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CANADIAN  
ARTHRITIS  
NETWORK

LE RÉSEAU  
CANADIEN  
DE L'ARTHRITE

# **Acronyms and Glossary for Consumers Involved in Research**

**by the  
Consumer Advisory Council  
in collaboration with the  
Allied members**

## **Acronyms**

A2aR	A2a Receptor
AC	Arthritis Centres
ACAP	Alliance for the Canadian Arthritis Program <a href="http://www.arthritisalliance.com/">http://www.arthritisalliance.com/</a>
ACE	Arthritis Centre of Excellence (ON) Arthritis Consumer Experts <a href="http://www.arthritisconsumerexperts.org/">http://www.arthritisconsumerexperts.org/</a>
ACL	Anterior Cruciate Ligament
ACR	American College of Rheumatology
ACREU	Arthritis Community Research and Evaluation Unit
ACT	Arthritis Consumer Team (AB)
ADL	Activities of Daily Living
AE	Adverse Effects
AHPA	Arthritis Health Professions Association
AIMS	Arthritis Impact Measurement Scale
ANA	Antinuclear Antibody
ARA	American Rheumatology Association
ARC	Arthritis Research Campaign Arthritis Research Centre of Canada (BC) <a href="http://www.arthritisresearch.ca/">http://www.arthritisresearch.ca/</a>
ARI	Arthritis Rheumatism International
ARMA	Arthritis and Musculoskeletal Alliance
AS	Ankylosing Spondylitis
ASES	Arthritis Self-Efficacy Scale
ASMP	Arthritis Self Management Program
bACL	Bioengineered ACL
BAT	Bioartificial Tendon
BASDAI	Bath Ankylosing Spondylitis Disease Activity Index
BASFI	Bath Ankylosing Spondylitis Functional Index
BJD	Bone and Joint Decade 2000-2010 <a href="http://www.boneandjointdecade.org/">http://www.boneandjointdecade.org/</a>
BRM	Biological Response Modifier
CAB	Consumer Advisory Board (of the Arthritis Research Centre of Canada (BC)) <a href="http://www.arthritisresearch.ca/">http://www.arthritisresearch.ca/</a>
CAC	Consumer Advisory Council (of the Canadian Arthritis Network) <a href="http://www.arthritisnetwork.ca/consumer_advisory_council/cac_index.asp">http://www.arthritisnetwork.ca/consumer_advisory_council/cac_index.asp</a>
CAF	Children's Arthritis Foundation
CAN	Canadian Arthritis Network <a href="http://www.arthritisnetwork.ca/">http://www.arthritisnetwork.ca/</a>
CAPA	Canadian Arthritis Patient Alliance <a href="http://www.arthritis.ca/capa">http://www.arthritis.ca/capa</a>
CBT	Cognitive Behavioural Therapy
CCAR	Canadian Council of Academic Rheumatologists
CCN	Cochrane Consumer Network
CCP	Canadian Centre of Philanthropy
CGA	Candidate Gene Approach

CI	Confidence Interval
CIHI	Canadian Institute of Health Information
CIHR	Canadian Institute of Health Research
CJRR	Canadian Joint Replacement Registry
CMSG	Cochrane Musculoskeletal Group
COA	Canadian Orthopaedic Association
COF	Canadian Orthopaedic Foundation
COPM	Canadian Occupational Performance Measure
COX	Cyclooxygenase
CPP	Cartilage-Porous Calcium Polyphosphate
CRA	Canadian Rheumatology Association
CRP	C-Reactive Protein
CRRC	Canadian Rheumatology Research Consortium
DAP	Discovery Advancement Program
DAS	Disease Activity State (also: Das28; Das44)
DIP	Distal Interphalangeal joint
DMARD	Disease Modifying Anti-Rheumatic Drug
DRP	Disease Repercussion Profile
DTCA	Direct to Consumer Advertising
EBM	Evidence Based Medicine
ERR $\alpha$	Estrogen-Related Receptor $\alpha$
ESR	Erythrocyte Sedimentation Rate
Et al	and others (et alii)
EuroQol	Euro Quality of Life
EULAR	European League Against Rheumatism
FDA	Food and Drug Administration
FSMP	Fibromyalgia Self Management Program
FU	Follow up
GHQ	General Health Questionnaire
GLP	Good Laboratory Practice
GP	General Practitioner
GSES	General Self-Efficacy Scale
GWS	Genome-Wide Scans
HAD	Hospital Anxiety Depression Scale
HAQ	Stanford Health Assessment Questionnaire
HC	Health Canada
HCCC	Health Charities Council of Canada
HQP	Highly Qualified Personnel
HRQoL	Health Related Quality of Life
IAIS	International Association of Inflammation Societies
ICERs	Incremental Cost-Effectiveness Ratios
IJD	Inflammatory Joint Disease
ILAR	International League of Associations for Rheumatology
IMHA	Institute for Musculoskeletal Health and Arthritis
IMPACT	Initiative on Methods, Measurements and Pain Assessment in Clinical Trials

