

Background Brief

Table of Contents

1. FINANCIAL AND SOCIAL NEEDS NAVIGATION	2
2. MEDICAID AND THE CHILDREN’S HEALTH INSURANCE PROGRAM (CHIP).....	4
3. FEDERAL POVERTY LEVEL AND OTHER SAFETY NET SUPPORTS AND SERVICES	6
4. OBTAINING AND USING HEALTH INSURANCE COVERAGE	8
5. EXPANDING ACCESS TO CARE THROUGH TELEHEALTH SERVICES	10
6. INTEGRATING PERSONALIZED AND VALUE-BASED CARE	13
7. TOTAL COSTS OF CARE AND TRANSPARENCY	14
8. SURPRISE MEDICAL BILLING.....	16
9. MEDICAL DEBT AND CREDIT PROTECTIONS.....	17
10. SKILLED COMMUNICATION, SHARED DECISION-MAKING AND PATIENT ENGAGEMENT	18
11. PALLIATIVE CARE, PAIN MANAGEMENT, PSYCHOSOCIAL SUPPORT AND REHABILITATION	19
12. CAREGIVERS ENGAGEMENT AND SUPPORT	21

Introduction

National Patient Advocate Foundation (NPAF) elevates patient and caregiver voices through person-centered advocacy that prioritizes equitable access to affordable quality care. A key aspect of our mission is to advance inclusive policies and practices responsive to the lived experiences and unmet needs of individuals coping with a broad range of disease diagnoses. Our work encompasses activities in four related areas: (1) skilled communication, (2) shared decision-making, (3) quality care improvement and (4) safety net services navigation. Health equity is a core objective guiding everything we do.

NPAF is the advocacy affiliate of Patient Advocate Foundation (PAF), which for more than 25 years has provided financial and social needs navigation and other direct charitable assistance for primarily low-income families with complex chronic conditions. PAF's services help reduce distressing burdens and material hardships caused by deteriorating health circumstances and costs of care. Experiences reported from the thousands of people served annually through PAF's efforts and input from our patient and caregiver grassroots network fuels NPAF's policy principles and advocacy agenda.

Advancing Equitable Access to Affordable Quality Care

The impact of social determinants of health (SDOH) on population health and health outcomes is receiving increased attention in health services research, public policy, and intervention initiatives to mitigate health disparities. Reinvigorated commitment from the World Health Organization¹ and various stakeholders in the United States has spurred more deliberate and consistent consideration of the community-level conditions and the wider set of forces and systems that contribute to SDOH challenges, health inequities and financial hardships confronting patients and their families. These factors hit limited-resourced populations particularly hard.

Public and private sector initiatives and partnerships have emerged to tackle the root causes and conditions that contribute to poor health and disparate outcomes in the US. This work is occurring alongside efforts to expand access to Medicaid and other safety net supports and services in multiple states. Yet concerning policy trends that restrict eligibility and eliminate the entitlement to Medicaid services have thwarted progress in some states. Dismantling the harmful effects of these restrictive policies is a necessary part of restoring and expanding access to vital programs for the low-income populations of patients and families whose lives literally depend on them.

PAF has decades of dedicated experience assisting patients and families in identifying their unmet financial and social needs and guiding them to available resources and safety net supports. At PAF, case managers talk to many thousands of patients and caregivers every year and have developed specialized expertise in handling the challenges of these cost

¹ World Health Organization. What are Social Determinants of Health? https://www.who.int/social_determinants/en/

conversations and other financial concerns. Virtually every one of these individuals contacts PAF because they are experiencing distressing issues related to the costs of their medical care, often agonizing about balancing those costs with the day to day demands of their lives. They may be experiencing problems with insurance coverage, inability to pay or even comprehend the bills that are piling up. Most know very little about the health care system, billing practices, insurance appeals or utilization management processes until they become seriously ill or disabled. They benefit from PAF's direct services, and in so doing, learn skills and locate resources that often help them become better advocates for themselves and in many cases, for others.

1. Financial and Social Needs Navigation

Backed by PAF data gathered from patients and caregivers, NPAF is pursuing a portfolio of policy solutions to establish financial and social needs assessment and navigation as a standard of practice so these services can ultimately become sustainable and accessible for all populations who would benefit from them.

People coping with serious illness and disability contend with a constellation of costs related to their conditions and care. The high costs accumulate from out-of-pocket expenses for treatments and medical services as well as transportation, childcare, lost wages and other indirect expenses. Many families are forced to choose between paying for medical care and basic living expenses such as groceries, utilities and rent. Caregivers also often absorb costs related to medical care, long-term services and assistance with activities of daily living. These distressing circumstances have been associated with a greater likelihood of treatment nonadherence,² poorer quality of life³ and higher mortality than those who do not experience financial hardship.⁴

Individuals who have no insurance or are underinsured typically endure the highest level of financial distress, but most patients and families dealing with chronic conditions are affected by costs of care. Mounting medical bills, increasing copays and cost sharing and the emergence of more effective but high-priced treatments for many conditions all contribute to financial burden. It is important for practitioners to expressly acknowledge the normalcy of patients having concerns about costs so that these conversations become an expected part of the clinical workflow that allows solutions to be explored.⁵

Findings from NPAF costs of care project collaborations funded by Robert Wood Johnson Foundation demonstrated that patients want and need to have these conversations, but

² Dusetzina SB, Winn AN, Abel GA, et al. Cost Sharing and Adherence to Tyrosine Kinase Inhibitors for Patients with Chronic Myeloid Leukemia. *Journal of Clinical Oncology* 2014 32:4, 306-311

³ Fenn KM, Evans SB, McCorkle R et al. Impact of Financial Burden of Cancer on Survivors' Quality of Life. *J Oncology Prac.* 2014 10:5, 332-338.

