

A. Preface

The Patient Advocate Certification Board (PACB) is pleased to present these Ethical Standards for the patient advocacy profession. Agreement and adherence to this document is a condition of receipt of the Board Certified Patient Advocate (BCPA) credential.

The Patient Advocate Certification Board is an organization of professionals – including, but not limited to, healthcare and patient advocates, patient navigators, case managers, and others who work on behalf of patients, communities, and family caregivers – who share the goal of safe, effective, and compassionate healthcare. Board Certified Patient Advocates work with individual clients who need assistance navigating complex medical situations by partnering with them, seeking to empower them, and supporting their ability to make autonomous decisions.

Advocacy is a dynamic and developing field. Over time, these Ethical Standards may be revised. The Patient Advocate Certification Board welcomes questions, comments, and concerns about the standards or their implementation in professional practice.

B. Ethical Standards

1: The Role of an Advocate

The role of an advocate is to provide guidance and assistance to their clients in decisions related to their health needs. Advocates are committed to helping clients and client communities make informed choices and access resources, but at no time make decisions about specific treatment choices, provide clinical opinions, or perform medical care of any type, even if they possess clinical credentials.

This role shall be regarded as such at all times while using the title Board Certified Patient Advocate whether the advocate is under contract with the patient-client, working (and contracted or employed) by another individual or entity, or providing pro bono or reduced fee services.

2: Transparency and Honest Disclosure

Advocates are committed to integrity and transparency in the conduct of their practices. They develop clear client expectations related to their scope of practice. Advocates have a responsibility to ensure clients are fully aware of all conflicts of interest that might result from their conditions of employment.

Advocates providing fee-for-service assistance have an obligation to disclose their fees, training, education, experience, and credentials. They must also disclose existing contractual relationships with manufacturers or distributors of products or providers of services they recommend or use to assist their clients. Fee-for-service advocates must provide their CV/resume and references upon request. Advocates providing fee-for-service assistance are obligated to present their clients and guarantors with service agreements that clearly define their scope of practice, fee schedule, and terms. Advocates provide the client the projected length and scope of the relationship, keeping in mind criteria for appropriate termination of that relationship.

3: Protecting Confidentiality and Privacy

Advocates respect each client's right to privacy and abide by all relevant laws and regulations as they pertain to the confidentiality of records and personal identifiable information. Advocates shall, at all times, safeguard and protect the confidentiality of all medical records, and the identity of, and communications with, their clients.

Advocates will respect client's decisions concerning what health information is disclosed to others (family, friends, etc.), including the guarantor, in circumstances where the guarantor is not the client.

Before the termination of services to a client, the advocate will inform the client about the advocate's records retention policy.

4: Fostering Autonomy

Advocates shall treat all clients with compassion and respect. They will honor their clients' personal values concerning care and the right to be involved in all decisions that affect the clients' care. Advocates uphold and respect all patients' rights by promoting recognition of existing statutory rights and supporting the rights of disenfranchised people and communities to receive fair and equal treatment.

Advocates are dedicated to promoting their clients' right to exercise autonomous decision making and meaningful informed consent. They strive to ensure their clients are fully aware of and understand all care and treatment options, including potential risks, benefits, and available alternatives (Western, traditional, alternative, complementary, integrative or others). Advocates will attempt to provide clients with complete information to facilitate informed decision making. Advocates respect their clients' dignity and the freedom to make decisions grounded in each individual's cultural, spiritual, and ethical context. An advocate's role is to ensure a client's wishes, if known, are the guiding force behind decisions affecting medical care and the withholding or withdrawing of treatment.

In the event a legally designated surrogate becomes a client's decision-making agent, an advocate is encouraged to faithfully convey to the surrogate the client's relevant medical history, as necessary, as well as any personal conversations in which the client may have expressed certain wishes to the advocate.

Advocates shall encourage clients to complete necessary documentation as appropriate (e.g., Durable Power of Attorney for Healthcare; Durable Power of Attorney for Financial Affairs; Advance Directives).