IP	Intellectual Property
IPA	Interpretative Phenomenological Analysis
IPC	Interpenetrating Phase Composite
IRA	Informatics for Research in Arthritis
IWH	Institute for Work & Health
JA	Juvenile Arthritis
JBR	Jingle Bell Run
JIA	Juvenile Idiopathic Arthritis
JIM	Joints in Motion
JPBA	Joint Protection Behaviour Assessment
JRA	Juvenile Rheumatoid Arthritis
KTE	Knowledge Translation and Exchange
KTEE	Knowledge and Technology Exchange and Exploitation
LDAS	Low Disease Activity State
MACTAR	McMaster Toronto Arthritis Patient Preference Disability Questionnaire
MCID	Minimal Clinically Important Difference
MCP	Metacarpophalangeal (the bones in fingers)
MDT	Multi Disciplinary Team
MHAQ	Modified Health Assessment Questionnaire (see: HAQ).
MHIQ	McMaster Health Index Questionnaire
MHOQ	Michigan Hand Outcomes Questionnaire
MOH	Ministry of Health
MMP	Matrix Metalloproteinases
MOS SF-36	see: SF-36
MPC	Medical Planning Committee
MRC	Medical Research Council of Canada
MRI	Magnetic Resonance Imaging
MSK	Musculoskeletal
MSS	Modified Sharp Score
MTD	Multi Disciplinary Team Mixed Tissue Disease
MTP	Metatarsal-phalangeal (joint between the end of the foot and the toes)
MTX	Methotrexate
NCE	Network Centres of Excellence
NI	Network Investigator
NIAMS	National Institute of Arthritis and Musculoskeletal and Skin Diseases
NIH	National Institutes of Health
NSAID	Non Steroid Anti Inflammatory Drug
NSERC	Natural Science and Engineering Research Council
NVHA	National Voluntary Health Agencies
NVO	National Voluntary Organizations
OA	Osteoarthritis
OARSI	Osteoarthritis Research Society International
OMERACT	Outcome MEasures in Rheumatoid Arthritis Clinical Trials
OSC	Osteoporosis Society of Canada
OT	Occupational Therapy or Therapist

PASI	Patient Specific Index
PCA	Principal Component Analysis
PDE	Phosphodiesterase
PET	Problem Elicitation Technique
PGWB	Psychological General Well-Being Index
PI	Proximal Interphalangeal (small bone in fingers and toes)
PPIA	Patient Partners in Arthritis
PT	Physiotherapy or Physiotherapist
pt	patient
PVA-C/MAAA	Polyvinyl Alcohol-Carbonate/Methacrylic Acid
QALYs	Quality-Adjusted Life-Years
R&CD	Research and Career Development
R&D	Research and Development
RA	Rheumatoid Arthritis
RADAI	Rheumatoid Arthritis disease activity index
RAND-36	see: SF-36
RASE	Rheumatoid Arthritis Self-Efficacy scale
RAQoL	Rheumatoid Arthritis Quality of Life Questionnaire
RCT	Randomized Controlled Trial
RF	Rheumatoid Factor
RHA	Regional Health Authority
RMC	Research Management Committee
RNP	Rheumatology Nurse Practitioner
RNS	Rheumatology Nurse Specialist
Rx&D	Canada's Research Based Pharmaceutical Companies
SA	Spondylitis Ankylopoetica
SAARD	Slow Acting Anti-Rheumatic Drug
SCQM	Swiss Clinical Quality Management in rheumatoid arthritis
SD	Standard Deviation (statistical measure)
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 with 36 items
SJC	Swollen Joint Count
SLE	Systemic Lupus Erythematosis
SM	Synovial Membrane
SMAC	Scientific and Medical Advisory Council
SNP	Single Nucleotide Polymorphism
SODA	Sequential Occupational Dexterity Assessment
SRI	Strategic Research Initiative
SRID	Strategic Research Initiative Development
SRR	Strategic Research Resource
SS	Sjogrens Syndrome
SS-A	Social Support Appraisals Scale-A

SS-B	Social Support Appraisals Scale-B
SSHRC	Social Sciences and Humanities Research Council
SSZ	Sulfasalazine
TAS	The Arthritis Society <a href="http://www.arthritis.ca">http://www.arthritis.ca</a>
TEC	Training and Education Committee
TJC	Tender Joint Count
THR	Total Hip Replacement
TKR	Total Knee Replacement
TNF	Tumour Necrosis Factor
TPP	Therapeutic Products Program of Health Protection Branch of Health Canada
VAC	Veterans Affairs Canada
VAS	Visual Analog Scale
WHO	World Health Organization
WOMAC	Western Ontario and McMaster Universities Osteoarthritis Index

## Glossary

ABSTRACT – A very brief summary of the research study and its results or of the research proposal. It should tell you what the study tried to show, how the researchers went about it, and what they found.

