A. Attribution

PACB believes this document to be the strongest statement of ethics, adapted from, and with thanks to the individuals and organizations that built the foundation of professional patient advocacy. The goal is to establish patient advocacy as an honorable and principled profession, trusted by those who will work with these professionals, and above reproach in its reputation.

This document builds on several documents that have served as the basis of our profession. An ethical framework for patient advocacy was first proposed by H. Kenneth Schueler in 2010 to the Board of the National Association of Healthcare Advocacy Consultants (NAHAC). Variations of these tenets were later adopted by NAHAC as its Code of Ethics. Separately, in 2011, the Alliance of Professional Health Advocates (APHA) adopted and published its Code of Conduct and Professional Standards. In addition, NAHAC developed Best Practices that demonstrated the ethical standards that guide the work of patient advocates. These seminal and inspiring efforts have all contributed to making PACB’s Ethical Standards a lasting document that can serve to strengthen the quality of our work and respect for the profession of patient advocacy.

B. 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.

C. Ethical Standards

1: The Role of an Advocate
The role of an advocate is informational, not medical. Advocates are committed to helping clients and client communities make informed choices and access resources. Advocates shall not recommend specific treatment choices, provide clinical opinions, or perform hands-on 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 being paid) 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 that 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. They share with 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 personal information 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 their 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 that 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 that a client’s wishes, if known, are the guiding force behind decisions affecting medical care and the withholding of care.

In the event that 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 that they have adequate referral systems in place to assist clients who need services the advocate is unable to provide. Advocates express respect towards their clients and towards 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 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, and 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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