5: Provision of Competent Services

Advocates have a responsibility to inform clients of their specific areas of proficiency and only to assist clients within those areas in which they have demonstrated expertise. If a client needs assistance in an area in which an advocate does not have sufficient knowledge or training, the advocate is obligated to refer the client to the appropriate system or resource for assistance.

Advocates ensure they have adequate referral systems in place to assist clients who need services the advocate is unable to provide. Advocates express respect toward their clients and toward other medical and non-medical professionals with whom they work.

6: Avoidance of Impropriety and Conflicts of Interest

Advocates shall not accept remuneration for making referrals to other providers or services, nor steer clients to products or services from which the advocates will profit financially or earn a commission.

Advocates shall not accept paid advertising on their websites for products or other service providers. Advocates shall not require a client to purchase or subscribe to any outside service in order to benefit from the advocate's services.

A conflict of interest exists when there is a substantial risk that an advocate's services to a client will be materially limited by the advocate's personal or professional interests. An advocate shall not start or continue to provide services to a client when a conflict of interest exists, unless both of the following apply:

- a) the advocate will be able to provide competent and diligent services to the client, and
- b) the client gives informed consent, confirmed in writing.

A patient advocate may accept from a client a gift that is not substantial in value. A patient advocate shall not accept from a client multiple gifts with a combined value that is substantial. For purposes of this standard, a value greater than \$75 is presumed to be substantial.

7: Avoidance of Discriminatory Practices

Essential to the profession of advocacy is the belief that equal access to appropriate healthcare and treatment is the right of each individual. Advocates strive for clients' equal access to health services without regard to age, race, religious/spiritual practice, culture, ethnicity, sexual orientation or gender identity, or immigration status.

Advocates are committed to assisting clients of all cultural and ethnic backgrounds. They shall be mindful of the cultural context of medicine and each client's cultural contexts by respecting individual perspectives. When unfamiliar with a client's ethnic or cultural background, advocates will work to understand preferences, and to include that regard into the provision of the client's healthcare.

8: Continuing Education & Professional Development

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. Advocates participate in the continued learning of their colleagues by sharing information and resources for the benefit of the profession and the public.

Where applicable, advocates shall obtain continuing education credits as dictated by professional license and regulatory/credentialing bodies. Advocates shall consult with colleagues regarding challenging client situations as an opportunity to learn. In order to foster development of the advocacy profession and of junior colleagues, advocates will participate in the professional development of other patient advocates by mentoring or participating in professional education programs, as appropriate.

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Patient Advocate Certification Board

Competencies and Best Practices required for a Board Certified Patient Advocate (BCPA)

Attribution

The Patient Advocate Certification Board (PACB) recognizes the importance of this Competencies and Best Practices document as a guideline for professional practice in the field of patient advocacy and for development of an assessment process for certification.

The initial draft emerged from a diverse task force of advocacy practitioners and educators drawing on numerous sources and their own professional experiences. The draft was reviewed and edited by the PACB, then posted for a one-month period of public comment, during which time the PACB received valuable feedback from many advocates and other professionals. Those comments and suggestions led to extensive revisions and clarifications.

This current version reflects the broad knowledge and insights of our diverse professional community.

Introduction

Understanding that no advocate could ever be able to provide every service clients accessing the healthcare system might need or benefit from, these lists of competencies have been developed in two categories:

1. Core functions and skills which every advocate must be able to perform;
2. More specialized skills that an advocate may not possess but must be able to recognize and understand so that, when needed, they can refer their clients to the appropriate professionals.

The second category requires advocates to realize when clients' needs are beyond their own competencies. This realization is a skill unto itself; therefore, these competencies and best practices are categorized accordingly.