ACR CRITERIA – The American College of Rheumatology has determined a set of outcome criteria for 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.

ADENINE - One of the four nitrogenous bases in DNA and RNA. This base pairs with thymine.

ADVERSE REACTION - (Adverse Event.) An unwanted effect caused by the administration of drugs. Onset may be sudden or develop over time (See *Side Effects*).

ADVISORY COMMITTEE – A group of researchers, policy makers, healthcare professionals and service users who make decisions about *research strategy* and funding.

ADVOCACY AND SUPPORT GROUPS - Organizations and groups that actively support participants and their families with valuable resources, including self-empowerment and survival tools.

AIMS – Arthritis Impact Measurement Scale. Includes: pain, psychological functions and physical functions. First published: Meenan RF, Gertman PM, Mason JM.” Measuring health status in arthritis: the AIMS”, *Arthritis Rheum* 1980;23:146-153.

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.

ALLELE - A variation of a trait.

AMINO ACIDS - The monomers, or small organic molecule, that are put together to form proteins.

AMINOACYL attachment site - The site where an amino acid is attached to tRNA.

ANTICODON - The three nitrogenous bases complementary to a codon, located on tRNA, used to match the correct amino acids.

ANTI-TNF $\alpha$  – 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, are encouraging, they are not suitable for everyone.

APPROVED DRUGS - In the U.S., the Food and Drug Administration (FDA) - (in Canada, Health Canada) - must approve a substance as a drug before it can be marketed. The approval process involves several steps including pre-clinical laboratory and animal studies, clinical trials for safety and efficacy, filing of a New Drug Application by the manufacturer of the drug, FDA review of the application, and FDA approval/rejection of application (See *Food and Drug Administration*).

ARM – A controlled trial has at least two arms: that is, at least two groups of people experiencing different treatment. One of those is the *control* arm or group (that is, the people not receiving the experimental treatment). The experimental arms are the groups of people getting the treatment (or treatments) being tested. There might be one or more experimental arms, but there is always only one control group.

ARTHRITIS SELF-EFFICACY SCALE –The ASES consists of three subscales: pain, function, and other symptoms. Higher scores indicate better health. Lit.: Lorig K., et al. “Development and evaluation of a scale to measure perceived self efficacy in people with arthritis”, in: *Arthritis Rheum* 1989;32:37-44.

ASSESSMENT - The process of measuring one or several variables of interest in order to make decisions about individuals or inferences about a population.

AUDIT –A process used to ensure that any changes made in healthcare services are effective.

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.

BASDAI – Bath Ankylosing Spondylitis Disease Activity Index: Measures AS-specific disease activity. Range 0-10; higher values indicating higher disease activity. Lit.: Garrett S, et al. “A new approach to defining disease status in AS: the BASDAI”, J Rheumatol 1994;21:2286-91.

BASELINE – 1. Information gathered at the beginning of a study from which variations found in the study are measured. 2. A known value or quantity with which an unknown is compared when measured or assessed. 3. The initial time point in a clinical trial, just before a participant starts to receive the experimental treatment which is being tested. At this reference point, measurable values such as CD4 count are recorded. Safety and efficacy of a drug are often determined by monitoring changes from the baseline values.

BASE-PAIR - A pair of nitrogenous bases making up one "rung" of the DNA "ladder".

BASES - The nitrogen-containing parts of a nucleotide. In groups they code for amino acids during protein synthesis.

BASFI - Bath Ankylosing Spondylitis Functional Index: Measures AS-specific physical function. Range 0-10; higher values indicating worse function. Lit.: Calin A, et al. “A new approach to defining functional ability in AS: the development of the BASFI”, J Rheumatol 1994;21:2281-5.

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.

BATTERY - A set of tests given to an individual or group that have value individually and as well as collectively.

B-DNA - One of the two forms of DNA. B-DNA is a smooth spiral.

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.

BIOLOGICS – A new category *dmard's* based on the latest *biomedical research*. Examples are the anti-TNF $\alpha$  drugs.

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

BLIND / BLINDING / 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. Triple blind means that researchers, participants, and those assessing outcomes are unaware of what treatment the participant received.

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.

CASE-CONTROL STUDY – Compares people with a disease or condition ('cases') to another group of people from the same population who don't have that disease or condition ('controls'). A case-control study can identify risks and trends, and suggest some possible causes for disease, or for particular outcomes.

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.

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.

CHANGE SCORE - The difference between scores before and after a task or stressor. It indicates whether the variable measured are improving or digressing

CHROMOSOME - The most condensed form of DNA. Formed when condensed chromatin is wound tightly.

CHROMATIN - Nucleosomes that are wound into a spiral.

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

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.

CLINICAL - Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science.

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. <http://www.cochrane.org/index0.htm>

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](http://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.

CODONS - A set of three nitrogenous bases on mRNA that codes for an amino acid during protein synthesis.

