THE OMERACT GLOSSARY
FOR PATIENT RESEARCH PARTNERS

EDITORS PAMELA RICHARDS & MAARTEN DE WIT
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First edition of the OMERACT Glossary May 2004

Current edition of the OMERACT Glossary April 2012

The glossary logo represents the global and interlinked research collaboration of clinicians, patients and researchers in developing reliable, relevant and robust outcome measures in rheumatology. Pam Richards.
(logo by Eatcake Design http://www.eatcakedesign.co.uk/ )
1. Abbreviations

<   less than

>   more than

AAV;ANCA    Associated Vasculitis
ACR    American College of Rheumatology (also: ACR-criteria 20-50-70)
ADL    Activities of Daily Living (measuring functional ability doing normal tasks)
AE    Adverse Effects / Adverse Events
AIMS   Arthritis Impact Measurement Scale (also: AIMS2)
ANCA   Anti-Neutrophil Cytoplasmic Antibodies
APLAR  Asia Pacific League of Associations for Rheumatology
ARA    American Rheumatism Association
ARMA   Arthritis and Musculoskeletal Alliance
ARUK   Arthritis Research, United Kingdom (UK research charity)
AS    Ankylosing Spondylitis
ASAS   Assessment of SpondyloArthritis international Society
       (also: ASAS improvement and partial remission criteria)
ASDAS  Ankylosing Spondylitis Disease Activity Score
ASES   Arthritis Self-Efficacy Scale (measures how a person believes they can control their arthritis)
ASspiMRI Ankylosing Spondylitis spinal Magnetic Resonance Imaging
          (scoring system for assessment of changes in the spine)
AUC    Area Under the Curve Measurements
AVID:ANCA Vasculitis Index of Damage
BASDAI  Bath Ankylosing Spondylitis Disease Activity Index
BASFI   Bath Ankylosing Spondylitis Functional Index
BASMI   Bath Ankylosing Spondylitis Metrology Index
BHPR   British Health Professionals in Rheumatology (UK association of allied health professionals, e.g. nurses, physiotherapists)
BILAG  British Isles Lupus Assessment Group
BJD    Bone and Joint Decade 2000-2010
BMD    Bone Mineral Densitometry (showing bone density)
BRAF   Bristol RA Fatigue Scale
BRM    Biological Response Modifier
BSA    Body Surface Area
BVAS   Birmingham Vasculitis Score
BVAS/WG Birmingham Vasculitis Score for Wegener's Granulomatosis
CAT    Computer Adaptive Testing
CAHPS  Consumer Assessment of Health Plan Survey
CBT    Cognitive Behavioural Therapy
CCN    Cochrane Consumer Network
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>CCP</td>
<td>Anti-Cyclic Citrullinated Peptide antibodies</td>
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<tr>
<td>CDA</td>
<td>Combined Damage Assessment</td>
</tr>
<tr>
<td>CDAI</td>
<td>Clinical Disease Activity Index</td>
</tr>
<tr>
<td>CEQ</td>
<td>Cognitive Errors Questionnaire (a measure of negative thinking).</td>
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<tr>
<td>CFA</td>
<td>Confirmatory Factor Analysis (statistical test of whether several questions are measuring the same thing)</td>
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<tr>
<td>CI</td>
<td>Confidence Interval</td>
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<tr>
<td>CIS</td>
<td>Checklist Individual Strength</td>
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<tr>
<td>COMET</td>
<td>Core Outcome Measures for Effectiveness Trials</td>
</tr>
<tr>
<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
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<tr>
<td>CPK</td>
<td>Creatine Phosphokinase</td>
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<td>CRP</td>
<td>C-reactive protein</td>
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<tr>
<td>CTC</td>
<td>Common Toxicity Criteria</td>
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<tr>
<td>CTD</td>
<td>Connective Tissue Disease</td>
</tr>
<tr>
<td>DAS</td>
<td>Disease Activity State (also: Das28; Das44)</td>
</tr>
<tr>
<td>DIP</td>
<td>Distal Interphalangeal joint</td>
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<tr>
<td>DLQI</td>
<td>Dermatology Quality of Life Measure</td>
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<tr>
<td>DM</td>
<td>Dermatomyositis</td>
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<tr>
<td>DMARD</td>
<td>Disease Modifying Anti-Rheumatic Drug</td>
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<tr>
<td>DMOAD</td>
<td>Disease Modifying Osteoarthritis Drugs</td>
</tr>
<tr>
<td>DQoL</td>
<td>Dermatology Quality of Life questionnaire</td>
</tr>
<tr>
<td>DRP</td>
<td>Disease Repercussion Profile</td>
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<tr>
<td>DS</td>
<td>Destruction Score</td>
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<td>DVU</td>
<td>Discovertebral Unit</td>
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<td>EBM</td>
<td>Evidence Based Medicine</td>
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<tr>
<td>EC-17</td>
<td>Effective Consumer Scale</td>
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<tr>
<td>EF-WHOQOL-100</td>
<td>Energy and Fatigue scale – World Health Organisation Quality of Life Assessment Instrument</td>
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<tr>
<td>EMG</td>
<td>Electromyogram (measures the electrical activity of muscle at rest and during contraction)</td>
</tr>
<tr>
<td>EMG/NCS</td>
<td>Electromyogram (EMG) and Nerve Conduction Studies</td>
</tr>
<tr>
<td>ES</td>
<td>Erosion Score</td>
</tr>
<tr>
<td>ESR</td>
<td>Erythrocyte Sedimentation Rate</td>
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<tr>
<td>et al</td>
<td>and others</td>
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<tr>
<td>EuroQol</td>
<td>Euro Quality of Life</td>
</tr>
<tr>
<td>EQ5D</td>
<td>Euro Qualtiy of Life descriptive system measure</td>
</tr>
<tr>
<td>EULAR</td>
<td>European League Against Rheumatism</td>
</tr>
<tr>
<td>EWPS</td>
<td>Endicott Work Productivity Scale</td>
</tr>
<tr>
<td>FACIT</td>
<td>Functional Assessment of Chronic Illness Therapy Fatigue scale</td>
</tr>
<tr>
<td>FIQ</td>
<td>Fibromyalgia Impact Questionnaire</td>
</tr>
<tr>
<td>FJC</td>
<td>Fuchs Joint Count (measures 28 joints to assess how many are painful or swollen)</td>
</tr>
<tr>
<td>FMS</td>
<td>Fibromyalgia syndrome</td>
</tr>
<tr>
<td>FS</td>
<td>Fatigue Scale (Chalder)</td>
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</tbody>
</table>
FSI  Fatigue Symptom Inventory
FSS  Fatigue Severity Scale (Krupp)
FU   Follow up
GCA  Giant Cell Arteritis
Gd   Gadolinium
GHQ  General Health Questionnaire
GI Tract  Gastro Intestinal Tract
GP   General Practitioner
GRAPPA  Group for Research and Assessment of Psoriasis and Psoriatic Arthritis
GSES  General Self-Efficacy Scale
GSQS  Goningen Sleep Quality Scale
HAD  Hospital Anxiety Depression Scale
HAQ  Stanford Health Assessment Questionnaire
HAQ-DI  Health Assessment Quality of Life Disability Index
HIC  High Income Countries
HLQ  Health and Labour Questionnaire
HPQ  Health and Work Performance Questionnaire
HRPQ-D  Health-Related Productivity Questionnaire Diary
HRQoL  Health Related Quality of Life
HWQ  Health and Work Questionnaire
IBM  Inclusion Body Myositis
ICC  Intra class Co-efficient (assessing if things are stable)
ICERs  Incremental Cost-Effectiveness Ratios
ICF  WHO International Classification of Functioning Disability and Health
ICH  International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use
Ig  Immunoglobulin (antibodies and the antigen in the case of autoantibodies)
IL  Interleukin (a category of proteins / cytokines)
IL-1  Interleukin 1 (also IL-6 etc.)
IIM  Idiopathic Inflammatory Myopathies
ILAR  International League of Associations for Rheumatology
ILD  Interstitial (occurring between tissues) lung disease
IPA  Interpretative Phenomenological Analysis
IMID  Immune Mediated Inflammatory Disease (e.g. RA)
JPBA  Joint Protection Behaviour Assessment
IPR  Intellectual Property Rights
IRT  Item Response Therapy
JIA  Juvenile Idiopathic Arthritis
JSN  Joint Space Narrowing Score
JSW  Joint space and width measurement
LDAS  Low Disease Activity State
LMIC  Low and Middle Income Countries
Ln  natural logarithm
LOE  Lack of Efficacy
LOS  Longitudinal Observational Study
LFQ  Life Functioning Questionnaire
LFT  Liver Function Test
LR  Likelihood ratios
MACTAR  McMaster Toronto Arthritis Patient Preference Disability Questionnaire
MAF  Multi-dimensional Assessment of Fatigue scale
MCID  Minimal Clinically Important Difference
MCII  Minimal Clinically Important Improvement
MCIS  Minimal Clinically Important State
MCP  Metacarpophalangeal (the bones in fingers)
MDT  Multi Disciplinary Team
MEI  Mander Enthesitis Index
MFI  Multi-dimensional Fatigue Inventory
MHAQ  Modified Health Assessment Questionnaire (see: HAQ).
MHIQ  McMaster Health Index Questionnaire
MHOQ  Michigan Hand Outcomes Questionnaire
MMP's  Matrix Metalloproteinase
MMT  Manual Muscle Testing
MOS SF-36  see: SF-36
MRI  Magnetic Resonance Imaging
MS  Musculoskeletal disorders
MSS  Modified Sharp Score
MSU-  MonoSodium Urate
MTD  Multi Disciplinary Team
MTP  Metatarsal-phalangeal (joint between the end of the foot and the toes)
MTX  Methotrexate
NCS  Nerve Conduction Study
NHP  Nottingham Health Profile
NHS  National Health Service, United Kingdom
NICE  National Institute for Health and Clinical Excellence (UK)
NIH-PROMIS  National Institute of Health – Patient Reported Outcomes Measurement Information System
NPF  National Psoriasis Foundation Score
NPV  Negative predictive values
NRAS  National Rheumatoid Arthritis Society (UK support and advocacy charity)
NRS  Numeric Rating Score (function NRS, global NRS, pain NRS)
NSAID  Non Steroid Anti Inflammatory Drugs
OA  Osteoarthritis
OARSI  Osteoarthritis Research Society International
OAS  Overall Assessment of Satisfaction
OLA  Overall Lesion Assessment
OMERACT  Outcome Measures in Rheumatology Clinical Trials
ORQ  Occupational Role Questionnaire
OST  Osterhaus technique
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>OT</td>
<td>Occupational Therapy</td>
</tr>
<tr>
<td>PAMS</td>
<td>Patients’ Attitude to Medication Scale (a measure of beliefs about medications)</td>
</tr>
<tr>
<td>PARS</td>
<td>PsA Retingen Score</td>
</tr>
<tr>
<td>PASI score</td>
<td>Psoriasis Area Severity Index</td>
</tr>
<tr>
<td>PASS</td>
<td>Patient Acceptable Symptomatic State (linked to LDAS)</td>
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<tr>
<td>PCA</td>
<td>Principal Component Analysis</td>
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<tr>
<td>PET</td>
<td>Problem Elicitation Technique</td>
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<tr>
<td>PF</td>
<td>Physical Functioning</td>
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<tr>
<td>PGA</td>
<td>Physician Global Assessment</td>
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<tr>
<td>PhGA</td>
<td>Physician Global Assessment</td>
</tr>
<tr>
<td>PSARS</td>
<td>PsA Retingen Score</td>
</tr>
<tr>
<td>PGWB</td>
<td>Psychological General Well-Being Index</td>
</tr>
<tr>
<td>PI</td>
<td>Proximal Interphalangeal (small bone in fingers and toes)</td>
</tr>
<tr>
<td>PM</td>
<td>Polymyositis</td>
</tr>
<tr>
<td>PMR</td>
<td>Polymyalgia Rheumatica</td>
</tr>
<tr>
<td>PMR-AS</td>
<td>Polymyalgia Rheumatica Activity Score</td>
</tr>
<tr>
<td>PMN</td>
<td>Polymorphonuclear (cells, affecting synovium – neutrophils e.g. in RA, Gout)</td>
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<tr>
<td>POMS</td>
<td>Profile Of Mood State</td>
</tr>
<tr>
<td>PPV</td>
<td>Positive predictive values</td>
</tr>
<tr>
<td>PRO</td>
<td>Patient Reported Outcome</td>
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<tr>
<td>PROMIS</td>
<td>Patient Reported Outcomes Measurement Information System</td>
</tr>
<tr>
<td>PS</td>
<td>Proliferation Score</td>
</tr>
<tr>
<td>PsA</td>
<td>Psoriatic Arthritis</td>
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<tr>
<td>PsARC</td>
<td>Psoriatic Arthritis Response Criteria</td>
</tr>
<tr>
<td>PSRS</td>
<td>Patient Safety Reporting System (USA)</td>
</tr>
<tr>
<td>PT</td>
<td>Physio-Therapy / Physical Therapy</td>
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<tr>
<td>pt</td>
<td>patient</td>
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<tr>
<td>PtGA</td>
<td>Patient Glogal Assessment</td>
</tr>
<tr>
<td>PGIC</td>
<td>Patient Global Index of Change</td>
</tr>
<tr>
<td>QALYs</td>
<td>Quality-Adjusted Life-Years</td>
</tr>
<tr>
<td>QQ</td>
<td>Quantity and Quality Scale</td>
</tr>
<tr>
<td>RA</td>
<td>Rheumatoid Arthritis</td>
</tr>
<tr>
<td>RAI</td>
<td>Ritchie Articular Index</td>
</tr>
<tr>
<td>RADA1</td>
<td>Rheumatoid Arthritis disease activity index</td>
</tr>
<tr>
<td>RAES</td>
<td>R.A. Evaluation Survey Database (set up by Fred Wolfe)</td>
</tr>
<tr>
<td>RAND-36</td>
<td>see: SF-36</td>
</tr>
<tr>
<td>RAPPI-PI</td>
<td>Rheumatoid Arthritis Patient Priorities for Pharmacological Interventions (RAPP-PI) outcomes (Patient perspective of measuring treatment efficacy)</td>
</tr>
<tr>
<td>RASE</td>
<td>Rheumatoid Arthritis Self-Efficacy scale</td>
</tr>
<tr>
<td>RAQol</td>
<td>Rheumatoid Arthritis Quality of Life Questionnaire</td>
</tr>
<tr>
<td>RA-WIS</td>
<td>Rheumatoid Arthritis-Work Instability Scale</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized Controlled Trial</td>
</tr>
<tr>
<td>RF</td>
<td>Rheumatoid Factor</td>
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</tbody>
</table>
RFP  Rheumatoid Factor Positive
RAIJC  Ritchie Articular Index Joint Count (*measures 24 joints to assess how many are swollen or painful*)
RNP  Rheumatology Nurse Practitioner
RNS  Rheumatology Nurse Specialist
ROC  Receiver Operative Curve
SA  Spondylitis Ankylopoetica
SAE  Serious Adverse Events
SCQM  Swiss Clinical Quality Management in rheumatoid arthritis
SD  Standard Deviation (*statistical measure*)
SDAI  Simplified Disease Activity Index
SDC  Smallest Detectable Change
SDD  Smallest Detectable Difference
SEM  Standard Error of the Mean (*statistical measure*)
SEIQOL  Schedule for the Evaluation of Individual Quality of Life
SES  Standardized Effect Size (*see Effect Size*)
SF  Synovial Fluid
SF-36  Medical Outcome Study Short Form (*36 items measuring pain, fatigue, functional ability and depression*)
SIG  Special Interest Group
SJJ  Sacroiliac Joint
SJC  Swollen Joint Count
SLE  Systemic Lupus Erythematosis
SLEDAI  SLE Disease Activity Index
SM  Synovial Membrane
SM  Self Management interventions in arthritis
SODA  Sequential Occupational Dexterity Assessment
SpA  Spondyloarthritis
SPARCC  SPondyloAthropathy Research Consortium of Canada
SPS6  Stanford Presenteeism Scale- 6 items
SPS13  Stanford Presenteeism Scale- 13 items
SRM  Standardized Response Mean
SS  Sjogrens Syndrome
SS-A  Social Support Appraisals Scale-A
SS-B  Social Support Appraisals Scale-B
SSc  Systemic Scleroderma
SSZ  Sulfasalazine
STI  Stanford Toxicity Index
STIR  Short Tau Inversion Recovery
SUA-  Serum Uric Acid
T1-weighted  Method of imagining using MRI for detection of fat cells
THR  Total Hip Replacement
TJC  Tender Joint Count
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>TKR</td>
<td>Total Knee Replacement</td>
</tr>
<tr>
<td>TNF</td>
<td>Tumour Necrosis Factor <em>(a protein / cytokine)</em></td>
</tr>
<tr>
<td>US</td>
<td>Ultrasound</td>
</tr>
<tr>
<td>VAS</td>
<td>Visual Analogue Scale <em>(a way of measuring things by marking how you feel along a line between two extremes, e.g., no pain to worst pain imaginable)</em></td>
</tr>
<tr>
<td>V CRC</td>
<td>Vasculitis Clinical Research Consortium</td>
</tr>
<tr>
<td>VDI</td>
<td>Vasculitis Damage Index</td>
</tr>
<tr>
<td>VU</td>
<td>Vertebral Unit</td>
</tr>
<tr>
<td>WALS</td>
<td>Work Activity Limitations Scale</td>
</tr>
<tr>
<td>WHI</td>
<td>Work and Health Interview</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WLQ25</td>
<td>Work Limitations Questionnaire- 25 items</td>
</tr>
<tr>
<td>WLQ16</td>
<td>Work Limitations Questionnaire- 16 items</td>
</tr>
<tr>
<td>WLQ8</td>
<td>Work Limitations Questionnaire- 8 items</td>
</tr>
<tr>
<td>WOMAC</td>
<td>Western Ontario and McMaster Universities Osteoarthritis Index</td>
</tr>
<tr>
<td>WPAl-GH</td>
<td>Work Productivity and Activity Impairment- General Health</td>
</tr>
<tr>
<td>WPSI</td>
<td>Work Productivity Short Inventory</td>
</tr>
<tr>
<td>WRF/WL26</td>
<td>Work Role Functioning Questionnaire/Work Limitations- 26 items</td>
</tr>
<tr>
<td>WSS</td>
<td>Workstyle Scale</td>
</tr>
</tbody>
</table>
2. Methodology Terms

