



## SQUEEZE glossary

<i>ACPA</i>	Anti-Citrullinated Protein Antibodies. These antibodies bind PROTEINS which contain citrulline. There are several types of these antibodies – one of which is anti-CCP. Patients with these antibodies tend to have rheumatoid arthritis (though not all patients with rheumatoid arthritis have these antibodies).
<i>ACR</i>	The American College of Rheumatology. The ACR developed the 1987 classification criteria for RA. They also contributed to the ACR/ EULAR classification criteria for RA which were published in 2010. The 2010 criteria perform better than the 1987 criteria in certain respects but they are not perfect and studies are going on at the moment comparing the two sets of criteria.
<i>ACR20/50/70</i>	American College of Rheumatology Response; Reduction of a set of items by 20% or 50% or 70% over a certain period.
<i>ANTI-TNF<math>\alpha</math></i>	Anti-tumor necrosis factor 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, nor do they work in everyone.
<i>Antibody</i>	Antibodies are PROTEINS found in the blood which bind to other things in a very specific way. They are made by cells (B cells / plasma cells) of the immune system and their normal function is to fight off infections. Because of their specificity antibodies are also used as research tools, as a way to identify specific cell types (see CYTOMETRY) or as a way to measure the presence of specific things in complex mixtures.
<i>ARD</i>	Annals of the Rheumatic Diseases.
<i>Arthritis</i>	In the context of RA this means inflammation in the joint. In addition to pain, the joint would look swollen, or would be found to be swollen when you looked at the joint with an ultrasound or MRI scan.



<i>Autoantibody</i>	In certain situations ANTIBODIES are made which react against parts of people's own bodies. These are known as "autoantbodies". Such autoantibodies are associated with a number of diseases such as diabetes and thyroid disease. They can also be associated with RA. The most common types of autoantibody in RA are rheumatoid factor (RF) and ACPA (anti-citrullinated protein antibodies; a commonly used test for ACPA identifies anti-CCP antibodies). It is important to recognise that not all patients with RA have these antibodies – 20% of patients do not have RF and 40% of patients do not have ACPA. These patients are sometimes referred to as "seronegative" (as opposed to "seropositive") patients.
<i>Bias</i>	In clinical trails, bias is the systematic deviation from the true values of a treatment effect through the intentional or unintentional adjustment of results. Bias can result from aspects of trial design, the way a trial is carried out, or the way the results are analysed or evaluated.
<i>Biomarker</i>	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.
<i>Blinding</i>	In a single-blinded trial, the patients are unaware of whether they are taking the real drug or a placebo. In a double-blind trials, both patients and researchers are unaware of who is taking the real drug and who is taking the placebo.
<i>BMJ</i>	British Medical Journal
<i>Case study</i>	Something used or analysed in order to illustrate a thesis or principle.
<i>Care delivery value chain</i>	A framework that can help conceptualize the organization and structure of care delivery for medical conditions.
<i>CDAI</i>	Clinical Disease Activity Index. The number of swollen joints.
<i>Co-creation</i>	The integration of resources through activities and interactions with collaborators to realize the benefit of patients in the health care service delivery network.
<i>Cohort</i>	A group of people with a shared characteristic.



<i>Confounders</i>	A variable that might confuse or confound an association between factors that is seen in a study. For example, 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.
<i>Cytokines</i>	Cytokines are molecules produced by cells of the immune system that have been linked to the process of inflammation in RA. Whilst most are thought to cause inflammation some may have anti-inflammatory roles.
<i>Cytometry</i>	Literally “measuring cells”, this term encompasses multiple technologies such as flow cytometry (measuring ~12 parameters per cell), mass cytometry or CyTOF (measuring ~40 parameters per cell) as well as single cell RNAseq which measures the TRANSCRIPTOME of individual cells. Flow and mass cytometry require ANTIBODIES to identify specific cell types, through the presence or absence of specific targets on the surface of cells.
<i>CRP</i>	C Reactive Protein is a substance produced by the liver that is only present during acute inflammation; a test often used in assessing how active someone’s Rheumatoid Arthritis is.
<i>DALY</i>	Disability-Adjusted Life Years
<i>DAS28</i>	Disease Activity Score 28 joint count. A disease activity score, of which different versions exist. It allows to categorise the disease activity of patients in groups of remission, low, moderate and high disease activity.
<i>DMARDs</i>	Disease Modifying Anti-Rheumatic Drug. Disease modifying antirheumatic drugs or medications used to control arthritides, including rheumatoid arthritis. Designed to slow the progression of Rheumatoid Arthritis by slowing down structural damage to the joints.
<i>EBM</i>	Evidence Based Medicine. Patients bring their own evidence base when they gather, consolidate and report their own illness experiences. Experiential knowledge is associated to the definition of evidence-based medicine, defined as “the integration of best research evidence with clinical expertise and patient values”.
<i>Ecosystem</i>	A network of interconnected organizations, individuals, and technologies that work together to deliver healthcare services and solutions.



