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INTERNATIONAL FOUNDATION FOR AUTOIMMUNE & AUTOINFLAMMATORY ARTHRITIS

Knowledge = Empowerment Patient-Led Public Policy and Action Classroom Glossary

This is a living document, which means it is constantly updated. Have you heard a word in one of our lessons that you feel should be included but is not? Let us know! Email julia@aiarthritis.org and put Glossary in the Subject Line.

340B	The federal drug discount program created by Congress under Section 340B of the Public Health Service Act in 1992. It requires drug manufacturers to enter into pricing agreements with the federal government under which they agree not to sell covered outpatient drugs to participating providers above 340B ceiling prices.
Alternative Funding Program	Programs designed by for-profit third-party vendors that exclude coverage for certain high-cost, specialty medications and direct patients to alternative funding sources like manufacturer patient assistance programs, where the vendor diverts all of the available assistance to their bottom line.
Amendment	A change to an existing bill or resolution
Appeal	A request for your health insurance company/health plan to review a decision that denies a benefit or payment.
Appropriation	Legislation that provides funding for an authorized agency, program, or activity.
Authorization	Legislation to create or continue an agency, program, or activity.
Beneficiary	the person who benefits from the insurance policy/health plan. Typically the policyholder and any dependents also on the plan
Benefit Year	A year of benefits coverage under an individual health insurance plan. Most of the time this is January 1-December 31.
Bicameral	Literally, "two chambers", in a legislative body, having 2 houses. This is how half of the world's governments are designed. (Example, in the United States it is the Congress and Senate).[1]
Bill	A draft of what may become a law. **When there is a bill, groups -**

[1] https://www.thoughtco.com/why-we-have-house-and-senate-3322313

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	including Patient Organizations and patients, too, can voice their support or opposition.
Biomarker	A biomarker is any molecule that can be measured in tissues, blood, or other bodily fluids. The presence of a biomarker may be a sign of an abnormal bodily process or condition or disease. A biomarker may also be called a molecular marker, genotype, or signature molecule. Biomarkers can be used to determine whether a condition or disease is present, determine how aggressive the disease is, or predict how well the body will respond to a treatment for a disease or condition.
Biosimilar	A biosimilar is a replication of a biologic already on the market (which is called 'the reference product'). A biosimilar is different from a generic drug in that a biologic is made from living material, so it's impossible to replicate exactly. *(Keep in mind, a biologic is also living, so it also cannot be replicated exactly!)*
Bipartisan	When two political parties that usually oppose each other's policies agree on an issue (both support or oppose).
Brand Name	A drug sold by a drug company under a specific name or trademark that is protected by a patent. Brand name drugs may be available by prescription or over the counter.
Burden of Illness	The combined costs (financially and personally) as the result of a disease. This includes pain, lost wages, caretaker costs, mental health effects, and more. Studies that measure the “burden” of illness aim to examine things like the cost to the individual patient, possibly the cost to the employer, payer or insurance company, or even the cost to society.
Caucus	An informal meeting or group of members of the legislature commonly based on political party affiliation, but also other commonalities such as gender, religion, geographic location, policy priorities or race.
Chamber	A legislative chamber is a group, or assembly, of members. Most legislatures are bicameral, or 2 chambered, House and Senate. Legislatures can also be unicameral, or 1 chambered.