**BASELINE** – The initial assessment at the start of a ‘study’. The effect of an intervention (e.g. a new tablet) can be determined by comparing baseline scores to follow up scores.

**BASIC SCIENTIFIC RESEARCH** – This term is usually used to differentiate studies involving real live patients (e.g. a trial of a new type of physiotherapy, clinical research) from work based in a test tube, in a laboratory (basic scientific research). In rheumatology we need both. Basic scientists have been responsible for much of our knowledge about what goes wrong in a joint in a patient with arthritis.

**BIAS** – Something that distorts a process. This process could be a meeting where a person’s views may be ‘biased’ favouring only one way of looking at things, or the process of some research itself where results are distorted, for example by only including patients who can attend hospital, some studies are biased and the results cannot be generalised to patients who are less mobile and cannot therefore attend hospital as outpatients.

**BIOMEDICAL RESEARCH** – Scientific research that relates and applies to clinical medicine

**BLINDED TRIAL** – The principle that if you don’t know what treatment you are on (maybe you get a placebo), you can’t influence the results. Single blind means that only the patient doesn’t know whether he or she gets the real drug or a placebo. Double blind means that neither the patient nor the clinician (doctor, nurse or researcher) knows.

**CASE STUDY** – Research based on one or a few patients. Case studies may be very detailed and are a good way of finding out about rare conditions or illnesses. Case studies are usually retrospective (looking back at events), not prospective (or looking forwards to events as they happen) and so are not very useful for coming to conclusions about the safety or efficacy of different treatments.

**CLASSIFICATION AND DIAGNOSTIC CRITERIA** – Illnesses, or diseases, cause patients to have different symptoms and signs and are often associated with abnormal test (investigation) results. Not all patients have exactly the same pattern of complaints. The precise constellation of these problems allows doctors and researchers to classify the various types of arthritis they treat. This is useful because it allows them to predict (to some extent) which patients will do well, and which patients may need to be monitored closely for complications of their disease.

The disease classification can be useful to recruit patients to a trial, and be sure that the patients in the trial all have a similar type or severity of arthritis. Where a patient has a pre-defined set of features, which relate to a particular disease, he or she may be said to fulfil the Diagnostic Criteria for the disease.
In the ACR 1987 Criteria for the Classification of rheumatoid arthritis (http://www.rheumatology.org/publications/classification/ra.asp?aud=mem), joint stiffness, the areas and pattern of arthritis, the presence of rheumatoid nodules, rheumatoid factor in the blood and X-ray changes should all be taken into account in classifying a patient’s disease. These are the Classification Criteria. If 4 of the 7 criteria are fulfilled, then the patient is deemed to have rheumatoid arthritis and is said to have reached the diagnostic criteria. Patients are often further sub classified according to their exact disease pattern. Many patients’ symptoms and signs do not fit into a specific set of diagnostic criteria. In these cases, doctors and patients must work together to treat the illness, but both patient and doctor may need to live with some degree of uncertainty regarding the diagnosis, or label.

**CLINICALLY RELEVANT** – A principle, fact or study that is directly applicable to patient care.

**CLINICAL TRIAL** – see also: Case Study, Cohort Study, Randomised Clinical Trial (RCT) cf. Basic Scientific Research. Usually applied to studies that have direct applicability to patients and their care, or are carried out in patients, rather than in a laboratory.

**CLINIMETRY** – The science of clinical measurement

**COCHRANE** – The Cochrane Collaboration is an international not-for-profit research organisation that aims to help people make informed decisions about health care. It is a registered charity in the United Kingdom. Its name derives from Archie Cochrane, a British epidemiologist who drew attention to our great collective ignorance about the effects of health care. He recognised that people do not have ready access to reliable reviews of the available evidence.

**COCHRANE CONSUMER NETWORK (CCN)** – The CCN’s site contains a range of health care information, and information to help people understand health care research. It is also a resource for consumers and others who want to become involved in the Collaboration or other health research activities. More information: www.cochraneconsumer.com

**COCHRANE LIBRARY** – A collection of databases, published on disk, CD-ROM and the Internet and updated quarterly, containing the Cochrane Database of Systematic Reviews, the Cochrane Controlled Trials Register, the Database of Abstracts of Reviews of Effects, the Cochrane Review Methodology Database, and information about the Cochrane Collaboration.

**COCHRANE REVIEW** – A Cochrane Review is a systematic, up-to-date summary of reliable evidence of the benefits and risks of healthcare. Cochrane Reviews are intended to help people make practical decisions. For a review to be called a "Cochrane Review" it must be in the Parent Database maintained by the Cochrane Collaboration. The Parent Database is composed of modules of reviews submitted by Collaborative Review Groups (CRGs) registered with the Cochrane Collaboration. The reviews contributed to one of the modules
making up the Parent Database are referred by the editorial team of the CRG, as described in the CRG module. Reviewers adhere to guidelines published in the Cochrane Handbook. The specific methods used in a Review are described in the text of the review. Cochrane Reviews are prepared using Review Manager software provided by the Collaboration and adhere to a structured format that is described in The Cochrane Reviewers' Handbook.

