

These principles and the companion background brief constitute NPAF's board-approved policies for achieving equitable access to affordable quality care for all patients, caregivers and families. NPAF updates these policies annually to determine how to prioritize advocacy and public policy goals addressing the organization's core domains: equity, access, affordability and quality.

## Equity

Culture, ethnicity, geographic location and other societal factors may contribute to disparities that patients experience when trying to access care. NPAF supports policies that consider social circumstances and determinants of health that promote equitable access to care.

### 1. Financial Toxicity and Social Needs Navigation

- a. Patients and families should have equitable, expeditious access to financial and social needs navigation in the setting of complex or chronic conditions as a standard of practice for quality care delivery.
- b. All patients and families should be assessed to identify the need for financial assistance, transportation, social and household material support (i.e., food, energy, and housing) early in the course of illness and throughout the care continuum, with referral processes in place so they can secure quality navigation services and safety net resources.
- c. Research evaluating social determinants of health and the impact of financial toxicity, eligibility restrictions and the provision of navigation services in addressing these burdens should be prioritized to support accountability for quality care improvement and associated payment reforms.

### 2. Federal Poverty Level and other Safety Net Supports and Services

- a. Federal poverty threshold adjustments and other program eligibility requirements should not interfere with the health and well-being of patients and families who rely on these safety net supports and services to access needed care.
- b. Policymakers and investigators should prioritize research funding for the development and dissemination of effective interventions that link vulnerable populations with available safety net supports and services.

### 3. Medicaid and Children's Health Insurance Program (CHIP) Expansion

- a. Congress and the states should expand and sustain Medicaid and CHIP coverage and services to meet the needs of low-income adults and children, particularly families confronting complex chronic conditions.
- b. The Department of Health and Human Services (HHS) and the states must avoid limitations on Medicaid eligibility, coverage and benefits that impede equitable access to care, including block grant financing and burdensome cost-sharing or work requirements for beneficiaries.

## Access

NPAF promotes policies that ensure equitable access to insurance coverage and quality care under the Affordable Care Act, Medicare, Medicaid and other public and commercial plans, particularly to support needs of low-income and other disadvantaged populations.

### 1. Coverage Protections and Expansion

- a. All people regardless of race, ethnicity, gender, age or geographic location deserve access to adequate, affordable health insurance coverage options that meet their unique health care needs and socioeconomic circumstances.
- b. Understandable educational resources and information about health insurance coverage, accessibility and beneficiary responsibility should be readily available to the public.
- c. Key provisions that safeguard patients from discriminatory practices and disparate outcomes should be expanded or at least preserved among all health insurance plans and utilization review activities. This may include opposing any policies that will:
  - Remove pre-existing conditions restrictions
  - Impose continuous coverage requirements and penalties
  - Impede individual choices among plans and prescribed treatments
  - Significantly increase premium and out of pocket costs (deductibles, coinsurance and copayments)
  - Restrict coverage and impose lifetime limits
  - Destabilize the insurance market
  - Undermine federal cost-sharing reduction payments that lower out-of-pocket costs for qualifying, lower-income enrollees
- d. Policymakers should hold all health plans accountable for providing:
  - Adequate coverage of essential health benefits
  - Clear and understandable appeals processes
  - Transparent provider networks and formularies
  - Consistent coverage that does not make plan changes after open enrollment ends
  - Quality evaluation and understandable reporting about insurance plans available in the market

### 2. Insurance Benefit Design and Utilization Management

- a. Health plans and regulatory agencies should:
  - Ensure benefit design and utilization management practices are clear, understandable, flexible and evidence based.
  - Provide transparent processes that inform patients and practitioners about plan updates that may result in changes to prescribed treatments.
  - Complete utilization management determinations within 24 hours for urgent medical needs, and within 48 to 72 hours for all other medical need.
  - Structure step therapy protocols and other utilization management practices in a way that does not impede on professional clinical judgement or diminish the patient-clinician relationship and their shared decision-making.

