

Key Terms

Patient Advocate Certification Exam

(Updated June 21, 2019)

This list of Key Terms is a compilation of terms directly or indirectly related to the practice of patient advocacy. The list is not meant to be all inclusive and more may be added over time. Professional patient advocates are encouraged to be familiar with terms and concepts relevant to the practice of patient advocacy and the delivery of patient assistance.

Active Listening: Fully concentrating on what is being said rather than just passively ‘hearing’ the message of the speaker. Active listening involves listening with all senses, as well as giving full attention to the speaker. It is important that the ‘active listener’ is also ‘seen’ to be listening; otherwise, the speaker may conclude that what they are talking about is not important to the listener.

ADA: The Americans with Disability Act. Passed in 1990, the ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places open to the general public. The purpose of the law is to make sure people with disabilities have the same rights and opportunities as everyone else. The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. The ADA is divided into five titles (or sections) that relate to different areas of public life.

Advance Directives: Legally executed documents that detail an individual’s healthcare-related wishes and decisions for end-of-life. They are drawn up while the patient is competent and are used to understand the person’s wishes. They are also used if the person becomes incapacitated or incompetent to understand their wishes. These may include the Durable Medical Power of Attorney and Living Will (see below).

Adverse Events: Any untoward occurrence, which under most conditions are not natural consequences of the patient’s disease process or treatment outcome.

Appearance of Impropriety: When someone outside a situation (lay person) raises ethical questions without benefit of knowledge of the situation

Autonomy: A form of personal liberty in which a person holds the right and freedom to select and initiate their own treatment and course of action. The person takes control of their health. This fosters the person’s independence and self-determination.

Beneficence: The obligation and duty to promote good, to further and support a person's legitimate interest and decisions, and to actively prevent or remove harm.

Biomedical Ethics: The application of ethics to the field of medicine and healthcare.

Burden of Proof: The duty of producing evidence as the case progresses, and/or the duty to establish the truth of the claim by a preponderance of the evidence.

Care Coordination: The deliberate organization of patient care activities and sharing of information among the participants concerned with a patient's care to achieve safer and more effective care. The patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and this information is used to provide safe, appropriate, and effective care to the patient.

Clinical Pathway (Care Map or Critical Pathway): A timeline of patient care activities and expected outcomes of care. Addresses the plan of care of each medical discipline involved in the care of a specific patient. It is usually developed prospectively by an interdisciplinary healthcare team in relation to a patient's diagnosis, health problems, or surgical procedure.

Care Plan or Plan of Care: Based on an individual's unique needs and problems, a care plan is the outline and basis guiding the appropriate interventions, timelines and goals and expected outcomes.

Chronic condition: A human health condition or disease that is persistent or otherwise long-lasting in its effects or a disease that comes with time. The term chronic is often applied when the course of the disease lasts for more than three months.

Client Expectations: The anticipation or the belief about what is to be encountered in a consultation or in the healthcare system. It is the mental picture that patients or the public will have of the process of interaction with the system.

Compassionate Care: Medical and emotional care for patients with terminal diseases to make their lives more comfortable when treatment proves futile. It is also referred to as hospice care and frequently takes place in a patient's home. Compassionate care provides private medical treatment as well as emotional support to help patients cope with the final stages of life.

Competence: The mental ability and capacity to make decisions, accomplish actions, and perform tasks expected to perform adequately.

Competencies: The process of being competent in a practice. Being competent requires the professional to possess the required skill, knowledge, qualification, to perform a task.

Confidentiality: The right of an individual to have personal, identifiable health related information kept private.

Conflict of interest: A situation with the potential to undermine the impartiality of a person because of the possibility of a clash between the person's self-interest and professional interest or public interest.

Contract: A written or spoken agreement between two people concerning employment, sales, or tenancy, or performance of services that is intended to be enforceable by law.