**COHORT STUDY** – A research method concerned with observing events involving a particular group of people over time (such as a group of patients’ progress in long term treatment) in order to provide information, which is useful for identifying longer-term strategies, and treatments that are effective.

**COMPOSITE MEASURE** – Measurement instrument that combines different aspects of the disease into a single numerical value. Examples of composite measures for disease activity in RA are: Clinical Disease Activity Index (CDAI), Simplified Disease Activity Index (SDAI), Disease Activity Score (DAS) and Disease Activity Score 28 joint count (DAS28).

**CONSTRUCT VALIDITY** – Evidence that relationships among items, domains, and concepts conform to *a priori* hypotheses concerning logical relationships that should exist with other measures or characteristics of patients and patient groups. (Source: FDA on PRO’s, 2009)

**CONTENT VALIDITY** – Evidence from qualitative research demonstrating that the instrument measures the concept of interest including evidence that the items and domains of an instrument are appropriate and comprehensive relative to its intended measurement concept, population, and use. Testing other measurement properties will not replace or rectify problems with content validity. (Source: FDA on PRO’s, 2009)

**CONTROL GROUP** – see: controlled study

**CONTROLLED STUDY** – Early in the development of clinical research it became clear that it can be very difficult to disentangle the real effect of an intervention or treatment from the natural background variation in the way patients feel. In other words patients may feel better or worse and it is nothing to do with the study treatment. To address this problem, study designers often observe patients or volunteers who have not been given the active treatment and compare their progress with those that have. The former group is termed a control group and such a study a controlled study. To minimise *bias* such studies are often randomised (there is an equal chance of any individual being allocated to either the active or the control group) and (double or single blind) *placebo* controlled.

**CRITERION VALIDITY** – The extent to which the scores of a PRO instrument are related to a known *gold standard* measure of the same concept. For most PROs, criterion validity cannot be measured because there is no gold standard. (Source: FDA on PRO’s, 2009)
**CROSS-SECTIONAL** – A cross-sectional study is an observational study, in which the observations (e.g. responses to a questionnaire) are made on a single occasion. Cross-sectional studies generally focus on a single group of people representative of the population of interest. Cross-sectional studies can be a useful way of getting a lot of information quickly but are not considered as powerful as ‘prospective (or longitudinal) studies in which patients or a disease process are/is followed over time.

**DELPHI METHOD** – The Delphi Process is a means of reaching consensus through structured consultation between a group of people who may have very different perspectives and fields of expertise. It is particularly useful where there is little or no published information on the subject under consideration.

Unlike more familiar consultation methods such as steering groups, the Delphi Process doesn’t need participants to physically meet together and there is no limit on how many people can be involved. Since the process is anonymous, it avoids ‘power struggles’ because there is no opportunity for a strong individual to unduly influence the group and people can change their minds without losing face. The process also enables a combination of many opinions into a group response and can be completed in as short a time as possible. To ensure anonymity, the Delphi Process uses questionnaires. These involve a number of statements to which participants respond using a ranking system. Responses are analysed centrally and then fed back to all participants, enabling individuals to change their mind and re-rank their answers if they wish, in light of opinions expressed by the group. The process is repeated until consensus is reached. At the end, a statistical response is arrived at for each statement that equates to the strength of opinion felt by the group. The result can then be used as a benchmark for developing good practice.

**DOUBLE BLIND** – see: blinded trial

**EFFECTIVENESS** – The extent to which something actually works. In medicine this is a precise term and relates to the effect size (see below). Effectiveness of a specific treatment may be estimated from relevant research literature but many trials do not include patients with co-morbidity (there might be multiple exclusion criteria) and so the effect size may be less in a typical clinical setting.

**EFFECT SIZE** – (STANDARDIZED EFFECT SIZE) – A simple way to determine the degree of improvement (or otherwise) of a particular therapy after any placebo effect has been accounted for. The effect size is calculated as the ratio of the treatment effect (mean differences in treatment group minus differences in placebo group) to the pooled standard deviation of these differences.

**EFFICACY** – The extent to which a treatment improves outcomes under ideal circumstances, for example the maximum effect in patients who didn’t experience side effects and took all prescribed drugs.
EFFICIENCY – (A statistical measure). The mean (average) change in the measure divided by the standard deviation (a statistical measure of spread) of the change.

EMPIRICAL – A treatment derived from experiment and observation rather than theory. In practice this term applies to treatments based upon the individual’s clinician’s experience and judgement.

EVIDENCE BASED MEDICINE – Evidence-Based Medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgement that individual clinicians acquire through clinical experience and clinical practice. By best available external clinical evidence we mean clinically relevant research, often from the basic sciences of medicine, but especially from patient centred clinical research into the accuracy and precision of diagnostic tests (including the clinical examination), the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative, and preventive regimens. External clinical evidence both invalidates previously accepted diagnostic tests and treatments and replaces them with new ones that are more powerful, more accurate, more efficacious, and safer.

There are 4 levels of evidence:
1. Meta-analysis
2. Controlled trials (RCT’s)
3. Observational trials
4. Expert opinions

EXCLUSION CRITERIA – Pre-defined factors that exclude a subject from a trial. For example: Clinical studies often exclude patients that would be unable to attend for review for any reason. Many studies exclude subjects of less than 18 years old.

FACE SCALE – [gets around language barriers/translation, e.g. fatigue and tiredness mean the same thing in Dutch and Swedish]

FOCUS GROUP – A research method of gathering information from people while they are discussing a subject in small groups.

HAWTHORNE EFFECT – [The Hawthorne study, lighting and heating in a factory]
HEALTH INEQUALITY – A difference in health or health status between groups of people defined by social factors such as ethnicity, gender, social class, etc. Health inequity describes a difference in health or health status between groups that can be avoided or changed, but is also considered unfair or unjust (see M. Whitehead: The concepts and principles of equity and health. Health Promotion International 1991;6(3):217-28). Health equity, then, is a situation in which all people have the opportunity to attain the best health possible and avoidable differences in health are minimized.

HYPOTHESIS – A proposed mechanism that might explain a known fact or observation. A hypothesis may be tested by a well-designed research protocol. Unlike a theory it is not supported by direct evidence, rather it is the question we are asking in our research study.

INCLUSION CRITERIA – The predefined characteristics that allow a subject to be entered for consideration for a trial. In a study of osteoarthritis, inclusion criteria might be determined as pain on most days of 1 month and definite radiographic evidence of osteoarthritis of the affected joint.

INFORMED CONSENT – The decision by a person to give or not give permission for an action affecting them. The decision is based upon having all the information bearing on the situation including the advantages, disadvantages, and the various consequences involved.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING – ICF – refers to the International Classification of Functioning, Disability and Health. The ICF, which was approved by the World Health Assembly in 2001, is a conceptual model and classification system that comprehensively describes the functioning of patients. The ICF recognizes the environmental factors and personal factors that may influence the level of functioning and societal involvement of patients. The ICF is also a classification system which describes functioning of patients using so-called ICF categories or “descriptors”.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING ACTIVITIES AND PARTICIPATION – a component of the ICF which refers to the execution of a task or action by an individual (activity) and the involvement in a life situation (participation). Examples include lifting, walking, self-care, housework, and paid employment among others.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING BODY FUNCTIONS – a component of the ICF which refers to the physiological and psychological functions of body system. Examples include pain, energy, sleep, emotion, and muscle power among others.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING BODY STRUCTURES – a component of the ICF which refers to the anatomical parts of the body such as organs, limbs and their sub-structures. Examples include hip joint, ligaments, and cervical vertebral column among others.
INTERNATIONAL CLASSIFICATION OF FUNCTIONING CONTEXTUAL FACTORS – refer to both the Environmental Factors and Personal Factors

INTERNATIONAL CLASSIFICATION OF FUNCTIONING CORE SETS – refers to a short list of ICF categories or “descriptors” (from the ICF components Body Functions, Body Structures, Activities and Participation, and Environmental Factors) that are found to be relevant to a particular health condition or health-related event. ICF Core Sets are derived from quantitative and qualitative studies. For example, the ICF Core Set for Rheumatoid Arthritis consists of ICF categories that can be used in the assessment or study of patients with rheumatoid arthritis.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING ENVIRONMENTAL FACTORS – a component of the ICF which makes up the physical, social, and attitudinal environment in which people live and conduct their lives. Examples include drugs, health services, and attitudes of family among others.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING PERSONAL FACTORS – a component of the ICF which refers to the particular background of an individual’s life and living, and comprise features of the individual that are not part of a health condition or health states. Examples include age, gender, habits, profession, upbringing, and overall behavior pattern and character style among others.

LONGITUDINAL OBSERVATIONAL STUDIES – LOS – Measurements made repeatedly over a long period of time, sometimes decades.

MEDLINE-REVIEW – National Library of Medicine’s premier bibliographic database. It contains 9 million records of bibliographic citations and author abstracts from approximately 3.900 current biomedical journals. Direct access: www.annrheumdis.com

META-ANALYSIS – The process of combining the data from a number of independent studies (usually drawn from the published literature) and synthesizing summaries and conclusions addressing a particular issue. It aims to utilise the increased power of pooled data to clarify the state of knowledge on that issue. Meta analysis is often used in systematic reviews of effect studies of medical therapies to evaluate therapeutic effectiveness. The Cochrane Reviews are meta-analyses.

MINIMAL CLINICALLY IMPORTANT DIFFERENCE – A minimal clinically important (or relevant) difference (MCID) can be defined as the smallest difference in score on an outcome measure (e.g. pain, disability, quality of life), which patients perceive as beneficial. This MCID can be used as a criterion to assess if a therapy has potential beneficial effects. (See Jaeschke R, Singer J, Guyatt GH. Measurement of health status: ascertaining the minimal clinically important difference. *Control Clin Trials* 1989;10:407–15)
OUTCOME – The effect of treatment on a patient, which may be measured in a number of ways. Objective measures (outcomes) are independent of the opinion of the patient, e.g. radiologic joint damage (X-rays), biological blood tests (rheum factor, serum levels of MMPs, ECR and CRP). More subjective outcomes are based on the experience or opinion by the patient, e.g. questionnaires like HAQ. Outcome expectancy is a belief that certain behaviour will lead to a certain outcome (e.g. pacing one’s lifestyle will lead to reduced fatigue) and is based on the patient’s knowledge of RA management.

PARADIGM – A way of thinking about a particular problem or issue. For example one paradigm for the management of rheumatoid arthritis centres on early ‘aggressive’ drug treatment to improve the long-term outlook for patients.

PEER REVIEW – Research proposals and results are usually reviewed by a number of independent people who never the less have an interest in research, so that data, information and methods can be verified from a range of perspectives. Consumers often act as peer reviewers. They may not feel able to comment on the research method, but will have very valuable views about whether the research topic is an important one for consumers, and whether the research involves consumers in an appropriate way.

PLACEBO – A sham treatment. If the treatment is a tablet or capsule it will contain no active ingredient. The best placebos are identical to the real drug and help to maintain blinding in either single or double blind trials. Placebos are used to help separate the real effect of the active ingredient from any benefit (or side effects) that the subject may experience by chance or purely by the acting of taking tablets.

PROSPECTIVE STUDY – A study where patients are selected before any data collection starts.

PROTOCOL – The plan or set of steps to be followed in a study. A protocol for a systematic review for example should describe the rationale for the review, the objectives, and the methods that will be used to locate, select and critically appraise studies, and to collect and analyse data from the included studies.

