

Appendix I. PubMed search strategy

("Severity of Illness Index"[Majr] OR "Disease Progression"[Majr] OR "disease activity"[Title/Abstract] OR "disease severity"[Title/Abstract] OR "remission"[Title/Abstract] OR "flare"[Title/Abstract] OR "Severity of Illness Index "[Title/Abstract] OR "disease progression"[Title/Abstract] OR "disease course"[Title/Abstract])

AND ("Arthritis, Rheumatoid"[Majr] OR rheumatoid arthritis[Title/Abstract])

AND ("questionnaires"[Majr] OR "Patient Participation"[Majr] OR "Self examination"[Majr] OR "Self assessment"[Majr] OR patient index[tiab] OR patient administered[tiab] OR patient derived [tiab] OR patient based [tiab] OR patient assessed[tiab] OR patient assessment[tiab] OR patient assessments[tiab] OR patient reports[tiab] OR patient reported[tiab] OR patient monitor[tiab] OR patient monitoring[tiab] OR patient monitored[tiab] OR patient evaluated[tiab] OR patient evaluation[tiab] OR patient evaluations[tiab] OR patient examination[tiab] OR patient examinations[tiab] OR patient examined[tiab] OR patient rated[tiab] OR patient participation[tiab] OR self administered[tiab] OR self assessment[tiab] OR self assessments[tiab] OR self assessed[tiab] OR self report[tiab] OR self reported[tiab] OR self monitor[tiab] OR self monitoring[tiab] OR self monitored[tiab] OR self evaluate[tiab] OR self evaluation[tiab] OR self evaluations[tiab]OR self evaluated[tiab] OR self examine[tiab] OR self examination[tiab] OR self examinations[tiab] OR self examined[tiab] OR self rate[tiab] OR self rated[tiab])

AND ("instrumentation"[sh] OR "methods"[sh] OR Validation Studies[pt] OR Comparative Study[pt] OR "psychometrics"[MeSH] OR psychometr*[tiab] OR clinimetr*[tw] OR clinometr*[tw] OR "outcome assessment (health care)"[MeSH] OR outcome assessment[tiab] OR outcome measure*[tw] OR "observer variation"[MeSH] OR observer variation[tiab] OR "Health Status Indicators"[Mesh] OR "reproducibility of results"[MeSH] OR reproducib*[tiab] OR "discriminant analysis"[MeSH] OR reliab*[tiab] OR unreliab*[tiab] OR valid*[tiab] OR coefficient[tiab] OR homogeneity[tiab] OR homogeneous[tiab] OR "internal consistency"[tiab] OR (cronbach*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR (item[tiab] AND (correlation*[tiab] OR selection*[tiab] OR reduction*[tiab])) OR agreement[tiab] OR precision[tiab] OR imprecision[tiab] OR "precise values"[tiab] OR test-retest[tiab] OR (test[tiab] AND retest[tiab]) OR (reliab*[tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intra-observer[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant[tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-participant[tiab] OR kappa[tiab] OR kappa's[tiab] OR kappas[tiab] OR repeatab*[tiab] OR ((replicab*[tiab] OR repeated[tiab]) AND (measure[tiab] OR measures[tiab] OR findings[tiab] OR result[tiab] OR results[tiab] OR test[tiab] OR tests[tiab])) OR generaliza*[tiab] OR generalisa*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation*[tiab]) OR discriminative[tiab] OR "known group"[tiab] OR factor analysis[tiab] OR factor analyses[tiab] OR dimension*[tiab] OR subscale*[tiab] OR (multitrait[tiab] AND scaling[tiab] AND (analysis[tiab] OR analyses[tiab])) OR item discriminant[tiab] OR interscale correlation*[tiab] OR error[tiab] OR errors[tiab] OR "individual variability"[tiab] OR (variability[tiab] AND (analysis[tiab] OR values[tiab])) OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR "standard error of measurement"[tiab] OR sensitiv*[tiab] OR responsive*[tiab] OR ((minimal[tiab] OR minimally[tiab] OR clinical[tiab] OR clinically[tiab]) AND (important[tiab] OR significant[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR (small*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR meaningful change[tiab] OR "ceiling effect"[tiab] OR "floor effect"[tiab] OR "Item response model"[tiab] OR IRT[tiab] OR Rasch[tiab] OR "Differential item functioning"[tiab] OR DIF[tiab] OR "computer adaptive testing"[tiab] OR "item bank"[tiab] OR "cross-cultural equivalence"[tiab])

AND English[lang]

AND ("1994/01/01"[PDAT] : "2014/04/18"[PDAT])