Culturally and Linguistically Appropriate Services: A set of 15 action steps intended to advance health equity, improve quality, and help eliminate health care disparities by providing a blueprint for individuals and health and health care organizations to implement culturally and linguistically appropriate services.

Designated Healthcare Surrogate: An adult who is appointed to make healthcare decisions for a person when the person is unable to make decisions for themselves.

Diagnostic Tests: Approach used to gather clinical information for the purpose of making clinical decisions.

Disability: A physical or mental impairment that substantially limits the ability to perform one or more major life activity.

Disease: A particular abnormal condition that negatively affects the structure or function of part or all of an organism, and that is not due to any external injury.

Disclosure: The action of making information known.

Discriminatory Practices: Biased actions or behaviors against an individual based on age, race, culture, disability, ethnicity, gender, medical condition, nationality, appearance, religion, sexual identity, sexual orientation, or social class.

Do Not Resuscitate (DNR): A request not to have cardiopulmonary resuscitation (CPR) performed if the heart stops, breathing ceases or there is no brain activity.

Durable Power of Attorney: A durable power of attorney (POA) enables a person to appoint an "agent," such as a trusted relative, friend or attorney to handle specific health, legal and financial responsibilities. There are two types of power of attorney. Power of Attorney for healthcare gives a designated person the authority to make health care decisions on behalf of the person. Power of Attorney for finances giving a designated person the authority to make legal/financial decisions on behalf of the person.

Empathy: The ability to understand and share the feelings of another.

Empowerment: Authority or power given to someone to do something.

End of Life Care: The term used to describe the support and medical care given during the time surrounding death.

Ethical Standards: A set of standards that promote values such as trust, good behavior, fairness, and/or kindness.

Equal Access to Health Services: A health care system that is focused on ensuring that all have access to quality care when and where they need it, regardless of race and ethnicity.

Equity: The quality of being fair and impartial. Focus on fairness and impartiality for all.

Fee for Service: A payment model where services are unbundled and paid for separately.

Fee Schedule: A listing of fees used by Medicare or commercial payers to reimburse physicians and other providers/suppliers.

Guarantor: A person, organization, or thing that guarantees something, usually payment.

Handicap: This out of date term was used to describe the functional disadvantage and limitation of potential due to a physical or mental impairment or disability. It substantially limits or prevents the fulfillment of one or more major life activities otherwise considered normal for that individual based on age, sex, and social and cultural factors, such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, working, etc. Handicap is a classification of role reduction resulting from circumstances that place an impaired or disabled person at a disadvantage compared to others.

Habilitation: Health care services that help an individual with a disability keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn't walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings. (Healthcare.gov)

Health and Human Services Risk Management: The science of the identification, evaluation, and treatment of financial and clinical loss. A program that attempts to provide positive avoidance of negative results.

Healthcare Access: Refers to the ease with which an individual can obtain needed medical and behavioral health services.

Healthcare Proxy: A legal document that directs the healthcare provider/agency in who to contact for approval/consent of treatment decisions or options whenever the patient is no longer deemed competent to decide for self.

Healthcare System: The organization of people, institutions, and resources that deliver health care services to meet the health needs of target populations.

Healthcare Team: Those who provide care in the healthcare system.

HIPAA: Health Insurance Portability and Accountability Act. Developed by the Department of Health and Human Services, these standards provide patients with access to their medical records and more control over how their personal health information is used and disclosed. They represent a uniform, federal floor of privacy protections for consumers across the country. State laws providing additional protections to consumers are not affected by this new rule. HIPAA took effect on April 14, 2003.

Hospice: Hospice care is a type of care and philosophy of care that focuses on the palliation of a chronically ill, terminally ill or seriously ill patient's pain and symptoms, and attending to their emotional and spiritual needs

Hospital Acquired Infection: A hospital-acquired infection (HAI), also known as a nosocomial infection, is an infection that is acquired in a hospital or other health care facility.