COMPUTER ADAPTIVE TESTING (CAT) - A computer-administered questionnaire based on the item response theory (IRT). The examinee responds to a sequence of questions, selected from an item pool. A program calculates statistics after each response and determines the subsequent order of items based on the examinee's responses to the previous items. It attempts to determine the examinee's true ability.

CONCURRENT VALIDITY - A method of determining validity as the correlation of the test with scores from known valid measures.

CONDENSED CHROMATIN - Extended chromatin that is then wound up into yet a tighter helix.

CONFIDENCE INTERVAL - The likely range of values with a known probability of including the true value.

COHORT - In epidemiology, a group of individuals with some characteristics in common.

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.

COMMISSIONING – A process where research funders agree with researchers what research will be undertaken.

COMMUNITY-BASED CLINICAL TRIAL (CBCT) - A clinical trial conducted primarily through primary-care physicians rather than academic research facilities.

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.

COMPASSIONATE USE - A method of providing experimental therapeutics prior to final FDA approval for use in humans. This procedure is used with very sick individuals

who have no other treatment options. Often, case-by-case approval must be obtained from the FDA for "compassionate use" of a drug or therapy.

COMPLEMENTARY AND ALTERNATIVE THERAPY - Broad range of healing philosophies, approaches, and therapies that Western (conventional) medicine does not commonly use to promote well-being or treat health conditions. Examples include acupuncture, herbs, etc.

CONFIDENTIALITY REGARDING TRIAL PARTICIPANTS - Refers to maintaining the confidentiality of trial participants including their personal identity and all personal medical information. The trial participants' consent to the use of records for data verification purposes should be obtained prior to the trial and assurance must be given that confidentiality will be maintained.

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

CONSUMER – Someone who does or has used health services.

CONTRAINDICATION - A specific circumstance when the use of certain treatments could be harmful.

CONTROL - A control is the nature of the intervention control.

CONTROL GROUP - The standard by which experimental observations are evaluated. In many clinical trials, one group of patients will be given an experimental drug or treatment, while the control group is given either a standard treatment for the illness or a *placebo*.

CONTROLLED TRIALS - Control is a standard against which experimental observations may be evaluated. In clinical trials, one group of participants is given an experimental drug, while another group (i.e., the control group) is given either a standard treatment for the disease or a placebo.

CONVENIENCE SAMPLE – A population being studied because they are conveniently accessible in some way. This could make them particularly unrepresentative, as they are not a *random sample* of the whole population. A convenience sample, for example, might be all the people at a certain hospital, or attending a particular support group. They could differ in important ways from the people who haven't been brought together in that way: they could be more or less sick, for example.

COPING STRATEGIES (PASSIVE COPING) – The way that people react to radical events (life-strains or 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.

COPM – The Canadian Occupational Performance Measure (COPM) 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, Opzooomer A, Polatajko H, Pollock N. The Canadian occupational performance measure: an outcome measure for occupational therapy. Canadian Journal of Occupational Therapy, 1990 57(2):82-87; Law M, Polatajko H, Pollock N, McColl MA, Carswell A, Baptiste S. Pilot testing of the Canadian Occupational Performance Measure: clinical and measurement issues. Canadian Journal of Occupational Therapy, 1994,61(4):191-197).

CORRELATION COEFFICIENT - A value indicating the strength of a linear relationship between two variables in a sample.

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

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 degree to which a measure or test correlates with other measures or tests of the same construct assessed either concurrently or in the future; the ability of a test to predict a criterion. See also predictive validity.

CRITICAL APPRAISAL –The process of assessing and interpreting evidence, by systematically considering its validity, results, and relevance.

CROSS-OVER TRIAL –A trial where each of the groups will receive each of the treatments, but in a randomised order: that is, they will start off in one *arm* of the trial, but will deliberately 'cross over' to the other arm(s) in turn.

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.

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.

CYTOSINE - One of the four nitrogenous bases in DNA and RNA. This base pairs with guanine.

DAS – 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.

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.

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.

DEOXYRIBOSE - The five-carbon sugar that forms the "backbone" of DNA.

DEOXYRIBONUCLEIC ACID - The basic genetic material. Used as a template for the construction of mRNA.

DIAGNOSTIC TRIALS - Refers to trials that are conducted to find better tests or procedures for diagnosing a particular disease or condition. Diagnostic trials usually include people who have signs or symptoms of the disease or condition being studied.

DICHOTOMOUS RESPONSE - Selections to items containing two main category types (e.g. male and female, pass or fail, etc.) Also known as binary choice.

DISCRIMINANT VALIDITY - A type of validity that is determined by hypothesizing and examining differential relations between a test and measures of similar or different constructs. It is the opposite of convergent validity and is also known as divergent validity.

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

DNA - An acronym for deoxyribonucleic acid.

DNA POLYMERASE - The enzyme that pairs the bases when DNA replicates.

DOMINANT - An allele that is expressed when it is in an organism heterozygous for that trait.

DOSE-RANGING STUDY - A clinical trial in which two or more doses of an agent (such as a drug) are tested against each other to determine which dose works best and is least harmful.