<i>Effect modifier</i>	Effect modification is present when the effect of an intervention varies according to patient subgroups. The baseline characteristics describing the patient subgroups (or environment) are effect modifiers. For example, if the effect of a treatment is different for men and women, then sex is an effect modifier. Effect modifiers are assessed by performing a statistical test for interaction.
<i>Effect size</i>	The degree of improvement (or otherwise) of a particular therapy after any placebo effect has been accounted for. The treatment effect can be presented in several ways, such as the difference in change in an outcome between groups (i.e. treatment group vs placebo group) or as the difference in proportions of responders between groups.
<i>Engagement</i>	It refers to each stakeholder's investment of energy, skill, ability, effort, and eagerness in a defined project. This includes involvement and commitment and beyond, such as attending to task details and building strong connections and relationships.
<i>EMA</i>	European Medicine Agency
<i>Erosions</i>	In rheumatoid arthritis, synovial inflammation makes 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.
<i>ESR</i>	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.
<i>EULAR</i>	European Alliance of Associations for Rheumatology
<i>Experiential knowledge</i>	In the context of rheumatology research we define experiential knowledge as the knowledge that relates to your condition itself; challenges your condition creates for interacting with friends, family and others socially; going to school or managing a job; managing your condition; and, your experiences with healthcare. In this way experiential knowledge reflects the impact of a condition in all the ways it affects a person’s health and daily life.
<i>FDA</i>	Food and Drug administration
<i>FOREUM</i>	Foundation for Research in Rheumatology
<i>GCP</i>	Good Clinical Practice



<i>GDPR</i>	General Data Protection Regulation
<i>Gene</i>	Genes (which is made up of deoxyribonucleic acid (DNA)) contain the instructions needed to build and maintain cells. Although all cells carry all genes only certain genes are active in each cell. Which genes are active determines the characteristics of a cell - for example the genes active in a skin cell will be different from these in a cell of the joint lining. Lots of things influence whether genes are active – some of these are things we are exposed to in the environment such as cigarette smoke.
<i>Generalizability</i>	Refers to whether the results of a trial can be generalised to real-world patients in clinical practice.
<i>Gold standard</i>	The best scale or test that we currently have for something.
<i>GRADE</i>	Grading of Recommendations, Assessment, Development and Evaluation.
<i>HAQ</i>	Health Assessment Questionnaire. A questionnaire concerning functionality measured by 20 questions in 8 sections. Some versions of the HAQ have additional questions about aids used. The score can range from 0 to 3, with 3 representing the worst disability.
<i>Horizon 2020</i>	The EU Framework Programme for Research and Innovation (2014-2020).
<i>HP</i>	Health professionals
<i>HR-QoL</i>	Health Related Quality of Life measures
<i>HTA</i>	A widely used generic (disease non-specific) quality of life (QoL) instrument which allows comparisons between different patient groups and the general population.
<i>ICER</i>	Incremental cost-effectiveness ratio
<i>ICF</i>	International Classification of Function
<i>ICHOM</i>	International Consortium for Health Outcome Measurement
<i>IMI</i>	Innovative Medicine Initiative (EU Public / private partnership program).
<i>immune monitoring</i>	The use of multiple technologies to assess the composition and status of one's immune system, and through differential analysis to identify key determinants of disease progression, relapse, or resistance to treatment.



<i>Incidence</i>	Incidence rate is a measure of the frequency with which a disease or other incident occurs over a specified time period.
<i>Informed consent</i>	ICF
<i>Interleukin</i>	A particular type of CYTOKINE. Important examples in RA include IL-1, IL-6 and IL-17. All of these are thought to cause inflammation in the joint.
<i>Likert scale</i>	A unidimensional scale that researchers use to collect respondents' attitudes and opinions.
<i>Lymph node</i>	An oval-shaped organ of the immune system. Lymph nodes act traps for foreign substances and are important in the proper functioning of the immune system. They are packed with cells of the immune system and immune reactions against foreign substances often begin in these nodes.
<i>Lol</i>	Letter of Interest
<i>LOS</i>	Longitudinal observational studies
<i>Lupus Europe</i>	European Network of Lupus patient organisations.
<i>Macrophage</i>	Macrophages are type of immune cell which are found in the tissues of the body. One of their functions is to get rid of foreign things by 'eating' and 'digesting' them. They can also produce cytokines such as TNF.
<i>Mean</i>	The sum of the values divided by the number of values.
<i>Median</i>	The cut-off value of a series of measurement, where half are higher than this cut-off and the other half are lower.
<i>NRS</i>	Numerical Rating Scale
<i>OARSI</i>	Osteoarthritis Research Society International
<i>OMERACT</i>	Outcome Measures in Rheumatology
<i>OML</i>	EULAR Outcomes Measures Library
<i>Outcome</i>	The result.
<i>PARE</i>	People with Arthritis/Rheumatology in Europe.
<i>Patient-journey</i>	A term referring to a patient's experience throughout an episode of care, beginning at admission and concluding with hospital discharge. The renewed



focus on patient experience in recent years stems from growing trends in healthcare consumerization and value-based care initiatives.