Independent Patient Advocate: Advocates work directly for a client and are contracted by the client or by a guarantor (family, lawyer, etc.) on behalf of that client. A professional patient advocacy relationship in this category exists when there is a service agreement or contract that defines the responsibility of each party. Also known as Independent Health or Healthcare Advocate.

Informed Consent: Patient Criteria-In order for consent to be valid:

- A patient must be competent/have decision-making capacity: While general incompetence can be determined only by a court of law, healthcare providers must ensure that patients have the capacity to make good decisions about their care. The patient should be able to understand the material presented to them, including the benefits, risks and alternatives, and have the ability to make a rational decision in light of their values.
- A decision must be voluntary: The patient should not be unduly influenced by family members, healthcare professionals, or other agents, and should not be impaired by medications or uncontrolled stress when giving informed consent.
- A competent patient can withdraw informed consent at any time. Healthcare professionals must respect a patient's revocation of initial consent.
- A competent person may decline any treatment – no matter how strongly recommended by the healthcare team. Health care professionals must honor the patient's decisions, whether for or against the suggested treatment.

Informed Consent: Physician/provider criteria - The American Medical Association lists important elements of the information component of informed consent. Physicians must disclose to their patients:

- The patient’s diagnosis, if known;
 - The nature and purpose of the treatment or procedure;
 - Risks and benefits of the proposed treatment or procedure;
 - Reasonable alternatives;
 - Relevant risks, benefits, uncertainties of each alternative;
 - The risks and benefits of not undergoing a treatment or procedure.
- (azbioethicsnetwork.org)

Informed Decision Making (Also known as Shared Decision Support): A decision by a patient about a diagnostic or therapeutic procedure based on choice, which requires the decision to be voluntary by the person who has the capacity to understand information and make decisions on a set of values and goals.

Impairment: A general term indicating injury, deficiency or lessening of function. Impairment is a condition that is medically determined and relates to the loss or abnormality of psychological, physiological or anatomical structure or function. Impairments are disturbances at the level of the organ and include defect or loss of limb, organ or other body structures or mental function.

Institutional Patient Advocate: Institutional advocates are hired by an institution, organization, corporation (hospital, managed care company, cancer center, employer, social service agency, labor union, etc. The institutional advocate works with the clients in a variety of services based on their scope of services and their organization culture.

Insurance Risk Management: A comprehensive program of activities to identify, evaluate, and take corrective action against risks; these risks may lead to patient or staff injury with resulting financial loss or legal liability. The program aims at minimizing risk.

Integrity: Adherence to moral and ethical principles; soundness of moral character; honesty.

Interdisciplinary Care Teams: These teams play a vital role in improving patient care and quality outcomes. By treating the whole patient — physically, nutritionally, emotionally and psychologically — with a well-rounded team of clinicians and practitioners from a variety of professional disciplines, this holistic approach helps to ensure continuity of care.

Interpersonal Relationships: Interpersonal relationships are social associations, connections, or affiliations between two or more people.

Justice: Maintaining what is right and fair; making decisions that are good for a person.

Liability: Legal responsibility for failure to act appropriately or for action that does not meet the standard of care, inflicting harm on another person.

Lifelong Learning: Patient advocates are committed to lifelong learning to keep their knowledge and skills current, hone their professional expertise, and keep abreast of current conditions in the rapidly changing healthcare environment.

Living Will: A living will is a written document that helps tell doctors how a person wants to be treated if dying or permanently unconscious and they cannot make their own decisions about emergency treatment. In a living will, a person can say which of the procedures (ventilators, feeding tubes, CPR, etc.) they would want, which ones they wouldn't want, and under which conditions each of the choices applies. (National Institute on Aging) When combined with a Durable Medical Power of Attorney it becomes the Advanced Directive (see above).

Mediation: As used in law, mediation is a form of alternative dispute resolution (ADR), a way of resolving disputes between two or more parties with concrete outcomes. Typically, a third party, the mediator, assists the parties to negotiate a settlement.