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Clinical Benefit	The positive effect of a treatment or an intervention on a patient's health. For example, improvement in symptoms, mobility, or other aspects of a patient's quality of life that is most meaningful to them, can be considered a clinical benefit.
Coalition	A group of organizations that care about the same issues and unite to tackle those issues together as a group effort. Typically 1 or 2 organizations lead and the others participate.
Coinsurance	The percentage of costs of a service covered by a health plan that is paid by a patient (e.g. 20% coinsurance) after they have paid their deductible.
Committee (or subcommittee)	A panel (or subpanel) with members from the House or Senate (or both) tasked with conducting hearings, examining and developing legislation, conducting oversight and/or helping manage chamber business and activities. Committees are grouped by subject - i.e. Health and Human Services, Foreign Affairs, Homeland Security, Finance, etc.
Comorbidity	One or more additional diseases or conditions that occur along with a primary disease or disorder.
Companion Measure/Bill	Identical or substantially similar measures introduced in the both chambers simultaneously. Example S1196/A1673 are companion measures.
Comparative Effectiveness Research (CER)	CER compares the effectiveness of two or more interventions or approaches to health care, examining their risks and benefits. Comparing two or more interventions distinguishes CER from other types of clinical research, for example research where one treatment is compared to a placebo.
Constituent	A citizen residing within the district of a legislator.
Continuity of Care	The process by which the patient and their physician-led care team work together to manage their healthcare to make it more cohesive.
Continuum of Care	Continuum of care is a medical term used to define a full spectrum of care, tracking a patient from diagnosis and including all levels of care.
Copay	A copay is a fixed dollar amount you must pay when you obtain a covered service or medication.

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Copay Accumulator	A cost-containment tool used by most health plans that prevent copay assistance from third parties like manufacturers or non-profit foundations from counting toward a patient's deductible and out-of-pocket maximum. Plans use these programs to divert copay assistance to their own bottom line instead of the benefit of patients.
Copay Assistance	Copay assistance is financial assistance, usually from the pharmaceutical company who manufactures the drug, that helps pay the copay of patients with insurance.
Copay Maximizer	A copay maximizer program is a form of copay accumulator. It takes any amount the patient receives from third-party copay assistance, divides it by 12 (so it's evenly distributed throughout the year), then sets the copay of the medication to that amount. The health plan diverts the maximum amount of available copay assistance to their bottom line while none of the assistant counts toward the patient deductible or out-of-pocket maximum, so patients still pay the full deductible and OOP maximum for the year.
Cost Benefit	The relationship between the cost of a treatment or medication and the benefit that is achieved from it.
Cost Effectiveness	In the context of pharmacoeconomics, cost-effectiveness compares the results of different interventions by measuring a chosen outcome, usually in units (for example, life-years gained, deaths avoided, heart attacks avoided, or cases detected). Alternative interventions are then compared in terms of cost per unit of effectiveness in order to assess how it provides value for money. This economic evaluation can inform decision-makers who determine where to allocate limited healthcare resources and discussions on pricing. Some value frameworks incorporate cost-effectiveness analysis alone or with any other criteria in their recommendations.
Cost Sharing	The share of costs covered by the health plan that the patient pays out of his or her own pocket. This doesn't include the premiums you pay but does include deductibles, copays, coinsurance, etc.
Deductible	The amount you pay for covered health care services before your insurance plan starts to pay. With a $2,000 deductible, for example, you pay the first $2,000 of covered services yourself. After you pay

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	your deductible, you usually pay only a copayment or coinsurance and the insurer pays the rest.
Difficult to Treat (D2T)	A patient who is classified as D2T is a person who has failed more than 2 biologics (based on EULAR criteria 2023)[2]
Drug Affordability Review	A process where states (often through Prescription Drug Affordability Boards) evaluate the costs of prescription drugs to improve affordability for consumers and manage healthcare spending.
Efficacy	A measure of how well a treatment works under ideal circumstances (e.g., Does it work in a controlled setting, such as a randomized controlled trial?). For example, if a procedure is very successful at treating a disease, but only if administered by a top surgeon in a patient with no complications or comorbidities, it would be efficacious, but not necessarily effective in the real world.
Enacted	Made into law.
Engrossed Measure	Official copy of a measure as passed by one chamber, including the text as amended by floor action.
Equal Value of Life Years Gained (evLYG)	Equal Value of Life Years Gained evenly measures any gains in length of life, regardless of a treatment's ability to improve quality of life. This measurement is used in concert with QALY to measure the value of medications in health technology assessments, or value assessments.
European Medicines Agency (EMA)	The European Medicines Agency (EMA) is a decentralized agency of the European Union (EU) responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. Similar to the FDA but with a more focused scope.
First Reading	The first presentation of a bill or its title for consideration.
Fly-in	When member organizations or other interest groups want to raise their visibility on Capitol Hill (or in a state Capitol), one method of doing so is to hold a fly-in. Constituents from across the state or country to gather and advocate together. In recent years, virtual fly-ins have been organized as well.