QUALITATIVE RESEARCH – Research that gathers information, which is varied, in-depth and rich. The information sought is about how something is experienced and not specifically about facts and figures. Information from qualitative research is often more difficult to interpret, partly because it cannot be ‘measured’. The emphasis is on the quality and depth of information. These data might be collected in the form of in-depth interviews with patients. The interviews are taped and the transcripts are systematically analysed to see what ideas emerge.
QUANTITATIVE RESEARCH – Deals with facts, figures and measurements, and produces data which can be readily analysed. Measurable data is gathered from a wide range of sources, and it is the analysis and interpretation of the relationships across this data that gives the information researchers are looking for. These data are collected using numbers, perhaps through answers to questionnaires. The numbers are then examined using statistical tests to see if the results have happened by chance.

RANDOMISED CONTROLLED TRIAL – (RCT) (Synonym: randomised clinical trial) - An experiment in which investigators randomly allocate eligible people into (e.g. treatment and control) groups to receive or not to receive one or more interventions that are being compared. The results are assessed by comparing outcomes in the treatment groups and control groups.

RESPONSIVENESS – The ability of an instrument (methods, questionnaire etc.) to measure a significant change in disease-activity over time. The ACR and the Eular recommend different response criteria (or improvement criteria). Their criteria have comparable validity in RA. See also: Anke M. van Gestel et al. “ACR and Eular improvement criteria have comparable validity in RA trials”, J. Rheumatol 1999;26:3:705-711.

RETROSPECTIVE STUDY – A study where patients are selected then their medical records are used to find out what has happened to them.

SELF-EFFICACY – A belief that you could do something if you wanted to, for example, a belief that you could manage, or help to alleviate your pain by using a hot/cold compress. A high self-efficacy for a task may mean that you are more likely to try it out. Bandura A. defined self-efficacy as a belief in one’s ability to carry out a task, rather than a measure of whether or not one actually can or does perform it. Psychological Review 1977;84:2: 191-215

SENSITIVITY – This is the opposite of specificity: the extent to which a test gives ‘abnormal’ outcomes in ill people. A sensitive test gives only a few ‘false-negative’ outcomes. Sensitivity and specificity are interchangeable within one test by shifting the break off point.

SIGNIFICANT – What is a significant difference (improvement or change in disease activity)? It is important to know how many patients actually improved, i.e. is a good group result based on a large number of patients improving moderately, or on a small number of patients with a considerable improvement? In research, statistical tests will show whether a result arose by chance, or whether it is unlikely to have happened by chance and can therefore be said to be significant (eg a statistically significant change in pain on a new drug).

SMALLEST DETECTABLE DIFFERENCE – The SDD that can be seen on an X-Ray. Used as a basis for measuring Minimal Clinically Important Difference (MCID).

SPECIFICITY – A classical term in epidemiology, which means the extent to which a test gives ‘normal’ outcomes in healthy people. A specific test gives only a few ‘false-positive’ outcomes.
**SYSTEMATIC REVIEW** – A review of a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant research, and to collect and analyse data from the studies that are included in the review. Statistical methods (*meta-analysis*) may or may not be used to analyse and summarise the results of the included studies. See also: *Cochrane Review*.

**VALIDITY** – (external) – The extent to which the research findings can be generalised to the wider population of interest and applied to different settings. (Bowling, 1997).

**VALIDITY** – (internal) – The ability of an instrument (method, questionnaire) to measure what it has to measure (or what we think or expect to measure). This is what is called “truth” in the OMERACT filter. The validity of an instrument is not obvious. For example: RA patients do have high scores on some depression questionnaires. Not because they are depressed, but as the results of questions like: “I always have a slow start in the morning”, “I often feel tired” and “I can’t do the same as before”. For this reason one has to conclude that such a questionnaire is not valid for RA patients.

**VARIABLE** – (synonym: factor, outcome) – A variable is a factor you measure, such as pain, depression, disability, CRP. Different variables are measured in different ways for example:

- Dichotomous or ‘yes/no’ answers (e.g. alive or dead)
- Continuous measurements (e.g. length can be 61cm or 61.25 cm or 61.257 cm)
- Discrete measures have to be whole numbers (e.g. number of children cannot be 1.6!)
- Categories such as blue or green, no pain or some pain

Variables can also be labelled as:

- Primary – the main question the study is asking (e.g. change in pain)
- Secondary – the next question you would like to ask (e.g. change in disability)
- Clinical – health status, e.g. pain, disability
- Demographic – details such as age, gender, education level
- Confounding – variables which might confuse your answer (e.g. there seems to be an association between alcohol and lung cancer. But this does not mean alcohol causes lung cancer. The link is really between smoking and lung cancer - alcohol confounds or confuses the issue because people who drink alcohol are more likely to smoke and therefore get lung cancer
3. Rheumatology and Other Terms

ADHERENCE – see: Compliance

ALDOLASE – an enzyme (protein controlling biochemical reactions) that cleaves (split, cut path through or penetrate) an aldol (organic compound).

ADVERSE EVENTS – Side effects of a treatment

ANTI-TNFα – ANTI-TUMOUR NECROSIS FACTOR
TNF is a chemical made by the body’s immune system. When it is made in the joints it causes the process of inflammation and joint damage, as seen in rheumatoid arthritis. It was first discovered many years ago in experiments on cancer, where it was found to cause cancer cells to die, and so it was called Tumour Necrosis (i.e. the death of a piece of bone or tissue) Factor. In some patients with arthritis, treatment with anti-TNF removes the TNF from the joints and diminishes the inflammation. Whilst the results of using these drugs, Infliximab (Remicade) and Etanercept (Enbrel) are encouraging, they are not suitable for everyone.

BIOMARKER – A biomarker is something that can be measured (relatively) easily which tells us information about the presence, severity or progress of a disease process. It is usually thought of as a chemical that can be measured in blood or urine, but it could be other things. A common biomarker used in rheumatology is blood measurement of CRP (C-reactive protein). The blood concentration increases when there is more inflammation in the body. Most biomarkers provide only a rough indication of the process they are being used to measure, and very few are effective at predicting the future progress of disease.

BIOLOGICS – A new category dmard’s based on the latest biomedical research. Examples are the anti-TNFαdrugs.

BONE AND JOINT DECADE – The Bone and Joint Decade encompasses musculo-skeletal disorders such as, joint diseases, osteoporosis, osteoarthritis, rheumatoid arthritis, low back pain, spinal disorders, severe trauma to the extremities, crippling diseases and deformities in children.
The goal for the Bone and Joint Decade is to improve the health-related quality of life for people with musculo-skeletal disorders throughout the world.
They will do this through the following aims:
* To reduce the social and financial cost of musculo-skeletal disorders to society
* To improve prevention, diagnosis and treatment for all patients
* To advance research on prevention and treatment
* To empower patients to make decisions about their care
The Bone and Joint Decade is a multi-disciplinary initiative involving everyone concerned with the care of bone and joint disorders. The initiative was instigated by a group of healthcare professionals who felt that the significant impact from bone and joint disorders on
society, the healthcare system and the individual, needed to be addressed on an international level, with particular focus on the use of resources. An inaugural consensus meeting was held in Sweden in April 1998, which culminated in a proposal for the Decade of the Bone and Joint from 2000 to 2010 as well as the formation of the International Steering Group, consensus document and a plan of continued work. It has an International Steering Committee of 13 members (including both professional and patient organisations) and National Action Networks have been established in 52 countries.

**BRM – BIOLOGICAL RESPONSE MODIFIER** – The Biological response modifier is a type of Rheumatoid Arthritis treatment that is designed to block specific cells in the immune system such as cytokines, TNF alpha or interleukin-1. The treatment is administered by injection.

**CBT – COGNITIVE BEHAVIOURAL THERAPY** – The aim of Cognitive Behavioural Therapy is to help people understand that their negative beliefs or 'negative self-talk' are often inaccurate and can lead to self-defeating emotions and behaviours. Aaron Beck developed cognitive therapy; putting forward the view that emotions and behaviours are primarily determined by what or how a person thinks. It is particularly relevant in treating depression, where thoughts of low self-worth and low self-esteem are common. It works on the premise that thoughts of low self-worth are inaccurate and are due to faulty learning. The aim of therapy is to challenge these inaccurate, negative thoughts to help people feel better emotionally.

**CCP – ANTI-CYCLIC CITRULLINATED PEPTIDE ANTIBODIES** – (anti-CCP antibodies) have been identified as highly specific for rheumatoid arthritis and are therefore very useful for early diagnosis of RA.

**CHRONIC** – Describes a disease or condition that persists throughout a person’s life and must be managed because it cannot be cured.

**COMET** – The COMET (Core Outcome Measures in Effectiveness Trials) initiative brings together people interested in the development and application of agreed standardised sets of outcomes, known as ‘core outcome sets’. These sets represent the minimum that should be measured and reported in all clinical trials of a specific condition, and are also suitable for use in clinical audit or research other than randomised trials. The existence or use of a core outcome set does not imply that outcomes in a particular trial should be restricted to those in the relevant core outcome set. Rather, there is an expectation that the core outcomes will be collected and reported, making it easier for the results of trials to be compared, contrasted and combined as appropriate; while researchers continue to explore other outcomes as well. COMET aims to collate and stimulate relevant resources, both applied and methodological, to facilitate exchange of ideas and information, and to foster methodological research in this area.
COMORBIDITY – The existence of two chronic diseases in one person at the same time, for example, a patient with the joint disease Rheumatoid Arthritis and the skin disease Psoriasis.

COMPLIANCE – (Same as Adherence) How well the patient complies with an agreed treatment plan.

CONCOMITANT – (therapies) – Other treatments used at the same time as the treatment under investigation. They may be for the same condition or for unrelated conditions.

CONNECTIVE TISSUE – Joints, bones, cartilage and other tissue that supports and holds together different parts of the body.

COPING STRATEGIES – (PASSIVE COPING) – The way that people react to radical events (life-strains of stressors). People who have a chronic disease have to deal with the pain and stresses of their disease, e.g. uncertainties about the future, problems at work and in daily life, etc. When people experience an event as stressful, they begin to make efforts to ‘cope’ with that event. Coping is the process of attempting to manage demands that are seen as taxing or exceeding one’s resources. People can use various coping strategies. Two general types of coping strategies can be distinguished: strategies aimed at solving problems (problem-focused coping) and strategies aimed at controlling emotional reactions to a stressful event. Examples of problem-focused strategies people can use are problem-solving or information seeking. Emotion-focused strategies are for instance seeking of emotional support, venting of feelings, avoidance or denial. Coping strategies are of great importance in relation to the extent of the negative influence the disease has on the patient. Research has shown that people who react in an active way to the consequences of their disease, are more effective than people who react in a passive way. Lit. e.g. S.E. Taylor. Health Psychology, Boston: McGrawHill, pp. 218-230.

CORTICOSTEROID – A medication used for relief of inflammation and pain, sometimes called steroids.

CPK – CREATINE PHOSPHOKINASE – The CPK isoenzymes (functionally identical enzyme) test measures the different forms of creatine phosphokinase (CPK) in the blood (when CPK is present in the blood it indicates muscle damage). CPK is an enzyme found mainly in the heart, brain, and skeletal muscle.

CRP – C Reactive Protein is a substance produced by the liver that is only present during acute inflammation; a test often used in the diagnosis of Rheumatoid Arthritis.

CYTOKINES – Cytokines are immune system cells (found in synovial fluid) that have been linked to the Rheumatoid Arthritis disease process of inflammation and cartilage destruction.
**DEPRESSION** – Depression is a disorder of mood, characterized by sadness and loss of interest in usually satisfying activities, a negative view of the self and hopelessness, passivity, indecisiveness, suicidal intentions, loss of appetite, weight loss, sleep disturbances, and other physical symptoms. Some or all of these symptoms may be present in people suffering from depression.