Medical Error: A medical error is a preventable adverse effect of care, whether or not it is evident or harmful to the patient. Examples include an inaccurate or incomplete diagnosis or treatment of a disease, injury, syndrome, behavior, infection or other ailment.
(doi: [10.1197/jamia.M1232](https://doi.org/10.1197/jamia.M1232))

Medical Malpractice: Occurs when a hospital, doctor or other health care professional, through a negligent act or omission, causes an injury to a patient. The negligence might be the result of errors in diagnosis, treatment, and/or aftercare or health management.

Medical Durable Power of Attorney: A legal document which names a surrogate decision maker in the event the patient is unable to make his or her own healthcare decisions. It is often combined with the Living Will to become the Advanced Directive (see above).

Negligence: Failure to take proper care to do something. Behavior that shows failure to exercise appropriate or ethical care, harm caused as a result of failing to provide proper care or as a result of nonperformance or non-fulfillment of duty. Omission to act when there is a duty to do so. (Cornell Legal Information Institute)

Non-judgmental: Avoidance of judgment or criticism on the basis of one's personal standards or opinions. As a patient advocate, being open, tolerant, and accepting of difference is essential.

Palliative care: An interdisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing relief from the symptoms, pain, physical stress, and mental stress at any stage of illness. The goal is to improve quality of life for both the person and their family.

Patient Abandonment: The legal term for terminating the physician-patient relationship in such a manner that the patient is denied necessary medical care. This should always be avoided. The legal liability becomes significant when the patient is injured by the failure to receive medical care. Abandonment can be intentional or inadvertent. Intentional abandonment is legally riskier because a jury may choose to award punitive damages as punishment for intentionally putting a patient's health at risk. (biotech.law.lsu.edu)

Patient Advocate: A professional who provides services to patients and those supporting them who are navigating the complex healthcare continuum. Advocates work directly with clients (or with their legal representatives) to ensure they have a voice in their care and information to promote informed decision making. Advocates may work independently or in medical or other organizational settings. They serve individuals, communities, disease-specific populations, and family caregivers. Synonyms may include health advocate, healthcare advocate, healthcare advocacy consultant, healthcare consumer advocate, and other phrases that imply this role.

Patient Rights: Patients' rights can be guaranteed by federal law, such as the right to get a copy of your medical records, and the right to keep them private. Many states have additional laws protecting patients, and healthcare facilities often have a patient bill of rights. An important patient right is informed consent. This means that if you need a treatment, your health care provider must give you the information you need to make a decision.

Patient Safety Issues: The patient safety field uses the term adverse events to describe patient harm that arises as a result of medical care (rather than from the underlying disease). Important subcategories of adverse events include:

- Preventable adverse events: those due to error or failure to apply an accepted strategy for prevention;
- Ameliorable adverse events: events that, while not preventable, could have been less harmful if care had been different;
- Adverse events due to negligence: those due to care that falls below the standards expected of clinicians in the community. (psnet.ahrq.gov)

POLST (Physician Orders for Life Sustaining Treatment): The POLST Paradigm is a process designed to improve patient care by creating a system using a portable medical order form (aka "POLST form") that records patients' treatment wishes to be used across settings of care. It is intended to be used by individuals with a serious illness or frailty toward the end of life.

<https://polst.org/about/>

Practice Guidelines: Guidelines systemically developed statements or medical practices that assist a practitioner in making decisions about appropriate diagnostic and therapeutic healthcare services for specific medical conditions. Practice guidelines are usually developed by authoritative professional societies and organizations.

Quality of life (QOL): An overarching term for the quality of the various domains in life. It is a standard level that consists of the expectations of an individual or society for a good life. These expectations are guided by the values, goals and socio-cultural context in which an individual lives. It is a subjective, multidimensional concept that defines a standard level for emotional, physical, material and social well-being.