[2] https://ard.bmj.com/content/80/1/31

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Food and Drug Administration (FDA)	The FDA is responsible for advancing public health by helping to speed innovations that make medical products more effective, safe, and more affordable and by helping the public get the accurate, science-based information they need to use medical products and foods to maintain and improve their health. The FDA also oversees the nation's food supply, cosmetics, and products that emit radiation.
Formulary	Insurer's list of covered medications is known as a formulary. It's typically divided into levels, or tiers. The higher the tier, the higher the out-of-pocket cost to patients. By placing a medication on a specialty or "non-preferred" tier, health insurers can effectively put a medication out of reach for patients.
Health Economics	A special field of economics that focuses on understanding and analyzing the efficiency, effectiveness, values, and behaviors involved in the delivery and use of health and health care. Most health economic work involves assessing costs, how dollars are spent, and the outputs/accomplishments from that spending related to the benefits patients receive from the treatment.
Health Economics and Outcomes Research (HEOR)	HEOR is a field of scientific research. Health care decision makers are often faced with the need to make choices between treatment options, including drugs, devices, and other health care services. However, the benefits and costs of these options can vary dramatically and can be economic, clinical, both, or can include things that are hard to measure directly. HEOR can help healthcare decision makers—including clinicians, governments, payers, health ministries, patients, and more—to adequately compare and choose among the available options.
Health Equity	Health equity simply means that people have opportunity based on their need to attain their highest health.
Health Technology Assessment (HTA)	Also known as a value assessment. A health technology assessment is an evaluation process that attempts to assign value to a healthcare treatment or service. Health technology assessment is done to understand if the perceived benefit is enough to justify the cost of the service or treatment. Health technology assessments are used by the people who determine which treatments or medications are put on the insurance company's formulary, or preferred list.

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Health-Related Quality of Life (HRQoL) measure	A type of patient-reported outcome measure that has many dimensions and represents a patient's overall view of the effect of illness and treatment on their physical, psychological, and social aspects of life. A HRQoL measure typically evaluates whether a patient experiences difficulty completing normal activities (e.g., work, caring for children, etc.) and how these difficulties affect their relationships with family, friends, and social groups. It is important to note that the measures (questionnaires) used to collect HRQoL can either be specific to a certain disease, like breast cancer, or can be about health in general.
Hearing	A formal meeting of a congressional or state legislative committee (or subcommittee) to gather information from witnesses for use in its activities.
High Deductible Health Plan	A HDHP is an insurance plan that has a high deductible. This means the patient is going to pay more out of pocket before the insurer begins to pay and the patient is only responsible for copays and coinsurance. The idea is that insured people who pay a lot will make more frugal choices about their care - choosing cheaper drugs, avoiding unnecessary testing, or going to their doctor rather than the ER, etc. They were originally marketed as being great plans for healthy young people who had to obtain insurance as part of the Affordable Care Act. It went on to become a type of insurance that insurers like to push because it cost them less money.
In-network	For insurance coverage, these are healthcare people or services that are covered by your plan.
Insurance Premium	An insurance premium is the amount of money an individual or business pays for an insurance policy, not including any deductibles, coinsurance, copays, etc.
Joint Resolution	A form of legislative measure used to propose changes in law, or to propose an amendment to the US Constitution. Depending on the chamber of origin, they begin with a designation of either H.J. Res. or S.J. Res. In State legislatures, they may have different designations but serve the same purpose.
Legislation	Laws or bills that have been enacted or are in the process of being