**DISEASE ACTIVITY** – Signs and symptoms caused by inflammation due to rheumatoid arthritis. Rheumatologists use cut-off points to delineate different levels of disease activity. They often distinguish four states of disease activity: High, moderate, low or remission. A common definition of these four states is currently not available; the definition depends on the instrument that is used.

**DMARD** – Disease Modifying Anti-Rheumatic Drug, designed to slow the progression of Rheumatoid Arthritis by slowing down structural damage to the joints.

**DOMAIN** – Domain is an area of health, or which can impact health, such as pain, stiffness, physical function, relationships, emotional well-being, social activities. A tool / questionnaire instrument developed to measure treatments will often include number of domains. E.g. see DRP - Carr’s Disease Repercussion Profile.

**EMPOWERMENT** – Is a much abused and devalued word. Here we use it to mean making it possible for people who are disempowered to exercise power and have more control over their lives. That means having a greater voice in institutions, agencies and situations, which affect them.

**ENTHESITIS** – also called **ENTHESOPATHY** – is a condition that affects the entheses (the sites where tendons or ligaments insert into the bone). The entheses are any point of attachment of skeletal muscles to the bone, where recurring stress or inflammatory autoimmune disease can cause inflammation. One of the primary entheses involved in inflammatory autoimmune disease is at the heel, particularly the Achilles tendon. It is associated with plantar fasciitis and HLA B27 arthropathies like AS and PsA.

**EROSIONS** – In rheumatoid arthritis, synovial inflammation and synovial hyperplasia make the synovium invade and eat into the cartilage and bone at the joints. On an x-ray, the bones can be seen to have damaged areas caused by this invasion, and they look like little bites out of the corners of the bones. These are called erosions. Sometimes this term is used for other forms of imaging, such as MRI scans, but this is a much less precise use. Sometimes 'erosions' is used to describe any little bite out of a bone seen on an x-ray in any condition, but this also is a much less precise use.
ESR – ERYTHROCYTE SEDIMENTATION RATE – The ESR is a test to measure how quickly red blood cells fall to the bottom of a tube. A faster rate indicates the presence of nonspecific inflammation. Nonspecific means the test does not identify the source of the problem or illness causing the inflammation. It is sometimes called the ‘sed rate’ for short. The ESR is one of the most widely used laboratory tests to assess inflammation in Rheumatoid Arthritis.

FEASIBILITY – One of the three components of the OMERACT filter, along with truth and discrimination. A test must be feasible (i.e. not costly in time, effort or finance) otherwise it may be too difficult or too expensive to complete. For example, if an outcome measure included 300 questions which patients must answer, then that would be considered too physically taxing and therefore not be feasible. Similarly, if an outcome measure took a clinician one hour to complete for each patient, then that too would not be feasible because of the excessive time and expense.

GRAPPA – An organisation, formed in 2003, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), is an example of international collaboration. The first meeting of this group took place in August 2003 in New York City followed by meetings, including discussions held in a psoriatic workshop at the seventh meeting of Outcome Measures in Rheumatology (OMERACT) in May 2004. GRAPPA counts in 2005 over 125 physicians and other individuals who have a dedicated interest in clinical care, education, and research involving patients with psoriasis and PsA. The mission of GRAPPA includes the following elements:
• increasing awareness and early diagnosis of psoriasis and PsA
• development and validation of research assessment tools to measure clinical status and disease outcome
• evaluation of treatment modalities
• supporting and conducting basic research on disease pathophysiology
• fostering communication between rheumatologists, dermatologists, representatives of patient advocacy organisations, biopharmaceutical companies, regulatory agencies, and others who are interested in the advancement of care of psoriasis and PsA.

IBM – INCLUSION BODY MYOSITIS – (inflammation of your skeletal muscles, which are also called the voluntary muscles. These are the muscles you consciously control that help you move your body)

IDIOPATHIC – Disease or condition of unknown course or which arises spontaneously

INTERLEUKIN 1 – IL-1 is one of the pro-inflammatory cytokines in the immune system thought to play a role in the disease process of Rheumatoid Arthritis, including bone erosion; the IL-1 receptor is the target of a new Biological Response Modifier, Anakinra.
**INFLAMMATION** – The body’s response to tissue injury or foreign substances that usually produce symptoms of heat, swelling, redness and pain.

**LIFE IMPACT MEASURES** – Consequences of diseases such as arthritis can be seen very close to the underlying problem (for example pain and swelling in a particular joint), in the whole person with the disease (for example ability to perform activities of daily living like washing and dressing), or in the way the person functions in society (for example, they cannot do the shopping or go to a dance with their friends). Tools, such as questionnaires, used to measure these broader effects of a disease on life as a whole have been called life impact measures.

**MYOSITIS** – Myositis is a rare disease, (thought to an auto-immune disease) in which the muscle fibers and skin are inflamed and damaged, resulting in muscle weakness. There are several types of myositis that affect different parts of the body. The persistent inflammation that is associated with myositis develops slowly over weeks to months and often years, with progressive weakening of the muscles. Later in the course of the disease development muscle wasting or shortening (contracture) may develop. Myositis can range in severity from mild to debilitating. (Also see Polymyositis or Dermatomyositis)

**MULTI-DISCIPLINARY** – A team which includes a patient and all of the health professionals involved in the patient’s care.

**NSAID** – Non-Steroidal Anti-Inflammatory Drugs help relieve pain and swelling. They include aspirin, ibuprofen and cox-2 inhibitors.

**PATIENT REPORTED OUTCOME** – A patient reported outcome, often shortened to PRO, is any consequence of an illness reported by patients. Examples include pain, disability, inability to work normally, becoming fatigued, etc.

**PM –POLYMYOSITIS** – inflames and weakens muscles in many parts of the body, and especially those parts closest to the trunk. With polymyositis, dysphagia (difficulty, pain or discomfort in speaking or swallowing), fatigue and pain in the muscles are common. PM rarely affects people under the age of 20, with the peak onset between the ages of 30 and 60.

**SELF MANAGEMENT** – is defined as a constant process of behavioural choices and decision making which can be achieved by changing knowledge, skills and attitudes and initiating behaviour change. Taal E. et al Patient education and self-management in the rheumatic diseases: a self-efficacy approach. Arthritis Care Res 1996;9:229-38.

**SOCIAL SUPPORT** – The interpersonal relations that offer information, emotional relief, material aid and self-reliance (Revenson and Gibofsky, 1995). Although assessment scales such as the SS-A (Social Support Appraisals Scale) and SS-B (Social Support Behaviours Scale) have been developed, it is not yet possible to comprehensively measure the main components of the support a person receives from family and friends.
SYNOVITIS – Synovitis is inflammation in the synovium, which is the name of the lining inside most of our joints (and also along the course of some of our tendons). Synovitis occurs in many types of arthritis, and is due to entry into the synovium of inflammatory immune system cells from the blood. In rheumatoid arthritis there is a mixture of synovitis and overgrowth of the synovial cells themselves - called synovial hyperplasia.

SYNOVIAL – The synovium is a thin, delicate structure which lines the outside of a joint and makes molecules which lubricate the joints to enable the joint to move smoothly. It also provides nutrients to cartilage.

SYSTEMIC – A systemic condition affects the whole or many parts of the body.

T-CELLS – T-cells are a type of white blood cell which defend the body against disease but sometimes they start attacking the body's own tissue as in rheumatoid arthritis.

TOKENISM – It is about having a patient on the research committee just to be politically correct. You take very little notice of them and dismiss much or all of their contribution; they may even just sit there and not be facilitated to contribute, i.e. including them is only a token gesture, not genuine, valued inclusion!
4. OMERACT, Core Sets and Other Criteria

ACR CORE SET – for clinical trials in rheumatoid arthritis (this is identical to the WHO-ILAR core set).

The American College of Rheumatology (ACR) has determined a set of outcome criteria for Rheumatoid Arthritis (RA). This set uses seven measures:

1. Tender joints
2. Swollen joints
3. Pain, according to the patient (VAS or Lickert scale)
4. Disease activity, according to the patient (VAS or Lickert scale)
5. Disease activity, according to the consultant (VAS or Lickert scale)
6. Functions in daily life (for example assessed by the HAQ)
7. Acute Phase Reactant (CRP or blood sedimentation)

If a patient improves 20% or more regarding the amount of tender and swollen joints (criteria 1 and 2) and improves 20% or more regarding at least three of the other five criteria, we talk about an ACR20-response. Improvements of at least 50% or at least 70% are indicated as ACR50-response and ACR70-response. See: Felson et al. “The ACR preliminary core set of disease activity measures for RA clinical trials” in: Arthritis Rheum 1993;36:729-40. And: Felson et al. “ACR preliminary definition of improvement in RA” in: Arthritis Rheum 1995;38:727-35.

ACR RESPONSE CRITERIA – In clinical trial for rheumatoid arthritis, standard criteria to compare the effectiveness of various arthritis medication or arthritis treatments, or to compare one trial to another trial has become widely used. The criteria, known as ACR Criteria, is referred to in nearly all published studies assessing efficacy. ACR criteria is indicated as ACR 20, ACR 50, and ACR 70. ACR criteria measures improvement in tender or swollen joint counts and improvement in three of the following five parameters:

• acute phase reactant (such as sedimentation rate)
• patient assessment
• physician assessment
• pain scale
• disability/functional questionnaire

ACR 20 RESPONSE – An ACR 20 response requires a patient to have a 20% reduction in the number of swollen and tender joints, and a reduction of 20% in three of the following five parameters: physician global assessment of disease, patient global assessment of disease, patient assessment of pain, C-reactive protein or erythrocyte sedimentation rate, and degree of disability in Health Assessment Questionnaire (HAQ) score.

ACR 50 RESPONSE – An ACR 50 response requires a patient to have a 50% reduction in the number of swollen and tender joints, and a reduction of 50% in three of the following five parameters: physician global assessment of disease, patient global assessment of disease, patient assessment of pain, C-reactive protein or erythrocyte sedimentation rate, and degree of disability in Health Assessment Questionnaire (HAQ) score.

ACR 70 RESPONSE – An ACR 70 response requires a patient to have a 70% reduction in the number of swollen and tender joints, and a reduction of 70% in three of the following five parameters: physician global assessment of disease, patient global assessment of disease, patient assessment of pain, C-reactive protein or erythrocyte sedimentation rate, and degree of disability in Health Assessment Questionnaire (HAQ) score.


ASAS – treatment response criteria include various cut-offs (20%, 40%) for improvement in independent domains - spinal pain, physical function measured by the BASFI, patient global assessment and inflammation measured as the mean of the last 2 BASDAI questions (intensity and duration of morning stiffness) - and the measures can be combined into a dichotomous variable of “improved” or “not improved” after a defined intervention. A 0-10 NRS or a 0-100mm VAS can be used for each domain.

ASAS20 – treatment response is defined as improvement of ≥20% and ≥1 unit (in a scale of 1-10) in at least 3 of the 4 above domains, and no worsening of ≥20% and ≥1 unit in the remaining 4th domain. ASAS40 treatment response is defined as improvement of ≥40% and ≥2 units (in a scale of 1-10) in at least 3 of the 4 above domains, and no worsening in the remaining 4th domain. The ASAS partial remission criterion is fulfilled if the value for all four domains is below 2.
CLASSIFICATION AND DIAGNOSTIC CRITERIA – Illnesses, or diseases, cause patients to have different symptoms and signs and are often associated with abnormal test (investigation) results. Not all patients have exactly the same pattern of complaints. The precise constellation of these problems allows doctors and researchers to classify the various types of arthritis they treat. This is useful because it allows them to predict (to some extent) which patients will do well, and which patients may need to be monitored closely for complications of their disease. The disease classification can be useful to recruit patients to a trial, and be sure that the patients in the trial all have a similar type or severity of arthritis.

