

Policy Principles

These principles constitute National Patient Advocate Foundation's (NPAF) board-approved policy options for advancing its person-centered agenda to position patients and caregivers as engaged partners at the heart of healthcare.

Explicitly embedding a strong health equity foundation, NPAF's policy principles affirm holistic health system approaches for supporting patients' physical, behavioral and financial health needs that are essential for well-being. NPAF policy staff review these principles annually to consider updates that improve alignment of our health equity focus with policy and advocacy efforts addressing unmet needs of limited-resourced populations in their communities. These considerations guide NPAF's operational determination of specific positions and priorities for community outreach, grassroots mobilization, and legislative, regulatory, and other influential advisory roles and advocacy actions taken throughout the year.

Advancing Person-Centered Care: Equitable Access, Affordability and Quality

Social determinants of health (SDOH), race, literacy, and the complexity of the US health care system contribute to access barriers and other disparities that impact physical, behavioral and financial health. These burdens are exacerbated for patients with complex chronic conditions living on low-income and in medical shortage areas. The costs of care often force families to choose between paying for treatments and meeting living expenses. These burdens drive up distress and household material hardships that disproportionately affect limited-resourced populations,

NPAF prioritizes policy approaches that are culturally sensitive and expressly consider SDOH and other social factors as part of improving equitable access, affordability and quality. Through our strategic advocacy efforts, we build critical community connections and collaborative partnerships across multiple stakeholder sectors to pursue health system solutions aligned with the following principles:

1. Financial and Social Needs

- a. Establish expeditious access to financial and social needs navigation as a standard of practice for quality care delivery.
- b. Integrate needs navigation services that assess and address individuals' financial and social concerns by linking patients to available financial assistance, household material supports (i.e., food, energy, housing, transportation) and other safety net resources in all care settings early on and throughout the course of complex chronic conditions.
- c. Intensify research investment to develop evidence evaluating the impact of needs navigation in addressing SDOH, financial and psychosocial distress, safety net utilization and outcomes disparities.

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

- a. Strengthen the coverage, services, and overall experience of Medicaid and CHIP to meet the multidimensional needs of all limited-resourced families confronting complex chronic illness.
- b. Avoid limitations on Medicaid eligibility, coverage and benefits that impede access to care, including block grant financing, enrollment hurdles, and burdensome cost-sharing or work requirements for beneficiaries.

3. Federal Poverty Level and other Safety Net Supports and Services

- a. Federal poverty threshold adjustments and other program eligibility requirements must not interfere with health and well-being of patients and families who rely on these safety net supports and services.
- b. Increase research investments supporting development and dissemination of effective interventions that link limited-resourced populations with available financial support and safety net programs.

4. Obtaining and Using Health Insurance Coverage

- a. All people must have access to adequate and affordable medical and behavioral health care through insurance coverage that provides essential health benefits and supports social needs regardless of race, ethnicity, gender, age, geographic location, employment and disability status.
- b. Protect all patients from discriminatory insurance policies and practices that can lead to disparate health outcomes. This may include policies that restrict coverage for pre-existing conditions, impose burdensome cost-sharing requirements or penalties, and impose lifetime coverage limits.
- c. Reinforce health insurance plan accountability for conducting robust quality evaluation and providing understandable and person-centered reporting about insurance options, benefits and coverage limitations.
- d. All health insurance plans must play a meaningful role in mitigating inequities that includes transparency in providing understandable and person-centered:
 - 1) *Information and resources* explaining beneficiary rights and responsibilities as well as how to enroll in coverage and utilize benefits. This includes benefit design features, costs of care, and processes such as prior authorization, step therapy, and appeals.
 - 2) *Processes* that are evidence-based and flexible to account for patients' personal health, financial, and social circumstances and support meaningful patient connections to information, resources and services they need to choose and use their plan coverage and benefits effectively.
 - 3) *Communications* in multiple formats (written, virtual, by phone) that are culturally sensitive and linguistically appropriate, understandable for various health literacy and reading levels and accessible to accommodate hearing, visual or other functional impairments.
 - 4) *Protections* that preserve patient-practitioner relationships and shared decision-making.

5. Expanding Access to Care Through Telehealth Services

- a. Telehealth services via multiple means (phone, audio/video, other platforms) must be reliably and equitably available to all populations. Expanding services requires mitigating infrastructure, technology, language and other barriers that impede access for many rural communities and limited resourced populations and aligning with person-centered quality practice standards that reflect patient and caregiver needs and preferences.
- b. Assess all patients to identify their information technology access aligned with person-centered quality practice standards, and support needs for using telehealth services when they are appropriate and accessible. This includes having processes in place to assist in scheduling a telehealth appointment and equipping patients and caregivers with resources and personalized guidance they need to feel prepared for participating in a virtual visit by phone, audio/video or other platforms.
- c. Increase investment in research and skills development training for person-centered telehealth services delivery, including evaluating the quality, effectiveness and impact of these services on SDOH and other factors causing health disparities.
- d. Intensify research investment to develop and test practical approaches for using telehealth to alleviate healthcare access barriers while promoting accountability for quality improvement, with emphasis on expanding access to quality physical and behavioral health care services in medical shortage areas and for limited-resourced communities.