DOUBLE BLIND – (See *blind/ing/ed*)

DOUBLE-HELIX - The shape of DNA; two spirals intertwined.

DRP – 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.

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 – SES (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.

EIGENVALUE - A statistic that quantifies variation in a group of variables and its accountability by a particular factor.

ELECTROPHORESIS - The process by which genes are sorted by length in a gel with electric current.

ELIGIBILITY CRITERIA - Summary criteria for participant selection; includes Inclusion and Exclusion criteria.

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.

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.

ENDPOINT – Overall outcome that the protocol is designed to evaluate. Common endpoints are severe toxicity, disease progression, or death.

EPIDEMIOLOGY – The study of the health of populations and communities, not just particular individuals.

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 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.

ETHICS/ETHICAL – Morally correct.

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).

EULAR CRITERIA – The *Eular* core set of outcome measures – see: Van Gestel et al. “Development and validation of the European League Against Rheumatism response criteria for RA” in: *Arthritis Rheum* 1996;39:34-40.

EUROQol – The EUROQol is a short self-report questionnaire to measure generic health-related quality of life in 5 dimensions: mobility, self-care, usual activity, pain/discomfort, and anxiety/depression. Each dimension is measured with one item and scored between 0 to 1 (0 equals death and 1 perfect health). It also includes a 0-100 graphic rating scale to measure overall health status. The EuroQol (EQ-5D) was developed by the EuroQol Group in 1990. See: EuroQol Group. EuroQol: a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199-208.). More information see: <http://www.euroqol.org/>.

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. Lit: Sacket, D. et al. Evidence based medicine: what it is and what it isn't (Editorial). British medical journal 1996: 312:71-72

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.

EXPLORATORY FACTOR ANALYSIS - A theory-generated procedure that identifies factors and/or factor patterns associated with variables or measures. It determines the number or nature of factors correlated to specific variables. This analysis seeks to discover factors when prior research analysis is not present.

FACTOR ANALYSIS - A statistical technique used to examine the interrelations among a set of variables, or items, in order to identify an underlying structure to those items. This process can be confirmatory, which means that an underlying causal structure is hypothesized. Uses structural equation or covariance structures modeling. Another method is exploratory factor analysis which is typically used to identify common underlying constructs among a group of variables. Factor analysis can provide evidence to show if the relations between items on a test are consistent with underlying theoretical construct or constructs.

FALSE NEGATIVE - A person who has the condition in question, but tests negative for it. This is also considered a Type II error.

FALSE POSITIVE - A person who does not have the condition in question, but tests positive for it. This is also considered a Type I error.

FLESCH SCORE (FLESCH READING EASE AND FLESCH-KINCAID GRADE LEVEL) - The Flesch scores (Flesch-Kincaid Grade Level and Flesch Reading Ease) are based on the average number of syllables per word and words per sentence. The Flesch-Kincaid Grade Level score rates text based on the U.S. high school grade level system (i.e. a score of 7.0 would mean a 7th grader should be able to comprehend the text). The Flesch Reading Ease score is based on a 100 point scale; the higher the score, the easier it is to comprehend.

*Flesch-Kincaid Grade Level*

$(.39 \times \text{ASL}) + (11.8 \times \text{ASW}) - 15.59$

*Flesch Reading Ease*

$206.835 - (1.015 \times \text{ASL}) - (84.6 \times \text{ASW})$

ASL: average sentence length (number of words divided by the number of sentences)

ASW: average number of syllables per word (number of syllables divided by number of words)

FOOD AND DRUG ADMINISTRATION (FDA) - The U.S. Department of Health and Human Services agency responsible for ensuring the safety and effectiveness of all drugs, biologics, vaccines, and medical devices, including those used in the diagnosis, treatment, and prevention of HIV infection, AIDS, and AIDS-related opportunistic infections. The FDA also works with the blood banking industry to safeguard the nation's blood supply. Internet address: <http://www.fda.gov/>.

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

FUNDER (S) – Organisation (s) providing funding for a study through contracts, grants or donations to an authorised member of either the employing and/or care organisation.

GENE - A segment of DNA that functions as a unit.

GENE AMPLIFICATION - The process by which genes are extracted for experiments in the lab.

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.

GENERALISABILITY – Whether or not the results of a study are applicable or relevant to another group of people or populations.

GENETICS - The study of inheritance and hereditary traits.

GENOTYPE - The genetic make up of an organism.

GENOME - The sum of all the genetic information in a cell.

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.

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).

GRANT – A sum of money given to support a research project

GUANINE - One of the four nitrogenous bases in DNA and RNA. This base pairs with cytosine.

HAD – Hospital Anxiety Depression Scale. The Hospital Anxiety and Depression Scale 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](http://www.hqlo.com/content/1/1/29)

HAQ - 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](http://www.hqlo.com/content/1/1/20)

HETEROZYGOUS - An organism that has different alleles for both genes in the trait being considered

HISTONE - A small protein bead that is wrapped in DNA to form nucleosomes.