Where a patient has a pre-defined set of features, which relate to a particular disease, he or she may be said to fulfil the Diagnostic Criteria for the disease. In the ACR 1987 Criteria for the Classification of rheumatoid arthritis (http://www.rheumatology.org/publications/classification/ra.asp?aud=mem), joint stiffness, the areas and pattern of arthritis, the presence of rheumatoid nodules, rheumatoid factor in the blood and X-ray changes should all be taken into account in classifying a patient’s disease. These are the Classification Criteria. If 4 of the 7 criteria are fulfilled, then the patient is deemed to have rheumatoid arthritis and is said to have reached the diagnostic criteria. Patients are often further sub classified according to their exact disease pattern. Many patients’ symptoms and signs do not fit into a specific set of diagnostic criteria. In these cases, doctors and patients must work together to treat the illness, but both patient and doctor may need to live with some degree of uncertainty regarding the diagnosis, or label.

EULAR – The first European League Against Rheumatism congress took place in 1947. At that time there were 11 members. The congress was held every four years. Each year the EULAR organized a symposium. Because of the increasing number of members (42 countries in 2000) EULAR has organised a conference each year since 2000. There are scientific programs, programs for allied health professionals and for patient organisations (social league, since 1973).

EULAR CRITERIA – EULAR RESPONSE CRITERIA – The European League Against Rheumatism (EULAR) response criteria for rheumatoid arthritis (RA) can be used to assess whether an individual patient has a significant improvement of the disease activity, compared to baseline. These criteria are based on the DAS28, a clinical measure of RA disease activity that combines information from swollen joints, tender joints, the acute phase response, and general health. The EULAR response criteria classify individual patients as non-, moderate, or good responders by comparing the DAS28 on two different time points. The response criteria depend on the extent of change and the level of disease activity reached according to the table below:
DAS28 improvement →

<table>
<thead>
<tr>
<th>Present DAS28</th>
<th>&gt;1.2</th>
<th>0.6 - 1.2</th>
<th>&lt;0.6</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 3.2</td>
<td>good response</td>
<td>moderate response</td>
<td>no response</td>
</tr>
<tr>
<td>3.2 - 5.1</td>
<td>moderate response</td>
<td>moderate response</td>
<td>no response</td>
</tr>
<tr>
<td>&gt;5.1</td>
<td>moderate response</td>
<td>no response</td>
<td>no response</td>
</tr>
</tbody>
</table>


**GOLD STANDARD** – The best scale or test that we currently have to measure something. For example the HAQ is currently the gold standard for measuring disability (until someone develops a better one)

**OMERACT** – stands for ‘Outcome Measures in Rheumatology’. The acronym OMERACT was coined at the first conference held in Maastricht, the Netherlands in 1992, limited to ‘Outcome MEasures in Rheumatoid Arthritis Clinical Trials’. Since then, the OMERACT initiative has turned into an international informal network, working groups and gatherings interested in outcome measurement across the spectrum of rheumatology intervention studies. The acronym now reflects Outcome MEasures in Rheumatology Clinical Trials. OMERACT strives to improve outcome measurement through a data driven, iterative consensus process. More information: [www.omeract.org](http://www.omeract.org)

**OMERACT CORE SET** for Rheumatoid Arthritis is a minimum set of valid disease activity variables that are recommended to be used in clinical trials, to determine if a new treatment works. It consists of the following criteria:

- Pain
- Tender joints
- Swollen joints
- Function
- Patient’s opinion
- Clinician’s opinion
- X-rays

This core-set was defined during the first Omeract conferences and authorized by the ACR (published in 1993) as well as the WHO and ILAR (published in 1994). Both translated the OMERACT RA core set into different response criteria (criteria for improvement).

During OMERACT 6 patients stated that fatigue and sleep disturbance are important outcomes which had not been integrated in the RA core set.

**OMERACT FILTER** of truth (face, content, construct and criterion validity), discrimination (reliability and sensitivity to change) and feasibility. If a scale (outcome measure / questionnaire) passes these tests it is valid for use. First published by Maarten Boers et al. “The OMERACT filter for outcome measures in rheumatology”. J Rheumatol 1998;25:198-9.

**OMERACT MODULE** – ‘Workshop style’ session during and OMERACT conference where the aim is: *To reach consensus about a set of uniform criteria*. Modules are more substantial than an OMERACT Workshop. They involve small group as well as plenary meetings to talk about more mature topics. It is expected that modules will have specific areas to review and that some level of closure will be reached in modules during any one OMERACT meeting although it may require several meetings to finalize an entire agenda, particularly if new research needs to be performed. As with most of the OMERACT sessions (apart from SIGs), all OMERACT delegates participate, as there are no overlapping sessions.

**OMERACT MODULE UPDATE** – A workshop style session on a topic, which in previous years had been a full OMERACT Module.

**OMERACT PROCESS** – The goal of OMERACT is to develop instruments to evaluate (‘measure’) different treatments in a comparable way. This is possible when researchers all over the world use the same outcome-measurements (endpoints, criteria). This set of important criteria is called a *core-set*. OMERACT follows a process in which this goal can be attained. By biannual conferences experts on methodology, rheumatology, scientific research, patients and people from governmental drugs administrations try to develop consensus on the best use of measurement instruments. Parts of this process are preparatory papers, workshops, modules and interactive plenary (voting) sessions. After each conference the results are separately published in different international journals and participants start working on the next research agenda.

**OMERACT SPECIAL INTEREST GROUP (SIG)** – The SIGs are designed to bring together people who have an interest in a specific research topic, some of whom will already have formed small working group. It is the initial step towards developing a research agenda and may at a later stage lead to an OMERACT Workshop. The SIGs are smaller group sessions.
OMERACT WORKSHOP – To explore a certain topic and to set up a research agenda. An OMERACT Workshop is a several hour session during and OMERACT conference consisting of small group work, which would be used to define a specific area in Rheumatology that needs outcome measures for clinical trials to be defined; however, there is generally little work done up to the time the Workshop is held. Thus this would be work to initiate a more robust approach subsequent to defining and drawing up a research agenda.

REMISSION – Remission in RA is defined as a state of disease activity without any (significant) signs of inflammation. Clinical remission is based on the views of the patient regarding their symptoms, examination of the joints, and results of laboratory tests. The rheumatologist using a variety of instruments that measure disease activity can do this. When the score is below a set value the patient is in a state of remission (e.g. when a Disease Activity Score for rheumatoid arthritis is less than 2.6 a person may considered to be in remission). Clinical remission does not incorporate radiographic, MRI, ultrasound or other imaging outcomes. Sustained remission is a state of remission that is maintained during a longer period of time, e.g. more than 6 months.

In 2010 ACR and EULAR developed new remission criteria for RA resulting in two proposals for more stringent criteria for use in clinical trials: One is a Boolean-based definition (this means: having only two values, usually “true” and “false”), encompassing tender joint count, swollen joint count, CRP and patient global assessment, all at levels less than or equal to 1. The other definition is the Simplified Disease Activity Index ≤ 3.3.

5. Questionnaires or Measure Instruments


**AIMS-2** – A revised and expanded version of the AIMS. It has a priority function section limited to a choice of 3 of the areas covered by the AIMS2 scales. Lit: Meenan RF et al. “AIMS2. The content and properties of a revised and expanded AIMS health questionnaire”, Arthritis Rheum 1992;35:1-10.


**ASDAS** – ANKYLOSING SPONDYLITIS DISEASE ACTIVITY SCORE – As single component measures or indices have limitations because they measure only one aspect of the disease, are fully patient or physician oriented, or lack face- and/or construct validity. ASAS has developed a composite disease activity score for use in AS, the ASDAS. The development of the ASDAS was statistically derived in analogy with the development of the DAS in RA. The development process resulted in four candidate ASDAS scores. Two ASDAS versions included both ESR and CRP, and the other two ASDAS versions include either ESR or CRP (Lukas C, Landewé R, Sieper J, Dougados M, Davis J, Braun J, van der Linden S, van der Heijde D. Development of an ASAS-endorsed disease activity score (ASDAS) in patients with ankylosing spondylitis. Ann Rheum Dis 2009;68:18–24. The ASDAS formulas with one acute phase reactant were selected by ASAS members. ASDAS with CRP was preferred, but the ASDAS with ESR can be used in case CRP data are not available. The formulas are:

1) ASDAS-CRP = 0.121*total back pain + 0.110*patient global + 0.073*peripheral pain/swelling + 0.058*duration of morning stiffness + 0.579*Ln(CRP+1).
2) ASDAS-ESR = 0.113*patient global+ 0.293*√(ESR) + 0.086*peripheral pain/swelling + 0.069*duration of morning stiffness + 0.079*total back pain.

CRP in mg/litre and all patient assessments are on a 0-10 NRS.

**BARTHEL INDEX** – This index measures the extent to which somebody functions independently (in their activities of daily living such as bathing, walking and dressing) and has mobility. It also indicates the need for care. The Barthel Index contains 15 items. Each item is assessed by four scores: function intact (1), function limited (2), assistance is needed (3) and function impossible (4). The Barthel ADL Index was first developed by Mahoney and Barthel in 1965 and later modified by Collin et al in 1988.


**BRAF** – BRISTOL RHEUMATOID ARTHRITIS FATIGUE SCALES. The BRAF-MDQ is a multidimensional questionnaire (20 items) developed with patients. This suggests there are 4 distinct domains of fatigue in RA – Living with fatigue, Physical severity, Emotional fatigue and Cognitive fatigue (thinking). The BRAF-VAS is 3 single questions that measure the severity, impact and perceived ability to cope with RA fatigue. This was the PhD thesis of Dr Jo Nicklin and the papers are currently under review.

**CIS** – CHECKLIST INDIVIDUAL STRENGTH is a 20 item questionnaire designed to measure four aspects of fatigue over the last 14 days, namely: fatigue severity (8 items), concentration (5 items), motivation (4 items) and physical activity (3 items). Each item is scored on a 7-point Likert scale: Respondents rate the extent to which each statement is true for them in the past two weeks on a seven-point Likert scale ranging from 1 = “Yes, that is true” to 7 = “No, that is not true.” The CIS has demonstrated satisfactory psychometric properties, including high internal consistency and the ability to discriminate healthy individuals, patients with CFS and patients with multiple sclerosis. Finally, the CIS has shown sensitivity to treatment intervention in a randomized clinical trial of cognitive behavioural intervention for patients with CFS. However, the dimensions of the CIS, which may well characterize clinical depression as well as CFS, have not been tested within a primary depression population. Thus it is unknown if the CIS can differentiate the two disorders. In 2006 a 4-years study started in Nijmegen to validate the CIS in RA. A score of 35 or higher on the subscale fatigue severity indicates severe feelings of fatigue. Norm scores of different patients groups and healthy controls are available. Lit: Vercoulen et al.,1994; Vercoulen JHMM et al. The measurement of fatigue in patients with multiple sclerosis: a multidimensional comparison with chronic fatigue syndrome and healthy subjects. Arch Neurol. 1996; 53:642-9; Servaes et al., 2002.

