarditis for 6 months, or pericardiectomy	1
Peripheral vascular	
Claudication for 6 months	1
Minor tissue loss (pulp space)	1
Significant tissue loss ever (e.g., loss of digit or limb) (score 2 if >1 site)	1 (2)
Venous thrombosis with swelling, ulceration, or venous stasis	1
Gastrointestinal	
Infarction or resection of bowel below duodenum, spleen, liver, or gall bladder ever, for cause any (score 2 if >1 site)	1 (2)
Mesenteric insufficiency	1
Chronic peritonitis	1
Structure or upper gastrointestinal tract surgery ever	1
Musculoskeletal	
Muscle atrophy or weakness	1
Deforming or erosive arthritis (including reducible deformities, excluding avascular necrosis)	1
Osteoporosis with fracture or vertebral collapse (excluding avascular necrosis)	1
Avascular necrosis (score 2 if >1)	1 (2)
Osteomyelitis	1
Skin	
Scarring chronic alopecia	1
Extensive scarring or panniculum other than scalp and pulp space	1
Skin ulceration (excluding thrombosis) for >6 months	1
Premature gonadal failure	1
Diabetes (regardless of treatment)	1
Malignancy (exclude dysplasia)(score 2 if >1 site)	1 (2)

*Damage (nonreversible change, not related to active inflammation) occurring since onset of lupus, ascertained by clinical assessment and present for at least 6 months unless otherwise stated. Repeat episodes must occur at least 6 months apart to score 2. The same lesion cannot be score twice.

