Background and aims To evaluate the construct validity of the Lupus Low Disease Activity State (LLDAS), a treatment target in systemic lupus erythematosus (SLE).

Methods Fifty SLE case summaries based on real patients were prepared and assessed independently for meeting the operational definition of LLDAS. Fifty international rheumatologists with expertise in SLE, but with no prior involvement in the LLDAS project, responded to a survey in which they were asked to categorise the disease activity state of each case as remission, low, moderate or high. Agreement between expert opinion and LLDAS was assessed using Cohen’s Kappa.

Results Overall agreement between expert opinion and the operational definition of LLDAS was 77.96% (95% CI 76.34%–79.58%), with a Cohen’s Kappa of 0.57 (95% CI 0.55–0.61). Of the cases (22 of 50) that did not fulfil the operational definition of LLDAS, only 5.34% (59 of 22 × 50) of responses classified the cases as moderate/high activity. Of the cases that did not fulfil the operational definition of LLDAS, only 5.34% (59 of 22 × 50) of responses classified the cases as remission/low activity. Common reasons for discordance were assignment to remission/low activity of cases with higher corticosteroid doses than defined in LLDAS (prednisolone ≤7.5 mg) or with SLEDAI-2K>4 due to serological activity (high anti-dsDNA antibody and/or low complement).

Conclusions LLDAS has good construct validity with high overall agreement between the operational definition of LLDAS and expert opinion. Discordance of results suggests that the operational definition of LLDAS is more stringent than expert opinion at defining a low disease activity state.

Background and aims Patients with autoimmune diseases have to deal with their chronic disease, and it affects their quality of life. This study was aimed to compare the quality of life (QOL) of patient with systemic lupus erythematosus (SLE) and systemic sclerosis (SSc).

Methods This study was cross sectional study, done in rheumatology outpatient clinic Hasan Sadikin Hospital Bandung, Indonesia in 2015–2016. It was conducted by asking patients diagnosed of SLE and SSc to fill the SF-36 form. Baseline characteristic, including age, gender, and duration of disease, were collected during the visit. The Mann-Whitney U test was used to analyse the comparison.

Results One hundred seventy patients were involved into this study, consisted of 127 SLE patients and 43 SSc patients, mostly female 162 patients (96.3%). Median of age was 34 (19 to 62) year and 40 (16 to 69) year (min-max), and duration of disease was 72 (3–252) and 36 (1–228) months (min-max), consecutively for SLE and SSc.

All sections of quality of life in patient with SLE was significantly higher than patients with SSc with p<0.001, with exception on mental component score (MCS) was not significantly different in SLE compared to SSc (p=0.062).

Conclusions The quality of life of SLE patients is significantly higher than patients with SSc except mental component score was not significantly different.

Background and aims To determine the frequency, associations and outcomes of cerebrovascular events (CerVEs) in a multi-ethnic/racial, prospective, inception cohort of SLE patients.

Methods Patients were assessed annually for 19 neuropsychiatric events including 5 types of CerVEs: (i) Stroke; (ii) Transient ischemia; (iii) Chronic multifocal ischemia; (iv) Subarachnoid and intracranial haemorrhage; (v) Sinus thrombosis. Global disease activity (SLEDAI-2K), SLICC/ACR damage index (SDI) and SF-36 subscale, mental (MCS) and physical (PCS) component summary scores were collected. Time to event, linear and logistic regressions and multi-state models were used as appropriate.

Results Of 1826 SLE patients, 88.8% were female, 48.8% Caucasian, mean±SD age 35.1±13.3 years, disease duration 5.6±4.2 months and follow-up 6.6±4.1 years. CerVEs were the four most frequent NP event: 82/1,286 (4.5%) patients had 109 events and 103/109 (94.5%) were attributed to SLE. The predominant events were stroke [60/109 (55.0%)] and transient ischemia [28/109 (25.7%)]. CerVEs were associated with NP events attributed to SLE (HR (95% CI): (3.16; 1.73–5.75), non-SLE (2.60; 1.49–4.51) (p<0.001), African ancestry at US SLICC sites (2.04; 1.01–4.13) (p=0.047) and organ damage (p=0.041). Lupus anticoagulant increased the risk of first CerVE (1.77; 0.99–3.16). Physician assessment indicated resolution or improvement in the majority but patients reported a sustained reduction in SF-36 summary and subscale scores following CerVEs (p<0.0001).

Conclusions CerVEs, the fourth most frequent NP event in SLE, are usually attributable to lupus early in the disease course. In contrast to good physician reported outcomes, patients report a sustained reduction in health related quality of life following CerVEs.