The Domains of Patient Advocacy

1. Scope of Practice and Transparency
2. Empowerment, Autonomy, Rights, and Equity
3. Communication and Interpersonal Relationships
4. Healthcare Access, Finance, and Management
5. Medical Knowledge and the Healthcare System
6. Professionalism, Professional Development, and Practice

1. Scope of Practice and Transparency

Patient Advocates will:

- a. Provide to potential clients clear, accurate, and complete information about training, education, experience, credentials, and limitations, as well as any possible fees and areas of potential conflict of interest;
- b. Inform clients about the limits of their scope of practice and advise clients strictly within their defined area of proficiency;
- c. Develop clear and achievable expectations with the client to encourage a strong working relationship and productive advocacy;
- d. Obtain, maintain, and protect the privacy of any and all medical records required to serve the client's needs, sharing them with the client and anyone designated by the client;
- e. Abide by all relevant laws and regulations related to confidentiality of medical and identity information including, but not limited to, HIPAA;
- f. Avoid making any decision for, or on behalf of, a client;
- g. Avoid diagnosing or prescribing any medical/mental health treatment for clients, even if the advocate has additional licensure or training;
- h. Refer clients to qualified alternate professionals if a client's needs are outside the scope of the advocate's knowledge or training;
- i. Adhere at all times to the Ethical Standards defined by the Patient Advocate Certification Board (PACB);
- j. Provide a written service agreement to each guarantor and client, both paid and pro bono, that clearly sets forth the nature and scope of services, fee schedule, terms, projected length of the relationship, and the criteria for appropriate termination of the relationship.

2. Empowerment, Autonomy, Rights, and Equity

Patient Advocates will:

- a. Treat clients fairly regardless of age, race, religious/spiritual practice, culture, ethnicity, sexual orientation or gender identity, and immigration status;
- b. Promote equitable access to appropriate and safe health care and treatment;
- c. Offer continuous client-centered services that represent the best interests of the client, as determined by that client (or a legal healthcare proxy);
- d. Foster self-determination and client engagement, treating the client with respect and compassion in all interactions;
- e. Respect the right of clients to make their own decisions.
- f. Provide clients with information and resources to facilitate informed decision-making regarding care and treatment, including palliative and end-of-life care;
- g. Assist clients in understanding care and treatment options, including potential risks, benefits, and available alternatives;
- h. Convey relevant medical history, statutory patients' rights, and possible care options to any legally designated surrogate, as authorized by the client, including personal conversations in which the client may have expressed certain wishes that might guide informed decisions;
- i. Understand and apply current and appropriate laws, documents, and approaches (e.g., the national standards for Culturally and Linguistically Appropriate Services (CLAS); Beauchamp and Childress' Four Principles of Biomedical Ethics; or state and/or institutional statements of Patient Rights) to protect client's rights and choices;
- j. Educate clients about important decision-related healthcare documents which may include, but are not limited to: Durable Power of Attorney for Healthcare, Durable Power of Attorney for Financial Affairs, Advance Directives, Living Wills, Do Not Resuscitate orders (both in-hospital and out-of-hospital), and similar documents. Encourage clients to complete and save such documents, as appropriate.

3. Communication and Interpersonal Relationships

Patient Advocates will:

- a. Provide empathetic, non-judgmental, supportive listening and interactions that promote self-determination, well-being, resilience, and confidence;
- b. Collaborate effectively with other members of the healthcare team, both in and out of the hospital, to ensure appropriate and compassionate care for the client;
- c. Include the family and caregivers in the client's planning process according to the client's wishes;
- d. Provide any written communication and documentation requested by the client in a timely, appropriate, and professional manner;
- e. Incorporate into communications the complex interplay of biological, psychological, and social factors that enhance the client's functioning and well-being;
- f. Advocate to alleviate suffering, promote health, promote safe care, and encourage well-being whenever and wherever possible;
- g. Utilize appropriate style/approach to meet the client's cognitive, literacy, and personality characteristics;
- h. Utilize basic conflict management skills in interactions between the client and family, health professionals, or other relevant stakeholders;
- i. Integrate cultural, gender-based, and religious/spiritual perspectives that may influence the client's experience of illness, pain management, treatment, and health.