HOMOZYGOUS - An organism that has the same allele for both genes in the trait being considered.

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.

HYBRID - The offspring of a cross between two genetically different organisms.

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.

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.

IL-1 - INTERLEUKIN-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.

INCIDENCE – The number of occurrences of something in a population over a particular period of time: eg, the number of cases of a disease in a country over one year.

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.

INFLAMMATION – The body’s response to tissue injury or foreign substances that usually produce symptoms of heat, swelling, redness and pain.

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.

INSTRUMENT - A device or procedure created to assess a trait or characteristic of individuals.

INTENT TO TREAT - Analysis of clinical trial results that includes all data from participants in the groups to which they were randomized even if they never received the treatment.

INTERCORRELATION MATRIX - Measures correlation strength between the observed or measured variables. Noted as (F).

INTERVENTION – Anything meant to change the course of events for someone: surgery, a drug, a test, a treatment, counselling, giving someone a pamphlet - all of these are interventions.

INVESTIGATIONAL NEW DRUG - A new drug, antibiotic drug, or biological drug that is used in a clinical investigation. It also includes a biological product used *in vitro* for diagnostic purposes.

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).

LATENT STRUCTURE ANALYSIS - A method that finds latent categories using dichotomous data. Also known as latent class analysis.

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.

LINEAR REGRESSION - Fitting a straight line into a data set to determine future outcomes. A technique used to fit a straight line into a data set. This determines the effect of an independent variable on a dependent variable.

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.

MARKERS - The sequences surrounding a desired gene, used to locate that gene.

McCOY SEXUAL RATING SCALE – This scale covers sexual experience and responsiveness during the past 30 days. This instrument contains 10 items on a seven point scale relating to different aspects of sexual life, such as frequency of intercourse, orgasm frequency, sexual pleasure and satisfaction, lubrication, dyspareunia, arousal, sexual fantasies, and satisfaction with partner. Lit.: McCoy N, Davidson J. “A longitudinal study of the effects of menopause on sexuality”, *Maturitas* 1985;7:203-10.

MEASUREMENT - A logical rule for assigning numbers to observations to represent the quantity of a trait of characteristic possessed.

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.

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.

METHODOLOGY – The way in which you find out information; a methodology describes how something will be (or was) done. The methodology includes the methods, procedures, and techniques used to collect and analyse information.

MHAQ – Modified HAQ – see: HAQ

MHIQ – McMaster Health Index Questionnaire – A standard-item questionnaire on physical, social and emotional function.

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)

Morbidity – Illness or harm. (See also comorbidity).

MORTALITY – Death.

mRNA - Messenger RNA. This is the molecule produced by transcription. It is from this molecule that proteins

MSS – The Modified Sharp Score is a measure of joint damage as assessed radiographically, and is based on joint space narrowing and erosions. The MSS is developed by Van der Heijde, based on the original assessment method of Sharp.

MUTAGEN - A factor (substance, radiation, etc.) that causes a change in DNA.

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

MULTICENTRE – Research is mostly conducted within an area, or within a single hospital/GP practice/prison. A trial is sometimes conducted between a number of collaborating hospitals/GP practices/research organizations - particularly when very large numbers of people are needed to complete a trial. Those trials are called 'multicentre' trials, or trials conducted at several or multiple 'sites'.

NATURAL HISTORY STUDY - Study of the natural development of something (such as an organism or a disease) over a period of time.

NEGATIVE PREDICTIVE VALUE - The probability that an individual does not have the tested condition, given that the test result is negative.

NEW DRUG APPLICATION (NDA) - An application submitted by the manufacturer of a drug to the FDA - after clinical trials have been completed - for a license to market the drug for a specified indication.

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

NUCLEOSOMES - DNA wrapped around histones.

NUCLEOTIDES - The part of DNA or RNA that contains a base, a phosphate group, and a five-carbon sugar.

OBSERVATIONAL STUDY – A survey or non-experimental study. The researchers are examining and reporting on what is happening, without deliberately intervening in the course of events.

OFF-LABEL USE - A drug prescribed for conditions other than those approved by the FDA.

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. 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). More information about the *ACR-criteria* and *EULAR-Criteria*, see: Anke M. van Gestel et al. “ACR and Eular improvement criteria have comparable validity in RA trials”, *J. Rheumatol* 1999;26:3:705-711.

During Omeract 6 patients stated that fatigue and sleep disturbance are important outcomes that are not 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 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 PROCESS - 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 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.

ORDINAL SCALE - Rank order in which there is no zero point, and the differences between the ranks need not be equal. Used to answer items with scale responses. Compare with Likert-type response or dichotomous response.

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.

PARTICIPANTS – Patients, service users, relatives of the deceased, professional carers or members of the public agreeing to take part in the study.

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.

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.

PERSONAL DATA – Information about living people who can be identified from the information.

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.

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 well-being.