6. Integrating Personalized and Value-Based Care

- a. Expand access to personalized care, diagnostics and precision medicine to foster shared decision-making and value-based care that prioritizes patient and family needs while also improving health and quality of life outcomes.
- b. Increase investment in medical, behavioral and health services research with emphasis on integrating the perspectives of diverse patient populations.

- c. Improve accessibility and affordability in clinical trials for all patient populations regardless of diagnosis, income or location. Clinical trials expansion efforts must:
 - 1) Streamline implementation and enrollment processes
 - 2) Develop and disseminate clear and culturally sensitive information about clinical trials and enrollment opportunities collaboratively in communities to effectively reach diverse patient populations
 - 3) Cover routine health costs and non-medical costs associated with trial participation (e.g., transportation costs)
 - 4) Increase outreach, access to and participation from underrepresented populations
 - 5) Implement and improve 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

7. Total Costs of Care and Transparency

- a. Promote solutions that directly lower patients' out of pocket costs and mitigate potential outcomes that raise the amount that patients are expected to pay, including through deductibles, cost-sharing and premiums.
- b. Increase availability of understandable and transparent cost information, resources and public reporting to support consideration of 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. Enhance opportunities for patients and their families to learn about and meaningfully discuss the cost of their care, both before and after making a treatment decision, in ways that are culturally sensitive and responsive to their needs and circumstances.

- d. Apply pricing transparency regulations to all sources of patient cost and promote access to information that helps patients make more informed choices and prepare for the financial obligations associated with their care.
- e. Savings generated through discount programs or price negotiations must benefit low-income patients and limited-resourced populations.

8. Surprise Medical Bills

- a. Patients must not be held financially responsible for balance bills due to unexpected out-of-network care.
- b. Patients must be notified about out-of-network providers, facilities or services in a timely manner and have access to publicly available network information that is up-to-date and easily accessible. Disclosure, notice and consent forms cannot substitute for meaningful cost of care conversations.
- c. Accurate information about estimated out-of-pocket costs for health services must be provided to patients as early as possible during the time treatment is being discussed so they are aware of their options, costs and protections.

9. Medical Debt and Credit Protections

- a. Provide sufficient protections and time for all patients and caregivers to either contest or reconcile medical bills and debts with providers and payers.
- b. Apply equitable credit rating and fair reporting practices to minimize distressing medical debt burdens that can follow patients and families for years, even after the debt has been settled.

10. Skilled Communication, Shared Decisions and Patient Engagement

- a. Position patients and families as essential stakeholders for contributing person-centered quality care perspectives and expertise in all value-based assessment, quality measures development and health reform initiatives.
- b. Apply transparent processes that consistently include diverse patient and family perspectives throughout development, implementation and evaluation of new payment and delivery models.
- c. Value-based health reform initiatives must embed practice standards, quality measures and accountability for patient- and caregiver-reported outcomes that evaluate availability and effectiveness of skilled communication, shared decision-making, care coordination and essential support services that match treatments with patient-determined values.
- d. Promote development and dissemination of care planning resources and decision support tools that foster patient and caregiver communication about their personal values, priorities and preferences to support shared decision-making and goal concordant care.

11. Palliative Care, Pain Management, Psychosocial Support and Rehabilitation Services Integration

- a. Routinely assess all patients with complex chronic conditions for palliative care, pain management, psychosocial support and/or rehabilitation needs throughout the care continuum with appropriate services integration and referrals processes in place across care settings to maximize their quality of life and minimize distress and functional impairments.
- b. Integrate these supportive services with disease-directed treatment as the standard of care in all settings.
- c. Expand availability and accountability for completing professional skills development training in person-centered communication, care coordination

and shared decision-making competencies for inter-professional practitioners in all care settings.

- d. Increase health services and other research investments to improve early and integrated delivery of these supportive services that optimize quality of life and mitigate distress for patients and their families.

12. Caregiver Engagement and Support

- a. Explicitly identify family caregivers as part of the unit of care and routinely assess, document and address their particular information and support needs.
- b. Systemize equipping family caregivers with the information, training, benefits and resources they need to support them in their caregiving roles and responsibilities.
- c. Increase investment in research supporting the development and implementation of effective interventions, insurance and employment benefits design and other assistance for family caregivers.