Release: A contractual agreement by which one individual agrees to relinquish a claim or right under the law to another individual against whom such a claim or right is enforceable.

Resilience: Ability to recover and adapt in the face of adversity, trauma, tragedy, threats or stress: family/relationship problems, health problems or workplace/money issues.

Root Cause Analysis: Root cause analysis (RCA) is a structured method used to analyze serious adverse events. A central tenet of RCA is to identify underlying problems that increase the likelihood of errors while avoiding the trap of focusing on mistakes by individuals. RCA thus uses the systems approach to identify both active errors (errors occurring at the point of interface between humans and a complex system) and latent errors (the hidden problems within health care systems that contribute to adverse events). It is one of the most widely used retrospective methods for detecting safety hazards. (psnet.ahrq.gov)

Scope of Practice: Definition of the rules, the regulations, and the boundaries within which a fully qualified practitioner with substantial and appropriate training, knowledge, and experience may practice in a field of medicine or surgery, or other specifically defined field. Such practice is also governed by requirements for continuing education and professional accountability. (https://www.ncsbn.org/ScopeofPractice_09.pdf)

Second opinion: Obtaining an evaluation or clinical opinion by another practitioner for the purposes of becoming a more educated healthcare consumer, confirming a diagnosis is appropriate, confirming the recommended treatment is appropriate and/or comparing the outcomes of the treatments offered. (www.clevelandclinic.org)

Self-Determination: The Patient Self-Determination Act (PSDA) is a federal law, and compliance is mandatory. The purpose of this act to ensure a patient's right to self-determination in health care decisions be communicated and protected. Through advance directives--the living will and the durable power of attorney--the right to accept or reject medical or surgical treatment is available to adults while competent, so that in the event that such adults become incompetent to make decisions, they would more easily continue to control decisions affecting their health care.

Stakeholders: Those persons involved in an action or decision who have an interest in said action or decision.

Standard (individual): An authoritative statement by which a professional defines the responsibilities for which its practitioners are accountable.

Standard (Organization): An authoritative statement that defines the performance expectations, structures, or processes that must be substantially in place for an organization to enhance quality of care.

Standards of Care: statements that delineate the care expected to be provided to all clients. They include predefined outcomes of care clients can expect from providers and are accepted within the community of professionals, based upon the best scientific knowledge, current outcomes data, and clinical expertise.

Standards of Practice: Statements of the acceptable level of performance, or expectations for professional intervention or behavior, associated with one's professional practice. They are generally formulated by practitioner organizations based upon clinical expertise and the most current research findings.

Statute: An act of a legislature declaring, commanding, or prohibiting an action, in contrast to unwritten common law.

Statutory rights: A formal written law passed by a legislative body. Statutes are legally enforceable.

Terminal Illness or End-Stage Disease: Describes an incurable disease that cannot be adequately treated and is reasonably expected to result in the death of the patient.

Transitions of Care: The movement of a patient from one setting of care (hospital, ambulatory primary care practice, ambulatory specialty care practice, long-term care, home health, rehabilitation facility) to another or from one provider to another.

https://www.health.ny.gov/professionals/patients/discharge_planning/index.htm

Transparency: The Institute of Medicine (IOM) defines healthcare transparency as making available to the public, in a reliable, and understandable manner, information on the health care system's quality, efficiency and consumer experience with care, which includes price and quality data, so as to influence the behavior of patients, providers, payers, and others to achieve better outcomes (quality and cost of care). Performance transparency broadly refers to making available to the public information related to clinical quality, resource use, and experience of care with individual physicians, hospitals and other providers.

https://www.acponline.org/acp_policy/policies/healthcare_transparency_2010.pdf

Well-being: At minimum, well-being includes the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfillment and positive functioning. In simple terms, well-being can be described as judging life positively and feeling good. For public health purposes, physical well-being (e.g., feeling very healthy and full of energy) is also viewed as critical to overall well-being. (www.cdc.gov)