*Patient and public involvement (PPI)*

Actively working in partnership with patients and members of the public to plan, manage, design, and carry out research. It is “Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.

*Personalised medicine*

Personalised medicine seeks to target therapies and make the best decisions for groups of patients according to certain characteristics. For example, if evidence shows that a certain treatment has a better effect in certain groups of patients (e.g. women, the elderly or those with long disease duration), the treatment could be restricted (or ‘personalised’) to those who will benefit the most.

*Pearson's r*

A method for measuring the strength of association between two continuous or linear variables. Also known as the Pearson’s correlation coefficient.

*PICO*

Patients Intervention Controls Outcomes. A structure to address a research question.

*Placebo*

A dummy or inactive treatment. If the placebo is a medicine in the form of a tablet or capsule it will contain no active ingredient. The best placebos are identical in appearance to the real drug and help to maintain blinding in either single- or double-blind trials, so that patients and researchers are unaware of who is taking the real drug and who is taking the placebo. Placebos are used to help separate the real effect of the active ingredient being studied from any benefit (or side effects) that the subject may experience by chance or purely by the acting of taking tablets.

*Power calculation.*

Used to assess how many patients should be studied to be able to have sufficient data to answer the main research question.

*PRES*

Paediatric Rheumatology European Society

*Prevalence*

Prevalence is the proportion of a particular population found to be affected by a medical condition (typically a disease or a risk factor such as smoking or seatbelt use) at a specific time.

*PRO*

Patient Reported Outcome



<i>Patient Research Partner (PRP)</i>	A Patient Research Partner (PRP) is a person who collaborates with researchers and healthcare professionals to ensure that patient perspectives and priorities are included in the design, implementation, and dissemination of health research. PRPs typically have a lived experience with a health condition or have cared for someone with a health condition, and they bring their unique insights to the research process, working as equal partners with researchers.
<i>PUBMED</i>	The most often used database and free search engine for finding abstracts of scientific papers that are published in academic health and medical journals.
<i>Pyramid of evidence</i>	The evidence pyramid is an easy way to visualize this hierarchy of evidence, where the levels provide a way to visualize both the quality of evidence and the amount of evidence available.
<i>QALY</i>	Quality-Adjusted Life Years
<i>Questionnaire</i>	Measurement instrument developed by specific validation methodology. Physically, it is a form with fixed questions (items) that measures a specific construct (for example, quality of life) and produces a single final score (or in a small number of components) after the analysis of the items.
<i>RA</i>	Rheumatoid Arthritis
<i>RAID</i>	Rheumatoid Arthritis Impact of Disease Score
<i>RCT</i>	Randomised Controlled Trial
<i>Reliability</i>	The quality of being trustworthy or of performing consistently well.
<i>Remission</i>	Several definitions of remission exist. Usually patients are in remission when certain criteria are fulfilled or measured by a certain score, the values score below a defined cut-off. Remission should be a state were no disease activity is detectable and no progression or only minimal progression of disease consequences may appear in the future as long as remission is maintained.
<i>RMD</i>	Rheumatic and Musculoskeletal Diseases. A general term for diseases related to rheumatic conditions and those affecting bones and muscles of the body.
<i>SD</i>	Standard deviation
<i>SDAI</i>	A disease activity score that results by summing up the number of swollen joints, tender joints, the patient global assessment in cm, the evaluator global assessment in cm and the CRP. The results can be attributed to either remission, low, moderate or high disease activity.





<i>Sensitivity</i>	(True positive rate) is the probability of a positive test result, conditioned on the individual truly being positive.
<i>Serology</i>	The study of blood serum.
<i>SF36</i>	A health related quality of life questionnaire usually reported in two domains: physical and mental health.
<i>SLR</i>	Systematic Literature Review
<i>SOP</i>	Standardized Operational Procedures
<i>Specificity</i>	(True negative rate) is the probability of a negative test result, conditioned on the individual truly being negative.
<i>Synovitis</i>	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, from the blood, of cells of the immune system.
<i>Stakeholders</i>	A stakeholder is a person, group, organization, or system who affects and can be affected by an organizational action. In the health care system stakeholders include external, internal and interface stakeholders.
<i>Tokenism</i>	When a researcher is only motivated by strategic reasons, there is the risk of tokenism. When they only involve patients because it is a requirement to obtain funding, they are only motivated by extrinsic reasons which is not a solid foundation for successful collaboration.
<i>T Cells</i>	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.
<i>Transcriptome</i>	The genome is made up of genes (DNA) that contains the instructions needed to build and maintain cells. For these instructions to be carried out, DNA must be 'transcribed' into corresponding molecules of ribonucleic acid (RNA), referred to as transcripts. A transcriptome is a collection of all the transcripts present in a given cell.
<i>Validity</i>	Validity generally refers to how accurately a conclusion, measurement, or concept corresponds to what is being tested.
<i>VAS</i>	Visual Analogue Scale
<i>WHO</i>	World Health Organisation



*WP*

Work Package. A group of related tasks within a project, that look like projects themselves and are often thought of as sub-projects within a larger project; WPs are the smallest unit of work that a project can be broken down.