(Specialized) Communication and Interpersonal Relationships Skills:

The following skills are more specialized and may be referred services. See the Introduction section of this Competencies and Best Practices document.

Patient Advocates will:

- j. Recognize the need for advanced skills in conflict management or professional mediation and facilitate client access to such resources when the situation warrants;
- k. Recognize when cultural, gender-based and/or religious/spiritual perspectives will significantly affect client outcomes and facilitate client access to advanced expertise in this area when needed.

4. Healthcare Access, Finance, and Management

Patient Advocates will:

- a. Understand and be able to communicate generally how the healthcare system functions, and the roles, responsibilities, barriers, and constraints of patients, payers, and providers within the system;
- b. Facilitate the client's navigation through the complexities of the healthcare system continuum;
- c. Clarify care transitions and assist clients in appropriate aspects of these changes;
- d. Comprehend and apply the fundamentals of prescription drug costs and coverage for all clients;
- e. Recognize barriers to care coordination and work with clients and providers to overcome them, requesting provider-to-provider conversations and other client-focused collaboration as required;
- f. Understand and communicate to the client the basics of health insurance, Medicare, Medicaid, and other programs that affect payments for the client's medical needs, including appropriate state variations and differences among programs;
- g. Gain fluency in basic medical bill interpretation and apply the general provisions of insurance coverage to each client's situation;
- h. Offer information and empathy to clients experiencing the financial, emotional, and/or physical impact of medical debt;
- i. Integrate community-based resources to support and sustain the client's well-being;
- j. Utilize appropriate grievance, appeals, and complaints processes.

(Specialized) Access, Finance, and Management Skills:

The following skills are more specialized and may be referred services. See the Introduction section of this Competencies and Best Practices document.

Patient Advocates will:

- k. Recognize the need for advanced expertise in health insurance coverage regarding such issues as omissions, impediments, shortfalls, subsidies and tax credits, metrics, potential penalties, and alternative insurance providers, and facilitate client access to qualified professionals in this area;
- l. Recognize the need for advanced expertise in medical billing, claims, denials or other payment-related issues and facilitate client access to appropriate expertise when needed.
- m. Recognize limitations in standard grievance, appeals, and complaints processes and facilitate client access to appropriate legal expertise when needed.

5. Medical Knowledge and the Healthcare System

Patient Advocates will:

- a. Maintain familiarity with basic medical terminology, major life-threatening illnesses, and chronic diseases;
- b. Explain the structure and functionality of healthcare facilities and provider groups to clients and expose resources available through each system;
- c. Access the full range of healthcare providers and care delivery models and enable second opinion options;
- d. Assist clients to coordinate care among many clinicians, settings, and affiliated providers;
- e. Conduct research to uncover detailed and reliable medical information relevant to each client.
- f. Promote safe care and the patient's awareness of patient safety issues at all times, which may include but are not limited to diagnostic accuracy, and prevention of hospital-acquired infections, pharmaceutical and biologic drug or medical device errors, care coordination errors, radiologic (imaging) errors, and other potential health care related hazards and errors.

(Specialized) Medical Knowledge and the Healthcare System

The following skills are more specialized and may be referred services. See the Introduction section of this Competencies and Best Practices document.

- g. Recognize the need for advanced expertise in research on medical options and research trials and facilitate client access to qualified professionals when needed.

6. Professionalism, Professional Development, and Practice

Patient Advocates will:

- a. Assess the client relationship on a regular basis, continue to recognize, develop, and maintain professional boundaries as defined in the Ethical Standards for a Board Certified Patient Advocate and avoid situations that may jeopardize those boundaries;
- b. Maintain, update, and provide proof when required of all credentials, liability and business insurance, legal contracts, and other practice-related requirements;
- c. Continue to develop skills and maintain competence in all specific areas of expertise;
- d. Work within the scope of the BCPA credential and obtain continuing education credits, as required;
- e. Keep abreast of laws, policies, research developments, and trends that affect the practice of patient advocacy;
- f. Take initiative to seek out colleagues, mentors, and other experts regarding challenging client situations.

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