PHARMACOKINETICS - The processes (in a living organism) of absorption, distribution, metabolism, and excretion of a drug or vaccine.

PHASE I TRIALS - Initial studies conducted on small groups of 20-80 people to determine the metabolism and pharmacologic actions of drugs in humans, the side effects associated with increasing doses, and to gain early evidence of effectiveness; may include healthy participants and/or patients.

PHASE II TRIALS - Controlled clinical studies conducted on larger groups of 100-300 people to evaluate the effectiveness of the drug for a particular indication or indications in patients with the disease or condition under study and to determine the common short-term side effects and risks.

PHASE III TRIALS - Expanded controlled and uncontrolled trials after preliminary evidence suggesting effectiveness of the drug has been obtained, and are intended to gather additional information to evaluate the overall benefit-risk relationship of the drug and provide an adequate basis for physician labeling.

PHASE IV TRIALS - Post-marketing studies to delineate additional information including the drug's risks, benefits, and optimal use.

PhD – Doctor of Philosophy: A qualification obtained after undertaking a period (generally 3 years) of new research in a particular subject.

PHENOTYPE - The genes that are expressed in an organism.

PHOSPHATE GROUP - The part of DNA or RNA that acts as a glue, holding the sugars to each other.

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.

PLACEBO EFFECT - A physical or emotional change, occurring after a substance is taken or administered, that is not the result of any special property of the substance. The change may be beneficial, reflecting the expectations of the participant and, often, the expectations of the person giving the substance.

POLYPEPTIDES - A string of at least 2 amino acids, most containing 100 to 300 amino acids.

POLYTOMOUS RESPONSE - Selections to items containing more than two category types (e.g. always/sometimes/never; very strong/strong/neutral/weak/very weak).

POPULATION – In research, this term is applied to the group of people being studied, which may or may not be the population of a particular geographical area. The population in question in a research study, for example, may be 'all those people with cancer'. The study of the health of populations, as opposed to health of individuals, is *epidemiology*.

POSITIVE PREDICTIVE VALUE - The probability that an individual has the tested condition, given that the test result is positive.

POWER – Statistical power of a study: a study needs to have a specific level of 'power' in order to be able to reliably detect a difference that a treatment might cause. To be powerful enough, the study needs to have enough participants, who experience enough of the outcomes in question, to be able to come up with reliable results.

PRECLINICAL - Refers to the testing of experimental drugs in the test tube or in animals - the testing that occurs before trials in humans may be carried out.

PREDICTIVE VALIDITY - A type of criterion related validity in which a test is correlated with a criterion occurring at a later point in time.

PREVALENCE – The proportion of a population having a particular condition or characteristic: eg, the percentage of people in a city with a particular disease, or who smoke.

PRINCIPAL INVESTIGATOR – The authorised healthcare professional or researcher who takes primary responsibility for the conduct of the research.

PROBABILITY – The 'chance' or 'risk' of something happening.

PROSPECTIVE/RETROSPECTIVE – In a retrospective study, the outcomes of a group of people are examined after they have happened, using existing records. In a prospective study, the study is designed and people are then recruited and events recorded as they happen.

PROTEIN SYNTHESIS - The process of producing a protein.

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.

PSYCHOMETRICS - The study of how the measurement of psychological information is operationalized.

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.

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.

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.

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. Lit: Stucki G et al. “A self administered rheumatoid arthritis disease activity index (RADAI) for epidemiological research. Psychometric properties and correlation with parameters of disease activity”, in: *Arthritis Rheum* 1995;38:795-8.

RAND-36 – A general (not disease specific) questionnaire to measure quality of life. See also: SF36 Lit: Ware JE, Sherbourne CD. The RAND 36 Short-form Health Status Survey: 1. Conceptual framework and item selection. *Med Care* 1992; 30:473-81.

RANDOM ERROR - Measurement error that is apparently due to random causes. The opposite of systematic error.

RANDOM SAMPLE – When a group of people is being selected for study, one of the ways to try and ensure that the group studied is similar to the whole population, is to try and recruit people who have been selected randomly. This means that everyone in the population has an equal chance of being approached to participate in the survey, and the process is meant to ensure that a sample is as representative of the population as possible. The alternative method is to use a convenience sample: that is, a group that the researchers have more convenient access to.

RANDOMISATION – The process of randomly assigning participants into one of the *arms* of a *randomised controlled trial*.

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 and *control groups*. NOTE: when using randomised controlled trial as a search term (publication type) in *MEDLINE*, the US spelling (randomised) must be used.

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. Lit: Jong et al The reliability and construct validity of the RAQoL: a rheumatoid arthritis-specific quality of life instrument. *Br J Rheum* 1997;36878-83. And: Tjhuis et al The validity of the Rheumatoid Arthritis Quality of Life (RAQoL) questionnaire. *Rheumatology (Oxford)* 2001;40:1112-9.

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

RAW SCORE - The unstandardized score for a test or measure. It is typically not interpretable without additional information for reference.