NOT (Addresses[ptyp] OR Autobiography[ptyp] OR Bibliography[ptyp] OR Biography[ptyp] OR Case Reports[ptyp] OR Clinical Conference[ptyp] OR Congresses[ptyp] OR Consensus Development Conference[ptyp] OR Consensus Development Conference, NIH[ptyp] OR Dictionary[ptyp] OR Directory[ptyp] OR Duplicate Publication[ptyp] OR Editorial[ptyp] OR Electronic Supplementary Materials[ptyp] OR English Abstract[ptyp] OR Festschrift[ptyp] OR Government Publications[ptyp] OR Guideline[ptyp] OR Historical Article[ptyp] OR In Vitro[ptyp] OR Interactive Tutorial[ptyp] OR Interview[ptyp] OR Introductory Journal Article[ptyp] OR Lectures[ptyp] OR Legal Cases[ptyp] OR Legislation[ptyp] OR Letter[ptyp] OR Meta-Analysis[ptyp] OR News[ptyp] OR Newspaper Article[ptyp] OR Overall[ptyp] OR Patient Education Handout[ptyp] OR Periodical Index[ptyp] OR Personal Narratives[ptyp] OR Portraits[ptyp] OR Practice Guideline[ptyp] OR Retracted Publication[ptyp] OR Retraction of Publication[ptyp] OR Review[ptyp] OR Systematic [sb] OR Scientific Integrity Review[ptyp] OR Technical Report[ptyp] OR Twin Study[ptyp] OR Video-Audio Media[ptyp] OR Webcasts[ptyp])

NOT ("infant"[MeSH Terms] OR "child"[MeSH Terms] OR "adolescent"[MeSH Terms])

NOT "animals"[MeSH:noexp]

Appendix II. Embase search strategy

1. *Severity of Illness Index/ or *disease severity/ or *disease course/ or *disease activity score/ or disease activity.ti,ab,kw. or disease severity.ti,ab,kw. or remission.ti,ab,kw. or flare.ti,ab,kw. or Severity of Illness Index.ti,ab,kw. or disease progression.ti,ab,kw. or disease course.ti,ab,kw.

2. *rheumatoid arthritis/ or rheumatoid arthritis.ti,ab,kw.

3. *questionnaire/ or *patient participation/ or *patient assessment/ or *self examination/ or *self evaluation/ or *self report/ or *self monitoring/ or *patient monitoring/ or patient index.ti,ab,kw. or questionnaire.kw. or questionnaires.kw. or patient administered.ti,ab,kw. or patient derived.ti,ab,kw. or patient based.ti,ab,kw. or patient assessed.ti,ab,kw. or patient assessment.ti,ab,kw. or patient reports.ti,ab,kw. or patient reported.ti,ab,kw. or patient monitor.ti,ab,kw. or patient monitoring.ti,ab,kw. or patient monitored.ti,ab,kw. or patient evaluated.ti,ab,kw. or patient evaluation.ti,ab,kw. or patient examination.ti,ab,kw. or patient examined.ti,ab,kw. or patient rated.ti,ab,kw. or patient participation.ti,ab,kw. or self administered.ti,ab,kw. or self assessment.ti,ab,kw. or self assessed.ti,ab,kw. or self report.ti,ab,kw. or self reported.ti,ab,kw. or self monitor.ti,ab,kw. or self monitoring.ti,ab,kw. or self monitored.ti,ab,kw. or self evaluate.ti,ab,kw. or self evaluation.ti,ab,kw. or self evaluated.ti,ab,kw. or self examine.ti,ab,kw. or self examination.ti,ab,kw. or self examined.ti,ab,kw. or self rate.ti,ab,kw. or self rated.ti,ab,kw.