**COPM** – The Canadian Occupational Performance Measure is an outcome measure designed for use by occupational therapists to assess client outcomes in the areas of self-care, productivity and leisure. It is a measure of a client's self-perception of occupational performance in these areas. The COPM is administered using a semi-structured interview in which the client identifies significant issues in daily activities which are causing difficulty. Two scores, for performance and satisfaction with performance are obtained. (Law M, Baptiste S, McColl M, Opzoomer A, Polatajko H, Pollock N. The Canadian occupational

**DISEASE ACTIVITY SCORE** – The DAS is a scoring instrument widely used and adopted by the EULAR to assess RA disease activity. It is a criteria set that combines information from the Ritchie Articular Index, joint counts for tenderness and swelling, the erythrocyte sedimentation rate (ESR) and patient global assessment of their disease activity. The DAS has been validated both for full (DAS 44) and limited joint counts (DAS 28: foot joints are excluded). A DAS score <3.2 is regarded as low-level disease activity, a score of 3.2-5.1 as moderate and a score >5.1 as high-level disease activity. The DAS is used as a criterion for eligibility to have anti-TNF, at least in the UK and the Netherlands. The DAS was developed by Desiree van der Heijde et al. First published: “Judging disease activity in clinical practice in RA: first step in the development of a disease activity score”. Ann Rheum Dis 1990; 49:916-20. Later: “Development of a disease activity score based on judgement in clinical practice by rheumatologists” J Rheumatol 1993;20;579-81.

**DRP DISEASE REPERCUSSION PROFILE** – Carr’s Disease Repercussion Profile is an individualized measure that gives a profile of perceived impairment in 6 domains: functional activities, social activities, socio-economic status, relationships, emotional well-being, and body image. Patients specify the impairment they are experiencing in each of the domains and rate its severity on a 10 point graphic rating scale. The instrument is designed to help choose an intervention to suit patients rather than to assess outcomes of chosen interventions in groups of patients. Lit: Carr AJ, “A patient-centred approach to evaluation and treatment of RA: The development of a clinical tool to measure patient-perceived handicap”, Br J Rheumatol 1996;35:921-32.

**EFFECTIVE CONSUMER SCALE** – EC-17 is the short form of the Effective Consumer Scale. It asks 17 questions to test how effective people are at dealing with their chronic condition and making decisions about their health care. The questions cover finding and using health information, making and implementing health decisions, communicating with others, and taking a role in participating in and managing their health. Participants rate statements about knowledge, attitudes and behaviours based on how often the statements are true for them, i.e. never to always.

**EMG/NCS – ELECTROMYOGRAM AND NERVE CONDUCTION STUDIES** – An electromyogram (EMG) measures the electrical activity of muscles at rest and during contraction. Nerve conduction studies measure how well and how fast the nerves can send electrical signals.

Nerves control the muscles in the body with electrical signals called impulses. These impulses make the muscles react in specific ways. Nerve and muscle problems cause the muscles to react in abnormal ways.
**EuroQol EQ50** – *EuroQol* is primarily designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics and face-to-face interviews. It is cognitively simple, taking only a few minutes to complete. Instructions to respondents are included in the questionnaire. The EQ-5D-5L consists of 2 pages – the EQ-5D-5L descriptive system (page 2) and the EQ visual Analogue scale (EQ VAS) (page 3). The descriptive system comprises 5 dimensions (mobility, self care, usual activities, pain/discomfort, anxiety/depression). However, each dimension now has 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. See [http://www.euroqol.org/home.html](http://www.euroqol.org/home.html) for more information.

**FACIT-F – FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY FATIGUE SCALE** – is a 13-item questionnaire that assesses self reported fatigue. It gathers patient feedback about:

1. fatigued
2. Weak
3. Listless (“washed out”)
4. Tired
5. Trouble starting
6. Finishing things
7. Energy level
8. Ability to start or finish activities
9. Usual activities
10. Sleep during day
11. Need help
12. Frustrated
13. Limit social activity
14. Too tired to eat

Each item ranges from 0-4. Lower scores reflect increased fatigue. In rheumatoid arthritis, clinically meaningful (significant) improvement on this 52-point fatigue scale is defined as a four-point change. Clinically meaningful improvements have not been specifically defined for psoriatic arthritis.

Lit: Cella D, et al 2005

**FS – FATIGUE SCALE (Chalder)** – is a 14-item verbal rating measure of fatigue intensity with a four-choice response format that was developed with a sample of 374 general medical outpatients. The scale showed strong internal consistency and factor analysis yielded two dimensions, physical and mental fatigue. Physical fatigue refers to items such as “I get tired easily,” “I can no longer start anything” and “I feel weak,” while mental fatigue encompassed difficulties with concentration and memory. The Fatigue Scale has also shown sensitivity to treatment changes.

The limitations of the Fatigue Scale include its inability to distinguish between CFS and primary depression patients, an important diagnostic issue in CFS. In addition, a second factor analytic study of the Fatigue Scale in CFS patients calls into question the stability of the factor structure of the scale. Lit: Chalder T et al. Development of a fatigue scale. *J Psychosom Res.* 1993; 37:147-153. (see appendix 1)
**FSS – FATIGUE SEVERITY SCALE** (Krupp) – is composed of nine items with a seven-point response format. Sample questions include “I am easily fatigued” and “Exercise brings on my fatigue.” In the initial validation study, internal consistency for the Fatigue Severity Scale was high for specific illness groups (MS and lupus) and healthy controls. The scale clearly distinguished patients from controls and it was moderately correlated with a single-item visual analogue scale of fatigue intensity. In all patients, clinical improvement in fatigue was associated with reductions in scores on the Fatigue Severity Scale. In a recent study that compared the Fatigue Severity Scale to the Fatigue Scale, both were found to be useful measures of fatigue-related symptomatology within a general population of individuals with varying levels of fatigue. However, the Fatigue Severity Scale appeared to represent a more accurate and comprehensive measure of fatigue severity and functional disability for individuals with CFS-like symptomatology. The Fatigue Severity Scale is also a practical measure due to its brevity and ease of administration and scoring. On the other hand, a ceiling effect in the Fatigue Severity Scale may limit its utility to assess severe fatigue-related disability. Therefore, the true association between the Fatigue Severity Scale and other health-related measures may be underestimated.


**GHQ** – The General Health Questionnaire is a 12 item instrument and has been tested for reliability, validity, and sensitivity as a screening tool for mental disorder and as a measure of short-term psychological distress. Subjects score between 0 and 12, with high scores indicating high levels of distress. Lit.: Goldberg DP, Williams P., “A user’s guide to the general health questionnaire”, Windsor: Nfer-Nelson 1988.

**GENERAL SELF-EFFICACY SCALE** – The GSES is a general measure for self-efficacy. Whilst it is not disease specific, it is used for Rheumatoid Arthritis. Schwarzer R. Measurement of perceived self-efficacy. Psychometric scales for cross cultural research. Freie Universitat, Berlin, 1993.

**HAD HOSPITAL ANXIETY AND DEPRESSION SCALE** – The HAD was developed in 1983 by Zigmond and Snaith for people with physical health problems. It differs from many other measures of anxiety and depression in that it does not contain questions about physical symptoms. Many other measures include questions about symptoms such as aches and pains, loss of appetite, or inability to sleep, and treat these as indicators of depression or anxiety. Clearly this would not be appropriate for people with, say, arthritis where their aches and pains, and inability to sleep is more likely to be due to their physical illness rather than an indicator of depression. More info: www.hqlo.com/content/1/1/29

**HAQ HEALTH ASSESSMENT QUESTIONNAIRE** – HAQ – The Stanford Health Assessment Questionnaire – (the HAQ) was developed in 1980 by Fries et al. It is a measure of functional ability and is based on the belief that a patient desires to be alive, free of pain, functioning normally, experiencing minimal treatment toxicity, and financially solvent. A lot of patients have probably filled out the HAQ in clinic and it is in at least 28 languages. The
measurements are on a scale of 0 (best) to 3 (worst). It is a self-administered measure that evaluates four dimensions: disability, discomfort, drug side effects and costs. The disability section of the HAQ contains 20 questions about difficulties experienced with eight categories of activities of daily living, and four questions about the assistance used to perform these activities. The 'Modified HAQ', which contains only 8 of these questions, one from each category, is commonly used. More information: www.hqlo.com/content/1/1/20

HRQoL – The Health Related Quality of life "QoL" can be thought of as the overall impact of the illness and its treatment on patients physical, psychological and social functioning.

HUI – THE HEALTH UTILITIES INDEX – system of generic health profiles and preference-based utility measures currently comprises the HUI2 and HUI3. The HUI2 consists of seven domains which in combination describe 24,000 unique health states with valuations ranging from 1 to -0.03 (0 equals death, 1 perfect health, negative values are ‘worse than death’). The HUI3 has eight domains which describe 972,000 possible states with valuations ranging from 1 to -0.36. The HUI2 and HUI3 include negative valuations for health states rated as being worse than death. See: Horsman, J., Furlong, W., and Feeny, D. The health utilities index (HUI): concepts, measurement properties and applications. Health and Quality of Life Outcomes 2003;Oct 16;1:54.

ICER – Incremental Cost Effectiveness Ratio – Where effectiveness is measured in Quality Adjusted Life Years (see: QALYs), the Incremental Cost Effectiveness Ratio compares the cost per Quality Adjusted Life Year of two competing interventions in terms of a ratio. Thus if intervention 1 costs £32 000 per Quality Adjusted Life Year and intervention 2 costs £16 000 per QALY, the Incremental Cost Effectiveness Ratio is 32 000/16 000 = 2.

In order that fair, reasonable and justifiable decisions can be made when comparing treatments, the effects of treatments as well as the costs have to be considered. Often the way of doing this is to calculate an Incremental Cost Effectiveness Ratio. Usually a new treatment is compared with a current treatment and the ICER is calculated as: The difference in the cost of the treatments (the new minus the current treatment) divided by the difference in effectiveness of the treatments (the new minus the current).

When effectiveness is measured in Quality Adjusted Life Years the Incremental Cost Effectiveness Ratio answer is in cost per QALY gained (£ per QALY). For example if a new treatment costs £30 000 more than the current treatment but results in 3 extra Quality Adjusted Life Years then the ICER is 30 000/3 = £10 000 per QALY. By comparing ICER values (in £ per QALY) for a whole bunch of new treatments versus the current treatments (even treatments for a number of different diseases) the decision makers can be helped in figuring out which competing new treatments are worth adopting.

When two treatments are equal in effectiveness then the ICER cannot be calculated. Instead a cost minimisation analysis is done, which merely means the cheaper of the two treatments is identified and the cost difference quantified.
JPBA – Joint Protection Behaviour Assessment – was constructed by Hammond and associates to determine the effect of protection methods during everyday activities on the patient’s behaviour. It is not a questionnaire but an observational method (video-recorded and evaluated).

LFTs – LIVER FUNCTION TESTS – are groups of clinical biochemistry laboratory blood assays (analysis) designed to give information about the state of a patient's liver.

LIKERT SCALE – The Likert Scale is a type of attitudinal rating scale which asks people to show the extent to which they agree or disagree with statements. There are five to seven possible response choices. The most common scale is 1 to 5. Often the scale will be 1=strongly disagree, 2=disagree, 3=not sure, 4=agree, and 5=strongly agree. The result is obtained by calculating the average (i.e. mean) of all the results added together. Likert scales are often used in questionnaires to measure attitudes.

MACTAR – McMaster Toronto Arthritis Patient Preference Disability Questionnaire. This is an individualized functional priority questionnaire that was first published in 1987. The MACTAR is not only disease-specific but also patient-specific in that they take an individualized functional priority approach to the assessment of HRQoL in rheumatic arthritis. It asks patients to describe specific activity limitations caused by their arthritis (a top 3 or top 5) and to rank these problem areas. In order to ensure that the list of affected activities is as comprehensive as possible, a standard series of problems are read to the patient after the spontaneously generated problems. The MACTAR has undergone a number of revisions and is now also known as the Problem Elicitation Technique (PET). Lit.: Tugwell, P et al. “The MACTAR patient preference disability questionnaire – An individualized functional priority approach for assessing improvement in physical disability in clinical trials in rheumatoid arthritis. J Rheumatol 1987;14:446-51.