RECESSIVE - An allele that is not expressed when in an organism that is heterozygous for that trait.

RELIABILITY - A degree of consistency of a measure; the degree to which a test is free of random error. A test or measure that produces consistent results is said to have high reliability.

REPRODUCIBILITY - A test of measurement reliability, such as the test-retest method, in duplicating similar responses.

RESEARCH ETHICS COMMITTEE – A group that provides independent advice to participants, researchers, funders, sponsors, employers, care organisations and professionals on the ethical issues of the proposal. A research Ethics Committee always has lay members.

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.

RF – RHEUMATOID FACTOR, is a protein found in the blood of 80% of adults with Rheumatoid Arthritis.

RIBONUCLEIC ACID - Includes mRNA and tRNA. In contrast to DNA, it is single stranded, has uracil instead of thymine, and contains ribose instead of deoxyribose.

RIBOSE - The five-carbon sugar that acts as the RNA backbone.

RIBOSOMES - The site of protein synthesis. There are many of these organelles located within the cell.

RITCHIE INDEX – A scoring system for recording joint tenderness.

RISK-BENEFIT RATIO - The risk to individual participants versus the potential benefits. The risk/benefit ratio may differ depending on the condition being treated.

RISK FACTOR – A characteristic of a person or their environment that is a) present at the start of an illness and b) increases the risk of illness in individuals exposed to that factor compared to those who are not.

RNA - An acronym for ribonucleic acid.

RNA POLYMERASE - The enzyme that binds to DNA and joins complementary bases to form mRNA.

SAARD – Slow Acting Anti-Rheumatic Drug (e.g. Gold).

SCALE - An instrument that indicates the degree of a characteristic or trait in an ordered way.

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.

Lit.: Uitz E, et al. “Clinical quality management in rheumatoid arthritis: putting theory into practice. SCQM in RA”, in: Rheumatology (Oxford) 2000;39:542-9. And: Fransen J. “Effectiveness of a measurement feedback system on outcome in rheumatoid arthritis: a controlled clinical trial”, in: Ann Rheum Dis 2003;62:624-9.

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).

SELECT-RESPONSE - An assessment method in which testers are given predefined choices from which to choose in order to answer a given item.

SELF-ADMINISTERED - A method by which a measure is answered by the tester and which does not require a trained individual to administer or supervise its completion. Compare this method of test-taking to a measure that requires administration a licensed psychologist in order to rate the response.

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

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.

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.

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.

The 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.

SIDE EFFECTS - Any undesired actions or effects of a drug or treatment. Negative or adverse effects may include headache, nausea, hair loss, skin irritation, or other physical problems. Experimental drugs must be evaluated for both immediate and long-term side effects

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 – SDD, that can be seen on an X-Ray. Used as a basis for measuring MCID.

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.

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. Recently, the manual of the SODA on CD-ROM has been completed to enable occupational therapist to use the test more easily. Lit.: Lankveld, et al. SODA: Manual. Sint Maartenskliniek, Nijmegen, The Netherlands, 1995. Lankveld et al. “SODA: A new test to measure hand disability. Journal of Hand Therapy 1996;9:27-32. 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.

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.

STABILITY - A measure of reliability, known as the test-retest approach. It is often used when alternate forms of tests are not available. Tests that yield the same results over time are said to be stable, and hence, reliable.

STAKEHOLDER –Any group within or outside the organisation that has an interest in the organisation’s performance.

STANDARD TREATMENT - A treatment currently in wide use and approved by the FDA, considered to be effective in the treatment of a specific disease or condition.

STANDARDS OF CARE - Treatment regimen or medical management based on state of the art participant care.

STATISTICAL SIGNIFICANCE - The probability that an event or difference occurred by chance alone. In clinical trials, the level of statistical significance depends on the number of participants studied and the observations made, as well as the magnitude of differences observed.

STUDY ENDPOINT - A primary or secondary outcome used to judge the effectiveness of a treatment.

STUDY TYPE - The primary investigative techniques used in an observational protocol; types are Purpose, Duration, Selection, and Timing.

SURVEY - A technique used to determine specific information about a sample of individuals. It may or may not contain measures of constructs.

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

SYSTEMIC ERROR - Error introduced into a measure that is consistent in form; also known as bias.

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*.

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.

THYMINE - One of the four nitrogenous bases in DNA. This base pairs with adenine.

TOXICITY - An adverse effect produced by a drug that is detrimental to the participant's health. The level of toxicity associated with a drug will vary depending on the condition which the drug is used to treat.

TRANSCRIBED - The process through which an mRNA molecule is produced from a DNA template.

tRNA - Transfer RNA. This carries the amino acids to ribosomes during protein synthesis.

URACIL - The nitrogenous base in RNA that replaces thymine in DNA, and pairs with adenine.

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 (eg 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.

VAS – Visual Analog 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.

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.).

Z-DNA – One of the two forms of DNA. Z-DNA is a zigzag.