4. psychometry/ or outcome assessment/ or outcomes research/ or comparative study/ or intermethod comparison/ or multimethod study/ or feasibility study/ or validation study/ or correlational study/ or correlation analysis/ or replication study/ or validity/ or reliability/ or reproducibility/ or observer variation/ or psychometr*.ti,ab,kw. OR clinimetr*.ti,ab,kw. OR clinometr*.ti,ab,kw. OR outcome assessment.ti,ab,kw. OR outcome measure*.ti,ab,kw. OR observer variation.ti,ab,kw. OR reproducib*.ti,ab,kw. OR reliab*.ti,ab,kw. OR unreliab*.ti,ab,kw. OR valid*.ti,ab,kw. OR coefficient.ti,ab,kw. OR homogeneity.ti,ab,kw. OR homogeneous.ti,ab,kw. OR internal consistency.ti,ab,kw. OR (cronbach*.ti,ab,kw. AND (alpha.ti,ab,kw. OR alphas.ti,ab,kw.)) OR (item.ti,ab,kw. AND (correlation*.ti,ab,kw. OR selection*.ti,ab,kw. OR reduction*.ti,ab,kw.)) OR agreement.ti,ab,kw. OR precision.ti,ab,kw. OR imprecision.ti,ab,kw. OR precise values.ti,ab,kw. OR test retest.ti,ab,kw. OR (test.ti,ab,kw. AND retest.ti,ab,kw.) OR (reliab*.ti,ab,kw. AND (test.ti,ab,kw. OR retest.ti,ab,kw.)) OR stability.ti,ab,kw. OR interrater.ti,ab,kw. OR inter rater.ti,ab,kw. OR intrarater.ti,ab,kw. OR intra rater.ti,ab,kw. OR intertester.ti,ab,kw. OR inter tester.ti,ab,kw. OR intratester.ti,ab,kw. OR intra-tester.ti,ab,kw. OR interobserver.ti,ab,kw. OR inter observer.ti,ab,kw. OR intraobserver.ti,ab,kw. OR intra observer.ti,ab,kw. OR intertechnician.ti,ab,kw. OR inter technician.ti,ab,kw. OR intratechnician.ti,ab,kw. OR intra-technician.ti,ab,kw. OR interexaminer.ti,ab,kw. OR inter-examiner.ti,ab,kw. OR intraexaminer.ti,ab,kw. OR intra examiner.ti,ab,kw. OR interassay.ti,ab,kw. OR inter-assay.ti,ab,kw. OR intraassay.ti,ab,kw. OR intra assay.ti,ab,kw. OR interindividual.ti,ab,kw. OR inter individual.ti,ab,kw. OR intraindividual.ti,ab,kw. OR intra individual.ti,ab,kw. OR interparticipant.ti,ab,kw. OR inter participant.ti,ab,kw. OR intraparticipant.ti,ab,kw. OR intra participant.ti,ab,kw. OR kappa.ti,ab,kw. OR kappas.ti,ab,kw. OR repeatab*.ti,ab,kw. OR ((replicab*.ti,ab,kw. OR repeated.ti,ab,kw.) AND (measure.ti,ab,kw. OR measures.ti,ab,kw. OR findings.ti,ab,kw. OR result.ti,ab,kw. OR results.ti,ab,kw. OR test.ti,ab,kw. OR tests.ti,ab,kw.)) OR generaliza*.ti,ab,kw. OR generalisa*.ti,ab,kw. OR concordance.ti,ab,kw. OR (intraclass.ti,ab,kw. AND correlation*.ti,ab,kw.) OR discriminative.ti,ab,kw. OR known group.ti,ab,kw. OR factor analysis.ti,ab,kw. OR factor analyses.ti,ab,kw. OR dimension*.ti,ab,kw. OR subscale*.ti,ab,kw. OR (multitrait.ti,ab,kw. AND scaling.ti,ab,kw. AND (analysis.ti,ab,kw. OR analyses.ti,ab,kw.)) OR item discriminant.ti,ab,kw. OR interscale correlation*.ti,ab,kw. OR error.ti,ab,kw. OR errors.ti,ab,kw. OR individual variability.ti,ab,kw. OR (variability.ti,ab,kw. AND (analysis.ti,ab,kw. OR values.ti,ab,kw.)) OR (uncertainty.ti,ab,kw. AND (measurement.ti,ab,kw. OR measuring.ti,ab,kw.)) OR standard error of measurement.ti,ab,kw. OR sensitiv*.ti,ab,kw. OR responsive*.ti,ab,kw. OR ((minimal.ti,ab,kw. OR minimally.ti,ab,kw. OR clinical.ti,ab,kw. OR clinically.ti,ab,kw.) AND (important.ti,ab,kw. OR significant.ti,ab,kw. OR detectable.ti,ab,kw.)) AND (change.ti,ab,kw. OR difference.ti,ab,kw.)) OR (small*.ti,ab,kw. AND (real.ti,ab,kw. OR detectable.ti,ab,kw.)) AND (change.ti,ab,kw. OR difference.ti,ab,kw.)) OR meaningful change.ti,ab,kw. OR ceiling effect.ti,ab,kw. OR floor effect.ti,ab,kw. OR Item response model.ti,ab,kw. OR IRT.ti,ab,kw. OR Rasch.ti,ab,kw. OR Differential item functioning.ti,ab,kw. OR DIF.ti,ab,kw. OR computer adaptive testing.ti,ab,kw. OR item bank.ti,ab,kw. OR cross-cultural equivalence.ti,ab,kw.