### **3. Personalized and Value-Based Care**

- a. Access to personalized care, diagnostics and precision medicine should be equitably available to foster shared decision-making and value-based care that prioritizes patient and family preferences while also improving health and quality of life outcomes.
- b. Promoting equitable and affordable access to clinical trials for all populations is an essential aspect of quality care delivery, and trials participation expansion efforts should include:
  - Streamlined implementation and enrollment processes
  - Collaborative development and dissemination of culturally appropriate information about clinical trials and enrollment opportunities to reach diverse patient populations
  - Coverage of routine health costs and support for non-medical costs associated with trial participation (e.g., transportation costs)
  - Increased access to and participation from currently underrepresented groups
  - Implementation of and improvement in expanded access provisions that follow established ethical guidelines enabling therapeutic availability for individuals unable to participate in a clinical trial and who have exhausted other treatment options
- c. Medical and health services research should include investment in building the evidence base for delivery of person-centered care.

## **Affordability**

High total costs of care often force families to choose between the burdens of paying for treatments and meeting living expenses. To minimize financial distress and household material hardships that disproportionately affect vulnerable populations.

### **1. Total Costs of Care and Transparency**

- a. Policy makers should prioritize solutions that directly lower patients' out of pocket costs. Policies that affect other stakeholders should not inadvertently raise the amount that patients are expected to pay, including through deductibles, cost-sharing and premiums.
- b. Understandable and transparent cost information and resources should be publicly available so that patients may consider treatment benefits and tradeoffs in the context of person-centered care planning and shared decision-making throughout the care continuum and across all care settings.
- c. Patients should have opportunities to learn about and meaningfully discuss the cost of their care, both before and after making a treatment decision, in ways that are culturally appropriate and sensitive to their needs and circumstances.
- d. Pricing transparency regulations should be applicable to all sources of patient cost so that patients can make more informed choices and prepare for the financial obligations associated with their care.
- e. Savings generated through discount programs or price negotiations need to benefit low-income patients.

## **2. Surprise Medical Bills and Network Adequacy**

- a. Patients should not be held financially responsible for balance bills due to unexpected out-of-network care.
- b. Patients should be notified when they use out-of-network providers, facilities or services and information regarding network status should be publicly available, up-to-date and easily accessible.
- c. Patients should be directly informed of estimated out-of-pocket costs for health services prior to delivery when feasible so they have the opportunity to explore other options, if available, and consent to the services.

## **3. Medical Debt and Credit Protections**

- a. Patients should have sufficient protections and time to either contest or reconcile medical bills and debts with providers or payers.
- b. Consumer reporting agencies should prioritize equitable credit rating and fair reporting practices in order to minimize distressing medical debt burdens that can follow patients and families for years, even after the debt has been settled.

## **Quality**

Patients must be able to participate as partners in their care decisions in ways that shape a coordinated care experience and match treatments with personal values. NPAF encourages care teams to integrate person-centered care principles throughout the care continuum and in all aspects of value-based care reforms.

### **1. Skilled Communication, Shared Decision-Making and Patient Engagement**

- a. Patients and families should be positioned as essential stakeholders for contributing person-centered quality care perspectives and expertise in all value-based health reform initiatives including value assessments and clinical pathways.
- b. Health systems and insurers should outline and employ transparent processes that consistently include patient and family perspectives throughout development, implementation and evaluation of new payment and care delivery models.
- c. Value-based health reform initiatives should prioritize standards, quality measures and patient- and caregiver-reported outcomes to evaluate availability of skilled communication, shared decision-making, care coordination and essential support services that match treatments with values.
- d. In order to support shared decision-making and goal concordant care, care teams should provide patients and families with care planning resources and decision support tools to encourage communication about their personal values and preferences.

### **2. Palliative Care, Pain Management, Psychosocial Support and Rehabilitation Services Integration**

- a. Clinicians should routinely assess patients and families for palliative care, pain management, psychosocial support and/or rehabilitation needs throughout the care continuum. By appropriately integrating services and referral processes across care settings, clinicians can maximize their patients' quality of life and minimize functional impairments.

- b. Improving public and professional awareness about these supportive services as standard of practice in the setting of complex chronic conditions for quality care delivery alongside disease-directed treatment is imperative.
- c. Clinicians in all care settings should receive frontline clinician training in person-centered communication skills, care coordination and transitions, symptom management and shared decision-making.
- d. Policymakers and investigators should prioritize research on practices for improving palliative care, psychosocial support, impairment-driven rehabilitation and integrative pain management.

### **3. Caregivers Engagement and Support**

- a. Clinicians and health systems should routinely assess caregivers, an essential part of the unit of care, for their information and support needs.
- b. Caregivers should systematically receive the information, training and resources they need to perform their caregiving roles and responsibilities.
- c. Policymakers and investigators should prioritize new research focusing on the development and implementation of effective interventions for caregivers.