MAF – MULTIDIMENSIONAL ASSESSMENT OF FATIGUE SCALE is a 16 item questionnaire that measures overall impact of RA fatigue, and gives a single score. The MAF and the BRAF are the only scales that were developed specifically with RA patients.

MFI – MULTIDIMENSIONAL FATIGUE INVENTORY is a 20-item self report instrument designed to measure fatigue. It covers 5 dimensions of fatigue: general fatigue, physical fatigue, reduced activity, mental fatigue, and reduced motivation. Scores within the 5 dimensions range from 4 to 20, with higher scores indicating higher levels of fatigue. The psychometric properties of the MFI-20 have been tested in various populations and the results, by and large, support its validity. The MFI-20 has frequently been used in oncology research. It has also been applied in research on chronic conditions, e.g. Parkinson’s disease, chronic obstructive pulmonary disease, liver disease and rheumatic diseases. Lit: Smets EMA, Garssen B, Bonke B, de Haes JCJM. The Multidimensional Fatigue Inventory (MFI): psychometric qualities of an instrument to assess fatigue. J Psychosom Res 1995;39;315-25.
MHIQ – McMaster Health Index Questionnaire – A standard-item questionnaire on physical, social and emotional function.

MRI – MAGNETIC RESONANCE IMAGING – a scan which uses magnetic and radio waves, meaning that there is no exposure to X-rays or any other damaging forms of radiation. Radio waves 10,000 to 30,000 times stronger than the magnetic field of the earth are then sent through the body. This affects the body's atoms, forcing the nuclei into a different position. As they move back into place they send out radio waves of their own. The scanner picks up these signals and a computer turns them into a picture. These pictures are based on the location and strength of the incoming signals. Using an MRI scanner, it is possible to make pictures of almost all the tissue in the body.

MSS – THE MODIFIED SHARP SCORE – otherwise known as the SHARP VAN DER HEIJDE SCORE – a measure of joint damage as assessed radiographically, and based on joint space narrowing and erosions of the joints. The MSS was developed by Van der Heijde (the modification by Van der Heijde was the inclusion of foot joints), based on the original assessment method (Sharp Score) designed by Dr John Sharp which first enabled the efficacy of methotrexate in inhibiting radiographic progression to be demonstrated.

NCS – NERVE CONDUCTION STUDIES – nerve conduction studies measure how well and how fast the nerves can send electrical signals.

PASI – In the Patient Specific Index patients are asked to rate 21 complaints for severity and importance plus any additional complaints. Both severity and importance are rated on a 7 category ordinal rating scale. The score on the PASI includes only those items that the patient identifies as problems and is the sum of the products of severity and importance for each item. Since the number of problems can vary from patient to patient, scores are standardized by dividing by the maximum possible score for that patient and multiplying by 100.

- PhGA - Physician/observer global assessment;
- PtGA - Patient global assessment
(Visual Analogue Scale 1-10)
PET – Problem Elicitation Technique is a modified version of the MACTAR and allows patients to assess their ability to perform the daily physical activities most important to them. Patients continue to identify and rank their problems but are asked to rate on a VAS scale the degree of difficulty, frequency, or severity of the problem, depending on its type. Patients are also asked to rate the importance of each item on a VAS scale, and these values are used as weights. A VAS global health assessment is the final question.

PHYSICIAN GLOBAL ASSESSMENT – PhGA or PGA – Physician’s measure of disease activity in a patient from low to high disease high activity using Visual Analogue Scale (VAS) between 1-10 where 10 indicates high disease activity.

PGWB – Psychological General Well-Being Index is a self-assessed inventory related to general well-being and has been shown to be reliable and valid. The PGWB comprises 22 items with a six-point response scale. The factors of anxiety, depressed mood, positive well-being, self control, general health, and vitality are related to the total score. The subscales of these measured factors have three to five items. For each item, there are six response options that are rated on a scale of 1 to 6, according to the intensity or frequency of the affective experience. A value of 1 is given for the most negative options and 6 for the most positive options. The score range for the PGWB is 22-132; a higher score represents better wellbeing.

PMR-AS – POLYMYALGIA RHEUMATICA ACTIVITY SCORE – A measure of the severity of PMR decided on by a meeting of doctors. Made up of CRP (mg/dl) + patient severity VAS (0-10) + physician severity VAS (0-10) + minutes of patient reported morning stiffness x 0.1 + elevation of upper limb (score 0-3).


PROGRESS-Plus – This is a mnemonic used to help remember social factors that can lead to health differences between groups of people. “PROGRESS” stands for place of residence, race or ethnicity, occupation, gender, religion, education, socioeconomic status, and social network or capital. The “Plus” covers other factors such as age, disability, and sexual orientation.

QALYs – A Quality Adjusted Life Year is a measure that incorporates both health status and length of life into a single measure. A Quality Adjusted Life Year of 0 is death and 1 is one year of full health. It is used as the measurement of effectiveness of interventions. It is a useful measure of treatment effects because it allows comparisons between treatments for different diseases. For example one treatment for people with Rheumatoid Arthritis might increase joint mobility by 50% and reduce constant severe pain to mild pain occasionally, whilst another treatment for people with epilepsy might reduce seizure frequency from 80 per week to only 10 per week; how can we compare these? If the effects of both treatments are translated into health related quality of life measures (e.g. as QALYs) then they can be compared. You might ask why compare? It is because both treatments are paid for out of the
same limited pot of money and is subject of a multitude of demands. Someone (on our behalf) has to make a decision as to which treatments to finance.

**RADAI** – Rheumatoid arthritis disease activity index – The Radai is a five item patient assessed questionnaire, including arthritis pain, past and current global disease activity, duration of morning stiffness, and a tender joint list. The RADAI ranges from 0 to 10, where higher values are indicative of higher levels of RA disease activity. It has been shown to be reliable, valid, and responsive for the assessment of disease activity in RA.


**RAND-36** – A general (not disease specific) questionnaire to measure quality of life.


**RAQoL** – The Rheumatoid Arthritis Quality of Life Questionnaire is a disease specific Quality of Life instrument. It measures the impact of RA on activities of daily living, social interaction, emotional well-being, and relationships. The questionnaire consists of 30 statements that have a yes/no response. Items are scored 1 for yes and 0 for no. Scores for each item are summed to give an overall quality of life score.


**RASE** – The Rheumatoid Arthritis Self-Efficacy Scale has been developed as a measure of self-efficacy for use in British rheumatoid arthritis patients. There are 28 items and the stem question is ‘Do you believe you could do these things to help you with your arthritis.’ It uses a 5 point Likert response scale with high scores indicating high self-efficacy, i.e. strongly agree to strongly disagree, 1-5. Hewlett et al. Rheumatology 2001;40:1221-1230

**RF** – RHEUMATOID FACTOR – is a protein found in the blood of 80% of adults with Rheumatoid Arthritis. Therefore they are rheumatoid factor positive.

**RITCHIE INDEX** – A scoring system for recording joint tenderness.

**SCQM** – Swiss Clinical Quality Management in RA – The SCQM is introduced in 1997. It provides a measurement feedback system with which rheumatologists and their patients can monitor the course of RA disease activity, disability, and joint damage. Rheumatologists collect standardised clinical, laboratory, and patient data, and send them to a national coordination centre, where the data are processed in a computer and a feedback report is returned. With the help of the measurement feedback system, the individual treatment strategy can be adjusted to “titrate” RA disease activity until remission is reached or disease activity is optimally controlled.
SDAI – The Simplified Disease Activity Index is defined as number of tender joints (28) + number of swollen joints (28) plus Patient global assessment (using a 10cm VAS) plus physician global assessment (using a 10cm VAS) plus CRP (mg/dl).

SEIQoL – The Schedule for the Evaluation of Individual Quality of Life was developed by O’Boyle et al. and first published in 1991. It asks patients to list the 5 areas of life that they judge to be most important to their overall quality of life, which they then rate on a VAS. Areas can be for example family, work, leisure activities, religion and health. The SEIQoL is not a disease specific but a general measure instrument. There are two versions: the original “judgement analysis” method (-JA) and, since 1996, a quicker version called “Direct weighting” method (-DW).

SF 6D – The Short-Form 6-Dimension (SF-6D) can be derived from the SF-36, or alternatively the SF-12 generic health surveys. The SF-6D (SF-36) uses 11 of the 36 questions to create six domains, each rated with between four and six levels of severity which in combination describe a possible 18,000 states. Health state valuations range from 1 to 0.30 (on a scale where 0 equals death and 1 equals perfect health). See: Brazier, J., Roberts, J., and Deverill, M. The estimation of a preference-based measure of health from the SF-36. Journal of Health Economics 2002;21:271-292; Brazier JE, Roberts J. Estimating a preference-based index from the SF-12. Medical care 2004;42:851-859.

SF12 – Health Survey measures quality of life and is divided into a physical and mental component, with higher scores indicating better physical and mental health.

SF36 – The Medical Outcome Study Short Form 36 measures three major health attributes (functional status, wellbeing, overall health) in eight subscales. These include PF (Physical function), RP (role limitations due to physical health), BP (bodily pain), GH (general health), VT (vitality), SF (social function), RE (role limitations due to emotional health), and MH (mental health). For each variable item scores are coded, summed, and transformed to a scale from 0 (the worst possible health state) to 100 (the best possible health state). Lit: Ware JE, Sherbourne CD “The MOS 36-item Short-Form Health Survey (SF-36) I. Conceptual framework and item selection”, in: Med Care 1992;30:473-83.

SHARP VAN DER HEIJDE SCORE, see MSS.
SODA – Sequential Occupational Dexterity Assessment – This instrument has been developed at Sint Maartenskliniek Research and measures bi-manual functioning of the hands in standardised conditions. The SODA is a valid and reliable instrument to assess objective hand function, or dexterity. It was shown to be sensitive to change in patients with RA over a period of one year. The SODA was used in studies to evaluate surgical and non-surgical treatment of the hand in RA. Lit.: Lankveld et al. “The short version of the SODA based on individual task’s sensitivity to change”, Arthritis Care and Research 1999;12(6):417-424.

ULTRASOUND – also called sonography, uses sound waves to develop ultrasound images of what's going on inside the body. An instrument called a transducer emits high-frequency sound, inaudible to human ears and then records the echoes as the sound waves bounce back to determine the size, shape and consistency of soft tissues and organs.

VAS – Visual Analogue Scale – A VAS is a way of measuring by asking a person to put a mark on a line, for example a 100 mm. VAS, without scale indication. Only the endpoints are given, for example: no pain at all and extreme pain. In this way you can measure different criteria, like morning stiffness, fatigue or general well being. A Vas can be made by the consultant as well as by the patient.

VAS FATIGUE – For a global assessment of fatigue severity, one can use a 100-mm visual analog scale (VAS). For example: How would you rate your fatigue right now on a scale of 0–10, with ‘0’ being ‘no fatigue’ and ‘10’ being ‘fatigue as bad as it could be’

WOMAC – The Western Ontario and McMaster Universities Osteoarthritis Index is a self administered, disease specific instrument validated for OA. It consists of 24 items grouped into three subscales: pain (five questions), stiffness (two questions) and physical function (seventeen questions) with higher scores indicating greater disease severity. Lit. Bellamy N. “Osteoarthritis – an evaluative index for clinical trials”, Hamilton, Canada: McMaster University, 1982 (MSc thesis.).
### 6. Index

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