5. 1 and 2 and 3 and 4

6. limit 5 to (english language and yr="1994 -Current")

7. limit 6 to (book or book series or conference abstract or conference paper or conference proceeding or "conference review" or editorial or erratum or letter or note or "review" or short survey or trade journal)

8. limit 6 to (embryo or infant or child or preschool child <1 to 6 years> or school child <7 to 12 years> or adolescent <13 to 17 years>)

9. limit 6 to (consensus development or meta analysis or "systematic review")

10. limit 6 to (phase 1 clinical trial or phase 2 clinical trial or phase 3 clinical trial or phase 4 clinical trial)

11. 7 or 8 or 9 or 10

12. 6 not 11

Appendix III. Quality of evidence of measurement properties per study

Study	Internal consistency	Reliability ICC	Measurement error SDD	Content validity	Structural validity	Hypothesis testing	Criterion validity	Responsiveness
RADAI								
[42]							+(++) 0.58s	± (+) 0.88 AUC _{flare}
[20]	± (++) 0.87 α					++ (++)	++ (++) 0.53s	
[10]							± (+) 0.54s	
[21]	± (+) 0.895 α							
[54]								± (+) 0.773 AUC _{responder}
[55]						± (±)	± (+) 0.826s 0.947 AUC	
[57]	± (±) 0.91 α				± (±) 1 factor	± (±)		
[58]							± (+) 0.48s	± (+) 0.51s
[59]		- (+) 0.92	- (+) 1.49; 14.9% _{max} SDD					
[25]	± (+) 0.84 α				± (+) 1 factor		± (+) 0.53p	± (+) 0.54 p 0.77 AUC _{responder}
RADAI-5								
[39]							± (±) 0.662s	
[21]	± (+) 0.917 α				± (+) 1 factor	± (±)	± (+) 0.638s 0.290κ	± (+) 0.589s 0.295κ
[22]	+ (++) 0.906 α				+ (++) 1 factor	+ (++)	+ (++) 0.370τ	
[24]							- (±) 0.624-0.806s 0.236κ	
[53]							± (+)	

							0.655s	
PDAS I / II								
[9]	- (±) 0.5 / 0.4 α	± (±) 0.76-0.88		- (-)		± (±)	± (+) 0.89 / 0.76s	- (±)
Pt-DAS28								
[45]		± (±) 0.92 p	± (±) 0.8; 23.2% _{mean} SDD				± (±) 0.91p / 0.94p	
[10]						± (±)		
[11]							± (+) 0.757s	
[12]							± (+) 0.73s 0.54κ	± (+) 0.45κ
[13]							± (±) 0.91s	± (±)
Pt-SDAI								
[45]		± (±) 0.90p	± (±) 8.3; 59.9% _{mean} SDD				± (±) 0.92p / 0.93p	
[11]							± (+) 0.873s	
PAS I								
[54]								± (+) 0.785 AUC _{responder}
[26]						± (±)		
PAS II								
[26]						± (±)		
Rapid 2								
[23]								- (-)
Rapid 3								
[38]								- (±)
[39]							± (±) 0.637s	
[40]								- (-)
[41]							+ (+)	
[43]							± (+) 0.659pb 0.257κ	
[22]	+ (++)				+ (++)	+ (++)	+ (++)	

	0.871 α				1 factor		0.328 τ	
[46]								- (-)
[48]							\pm (+) 0.73s 0.53wk	\pm (+) 0.53wk
[49]							\pm (+) 0.32-0.42wk	\pm (+) 0.43wk
[50]								\pm (+) 0.616-0.641k
[51]							+ (++) 0.658s 0.44wk	
[52]							\pm (+) 0.43s 0.27wk	
[54]								\pm (+) 0.801 AUC _{responder}
[55]						\pm (\pm)	\pm (+) 0.838s 0.939 AUC	
[56]							\pm (+) 0.91s 0.634k	
[59]		- (+) 0.90	- (+) 1.48; 14.8% _{max} SDD					
Rapid 4 PtJC								
[38]								- (\pm)
[23]								- (-)
[51]							+ (++) 0.654s 0.44wk	
Rapid 4 MD								
[23]								- (-)
Rapid 5								
[23]								- (-)
[51]							+ (++) 0.692s 0.48wk	

[58]							± (+) 0.71s	± (+) 0.70s
PRO-Clara								
[54]								± (+) 0.823 AUC _{responder}
[55]	± (+) 0.893 α				± (+) 1factor	± (±)	± (+) 0.835s 0.949 AUC	
PRO-index C / M								
[47]								± (±)
GAS								
[44]							± (+) 0.453p _{phyglob}	
[58]							± (+) 0.54s	± (+) 0.50s

[..] reference number, Quality of evidence indicators: ++ excellent, + good, ± fair, - poor lowest subscore per property + (next best subscore when discarding lowest subscore), α Chronbach's alpha, ICC interclass correlation coefficient, p Pearson's correlation coefficient, SDD smallest detectable difference, %_{mean}SDD SDD as percentage of mean value of the outcome, %_{max}SDD SDD as percentage of maximum value of outcome, s Spearman's correlation coefficient, p Pearson's correlation coefficient, pb Passing-Bablok correlation coefficient, τ Kendall's Tau, phyglob physicians global assessment of disease activity as comparator, κ Kappa, wk Weighted Kappa, AUC_{flare} Area Under the Curve for patients with flare versus no flare, AUC_{responder} Area Under the Curve for patients responding to therapy versus not responding