**Search terms for retrieval of validation studies**

**PubMed:** ((((((validity[Title/Abstract] OR validation[Title/Abstract] OR responsiveness[Title/Abstract] OR responsive[Title/Abstract] OR sensitivity[Title/Abstract] OR floor[Title/Abstract] OR ceiling[Title/Abstract] OR reliability[Title/Abstract] OR consistency[Title/Abstract] OR sensitive[Title/Abstract] OR psychometric[Title/Abstract] OR psychometrics[Title/Abstract] OR properties[Title/Abstract] OR property[Title/Abstract]))) OR "Validation Studies" [Publication Type])) AND (("Lupus Erythematosus, Systemic"[Mesh]) OR ((lupus[Title/Abstract] OR sle[Title/Abstract])))) AND (((((((((((((((("Quality of Life"[Mesh]) OR "Patient Reported Outcome Measures"[Mesh]) OR "Fatigue"[Mesh]) OR "Activities of Daily Living"[Mesh]) OR ((((Life Quality) OR Health-Related Quality Of Life) OR Health Related Quality Of Life) OR HRQOL)) OR ((((((Patient Reported Outcomes) OR Outcome, Patient Reported) OR Outcomes, Patient Reported) OR Reported Outcome, Patient) OR Reported Outcomes, Patient) OR Patient Reported Outcome)) OR fatigue) OR (((((((((adl) OR Activities, Daily Living) OR Activity, Daily Living) OR Daily Living Activities) OR Daily Living Activity) OR Living Activities, Daily) OR Living Activity, Daily) OR Limitation of Activity, Chronic) OR Chronic Limitation of Activity)) OR "Self Report"[Mesh]) OR (((Report, Self) OR Reports, Self) OR Self Reports)) OR (((((((("physical function") OR "functional status") OR "physical functioning") OR "mental status") OR "mental health") OR "social") OR "global health") OR "global function")))))))

**EMBASE and MEDLINE:** ('systemic lupus erythematosus'/exp) AND (('patient-reported outcome'/exp) OR ('quality of life'/exp) OR ('short form 36'/exp) OR ('self report'/exp) OR ('fatigue'/exp) OR ('functional status assessment'/exp)) AND (('validation study'/exp OR 'validation study') OR ('validity'/exp) OR ('psychometry'/exp))

**Search terms for retrieval of RCTs**

**PubMed:** ((((((((((((("Quality of Life"[Mesh]) OR "Patient Reported Outcome Measures"[Mesh]) OR "Fatigue"[Mesh]) OR "Activities of Daily Living"[Mesh]) OR ((((Life Quality) OR Health-Related Quality Of Life) OR Health Related Quality Of Life) OR HRQOL)) OR ((((((Patient Reported Outcomes) OR Outcome, Patient Reported) OR Outcomes, Patient Reported) OR Reported Outcome, Patient) OR Reported Outcomes, Patient) OR Patient Reported Outcome)) OR fatigue) OR (((((((((adl) OR Activities, Daily Living) OR Activity, Daily Living) OR Daily Living Activities) OR Daily Living Activity) OR Living Activities, Daily) OR Living Activity, Daily) OR Limitation of Activity, Chronic) OR Chronic Limitation of Activity)) OR "Self Report"[Mesh]) OR (((Report, Self) OR Reports, Self) OR Self Reports)) OR (((((((("physical function") OR "functional status") OR "physical functioning") OR "mental status") OR "mental health") OR "social") OR "global health") OR "global function"))) AND (((((((( "Therapeutics/drug effects"[Mesh] OR "Therapeutics/drug therapy"[Mesh] OR "Therapeutics/therapy"[Mesh] ))) OR treatment\*[Title/Abstract])) AND ((((((lupus[Title/Abstract] OR sle[Title/Abstract]))) OR (( "Lupus Erythematosus, Systemic/drug therapy"[Mesh] OR "Lupus Erythematosus, Systemic/therapy"[Mesh] )))))) AND ((("Clinical Trial" [Publication Type]) OR (("clinical trial"[Title/Abstract] OR "clinical trials"[Title/Abstract])))))))

**EMBASE and MEDLINE:** ('systemic lupus erythematosus':ta,ab AND ([controlled clinical trial]/lim OR [randomized controlled trial]/lim) AND [article]/lim AND [humans]/lim AND [embase]/lim) AND (('patient-reported outcome'/exp) OR ('quality of life'/exp) OR ('fatigue'/exp) OR ('functional status'/exp) OR ('short form 36'/exp))

**List 1: Validated instruments not included in this review**

Beck depression inventory

Body Image Lupus Scale

Brief Fatigue Inventory Short Form

Brief pain inventory short form

Cognitive Symptoms Inventory

Evaluation of daily activity questionnaire

Fatigue assessment instrument

Hopkins Verbal Learning Test-Revised

Lupus Quality of Life Questionnaire

Lupus satisfaction questionnaire

Mini-mental state exam

Montreal Cognitive Assessment

Multidimensional Health Assessment Questionnaire

Neuro Quality of Life

Perceived Deficits Questionnaire-Short Form

Rating Scale Preference Measure

Rheumatology Attitudes Index

Routine Assessment of Patient Index Data 3

Short Form 6D

Systemic Lupus Erythematosus Family Questionnaire

Systemic Lupus Erythematosus Needs Questionnaire

Systemic Lupus Erythematosus Quality of Life

**List 2: RCT instruments not included in this review**

Brief Fatigue Index

Center for Epidemiologic Studies Depression Scale

Derogatis Sexual Functioning Inventory

Fatigue Assessment Scale

Fatigue Severity Scale

Influence of Rheumatologic disease on general health and lifestyle

McCoy Sex Scale Questionnaire

Medical Outcomes Study Sleep Problems

Profile of mood states

Psychological General Wellbeing Index

Systemic Lupus Erythematosus Symptoms Checklist

The Hopkins Symptoms Checklist