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	developed or enacted. When used with “Legislation phase and Regulation phase,” it refers to the *process of creating new* laws.”
Legislator	elected member of a legislative body
Majority leader	the head of the party in the majority in the House or the Senate. The majority party is the party that holds the most seats in that chamber.
Managed Care	A medical delivery system that attempts to manage the quality and cost of medical services that individuals receive. Most managed care systems utilize an HMO, EPO, PPO, or POS network design, limiting to varying degrees the number of providers from which a patient can choose, whether the patient has to use a primary care physician and whether out-of-network care is covered under the plan. Some managed care plans attempt to improve health quality, by emphasizing the prevention of disease.
Markup	A meeting by a committee or subcommittee during which committee members offer, debate, and vote on amendments to a measure.
Medicaid	Health care program that assists low-income families or individuals in paying for long-term medical and custodial care costs. Medicaid is funded primarily by the Federal Government and run at the state level, where coverage may vary depending on specific criteria. States may call this program something of its choosing - for example, in California Medicaid is called Medi-Cal.
Medically Necessary	Health care services or supplies that are needed to diagnose or treat an illness, injury, condition, disease, or its symptoms and that meet accepted standards of medicine.
Medicare	Medicare is the Federal health insurance program for people aged 65 and older, certain younger people with disabilities, and people with end-stage kidney disease. •Part A covers inpatient hospital services, skilled nursing facility stays, part of home health services, and hospice. •Part B covers physician visits, lab services, allied services, preventive services, durable medical equipment, and drugs administered by providers. •Part D covers both brand-name and generic prescription drugs

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	•Medicare Advantage (sometimes called Part C) is a program through which individuals can enroll in a private health plan and receive all Part A and Part B covered benefits. •Medicare supplement (Medigap) is insurance sold by private companies that can help pay for healthcare costs above and beyond what medicare covers..
Minority Leader	The leader of the party in the minority in the House or the Senate. The minority party is the party that holds the least seats in that chamber.
Multimorbidity	Having additional medical diagnoses that may exist separately from other diagnoses (example, a person with rheumatoid arthritis also has anxiety or diabetes. These diagnoses are treated independently from their rheumatoid arthritis).
Network	The facilities, providers, and suppliers your health insurer or plan has contracted with to provide health care services.
Non-Medical Switching	Non-medical switching is a strategy that health plans use to control costs and maximize profits by forcing stable patients to switch from current and effective treatments to drugs that may not be as effective for reasons unrelated to health.
Nonpartisan	Having no association or affiliation with a political party or point of view.
Omnibus Bill	A combined package of appropriations bills that leadership in both houses negotiate in order to pass as a single bill rather than many separate bills. Also called a Christmas Tree Bill.
Orphan Drug	Drugs and biologics developed *specifically* to treat a rare medical condition or disease (called orphan disease), usually affecting fewer than 200,000 people.
Out of pocket Maximum	The most you have to pay for covered services in a plan year. After you spend this amount on deductibles, copayments, and coinsurance for in-network care and services, your health plan pays 100% of the costs of covered benefits.
Out-of-Network	A health provider who is not covered in your insurance list of approved plan providers.

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Out-of-Pocket Costs	Expenses for medical care that are not reimbursed by insurance, including deductibles, coinsurance, and copayments for covered services plus all costs for services that aren't covered.
Patient-Centered Outcomes Research	A type of outcomes research that specifically focuses on the outcomes of interest to patients and stakeholders, while also incorporating their perspectives throughout the entire research process.
Payer	Payers in the healthcare industry are organizations, such as insurance companies, Medicare, and Medicaid, responsible for setting service rates, collecting payments, processing claims, and paying provider claims.
Personalized Medicine/ Personalized Therapy	This is when **preferences** are considered in a person's care. These can include medical history, choice of injection versus pill, complimentary options (diet, exercise), and overall working with a doctor to choose the best plan.
Pharmacy Benefit Manager (PBM)	A Pharmacy Benefit Manager (PBM) is a third-party administrator that manages prescription drug benefits for health plans and employers. In addition to processing claims, PBMs negotiate drug prices, create lists of preferred medications and pharmacy networks, and establish cost-containment protocols. PBMs play a key role in the healthcare system.
Precision Medicine	Precision medicine is "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, biomarkers, DNA - things in your blood and tissues. environment, and lifestyle for each person." It can help with diagnosis and more accurately predict which treatment and prevention strategies for a particular disease will work for certain groups of people.
Premium	The amount that you (or your employer) pay for your health insurance plan. Your premium is usually paid monthly, quarterly, or yearly.
Preventive Care	Routine health care, including screenings, checkups, and patient counseling, to prevent or discover illness, disease, or other health problems.

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Prior Authorization/ Preauthorization	Prior authorization is a process by which a medical provider must ask permission, or authorization, from the insurance company before performing a medical procedure or providing a medication. Prior authorization is not a promise that a health insurer will cover the cost.
Provider	Person or place that offers healthcare services (could be your doctor, a nursing facility, hospital, etc.).
Quality Adjusted Life Year (QALY)	A measure of the state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality of life. One quality-adjusted life year (QALY) is equal to 1 year of life in perfect health. QALYs are calculated by estimating the years of life remaining for a patient following a particular treatment or intervention and weighting each year with a quality-of-life score (on a 0 to 1 scale). It is often measured in terms of the person's ability to carry out the activities of daily life, and freedom from pain and mental disturbance.
Ranking Member	The most senior (though not necessarily the longest serving) member of the minority party on a committee (or subcommittee).
Recess	A temporary interruption of proceedings in the House or Senate. A break.
Reference Product	A reference product is the original biological product approved by the FDA. Some reference products have biosimilars, but not all.
Referral	A referral is an order from your primary care physician to see a specialist. This is sometimes required by insurance companies, and sometimes required by the specialist's office.
Regulation	When a law has been passed and now this is the process of implementing and enforcing them. *When used with "Legislation phase and Regulation phase," the legislation sets the rules and the regulation makes sure the rules are followed.*
Regulator	Any person, organization, or agency whose job is to control an activity or process and make certain that it operates as it should
Remission	The period in the course of a disease when symptoms lessen or disappear.
Session	1: A period during which the legislature meets

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	2: The daily meeting of the House or the Senate
Specialist	A provider focusing on a specific area of medicine or a group of patients to diagnose, manage, prevent, or treat certain types of symptoms and conditions (ex Rheumatology or Gastroenterology).
Specialty Drug	Specialty drugs are high-cost prescription medications used to treat complex, chronic conditions. These medications often require special handling and administration.
Sponsor	The legislator who presents the bill or resolution for consideration. may be joined by others, called cosponsors.
Step Therapy	Step therapy (also known as 'fail first') is a health plan cost-containment tool that prevents patients from receiving a treatment prescribed by their physician until they have failed on one or more alternative treatments favored by the plan.
Value	The value of a treatment is commonly viewed by health care payers (i.e., both public and private insurers) in terms of its effectiveness and cost. Generally, this considers the treatment's effects, both positive and negative, and the costs and cost savings associated with the treatment and its impact. For patients, value is individualized and disease dependent, and can evolve with the disease trajectory or stage of a patient's life.
Value Assessment	A value assessment is an assessment or evaluation process that attempts to assign value to a healthcare treatment or service. Value assessment is also sometimes known as a health technology assessment or HTA. A value assessment is done to understand if the perceived benefit is enough to justify the cost. Value assessments are used by the people who determine which treatments or medications are put on the insurance company's formulary, or preferred list.
Vertical Integration	Vertical integration occurs when a single company controls multiple layers of the supply chain—such as health insurance, PBM services, and pharmacy operations.

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