⁴ Ramsey SD, Bansal A, Fedorenko CR et al. Financial Insolvency as a Risk Factor for Early Mortality Among Patients with Cancer. *Journal of Clinical Oncology* 2016 34:9, 980-986

⁵ National Patient Advocate Foundation. Talking About the Costs of Health Care and the Impact of Financial Toxicity. 2019. Available at: <https://www.npaf.org/initiatives/cost-of-care-convo/>

often do not. The project's featured studies and stakeholder convenings revealed that: (1) patients and caregivers may be reluctant for a variety of reasons to bring up their financial concerns, (2) physicians are often uncomfortable talking about the costs of care or do not believe it is their role, and (3) both patients and professionals on their care teams often lack the skills and tools to facilitate these conversations.⁶ The bottom line is that health systems and practitioners within them must be supported with communication skills training and held accountable for establishing processes that integrate financial and social needs assessment and quality navigation referrals to effectively foster their patients' financial, physical and behavioral well-being.

Most research has studied the impact of financial distress on cancer patients, however, the extenuating circumstances are more severe in under-resourced individuals and likely span all diseases.^{7,8} Financial distress can affect anyone regardless of their insurance coverage and can be particularly concerning for the underinsured leading to uncertainty in navigating unexpected out-of-network costs, deductibles and copays among other complexities of the health care system.⁹ Moreover, patients in financial distress may experience a higher risk of bankruptcy,¹⁰ unemployment and loss of employer-sponsored health coverage.¹¹ Few hospitals, health systems, advocacy organizations and communities provide comprehensive financial and social needs support, but those that do have shown to significantly increase treatment adherence, improve outcomes and reduce overall costs for both patients and health systems.^{12,13}

NPAF's Roadmap findings and subsequent costs of care work reinforces the importance of communicating about these issues up front, regularly and as a normal part of care planning and shared decision-making. Literature also confirms that patients and families want information about insurance coverage and estimating expenses to avoid the worries of financial distress.¹⁴ Accordingly, NPAF's policy principles posit that health systems, payers and professionals should prioritize person-centered communication skills development and quality improvement initiatives that build competencies and accountability for identifying and discussing financial concerns sensitively and empathically as part of delivering high quality care.

⁶ National Patient Advocate Foundation. Talking About the Costs of Health Care and the Impact of Financial Toxicity. 2019.

⁷ Hincapie AL, Penm J, Burns CF. Factors Associated with Patient Preferences for Disease-Modifying Therapies in Multiple Sclerosis. *J Manag Care Spec Pharm.* 2017 Aug;23(8):822-830.

⁸ Valero-Elizondo J, Khera R, Saxena A et al. Financial Hardship from Medical Bills Among Nonelderly U.S. Adults with ASCVD. *JACC.* Feb 2019. 73(6):727-732

⁹ Chino F, Peppercorn JM, Rushing C, Kamal AH, Altomare I, Samsa G, Zafar SY. *Out-of-Pocket Costs, Financial Distress, and Underinsurance in Cancer Care.* *JAMA Oncol.* 2017;3(11):1582-1584. doi:10.1001/jamaoncol.2017.2148.

¹⁰ Ramsey S, Blough D, Kirchoff A et al. Washington State Cancer Patients Found To Be At Greater Risk For Bankruptcy Than People Without A Cancer Diagnosis. *Health Affairs.* 2013. 32(6):1143-1152

¹¹ Yabroff KR, Dowling EC, Guy Jr GP et al. Financial Hardship Associated With Cancer in the United States: Findings From a Population-Based Sample of Adult Cancer Survivors. *Journal of Clinical Oncology* 2016 34:3, 259-267

¹² Yezefski T, Steelquist J, Watabayashi K et al. Impact of Trained Oncology Financial Navigators on Patient Out-of-Pocket Spending. *Am J Manag Care.* 2018;24(5 Suppl):S74-S79

¹³ Ell K, Vourelkis B, Xie B et al. Cancer Treatment Adherence among Low-Income Women with Breast or Gynecologic Cancer: A Randomized Controlled Trial of Patient Navigation. *Cancer.* 2009 October 1; 115(19): 4606-4615.

¹⁴ Khandelwal N, Engelberg RA, Hough CL et al. The Patient and Family Member Experience of Financial Stress Related to Critical Illness. *J of Palliative Medicine.* Jan 2, 2020.

The Comprehensive Score for Financial Toxicity (COST) measure has demonstrated reliability and validity as a clinically relevant patient-reported outcome for measuring financial distress and its correlation with worse health-related quality of life.¹⁵ Other tools providing frameworks for assessing financial distress and patients' health-related social needs include PRAPARE¹⁶ and Health Leads' Social Needs Screening Toolkit.¹⁷ NPAF'S 2020 environmental scan revealed that the evidence behind financial and social needs assessment and navigation services is building, and the field is increasingly well-positioned to coalesce behind consensus-based practice guidelines development for quality accountability. At this stage, existing navigation programs range from comprehensive, individualized support to services that simply determine eligibility for financial assistance.

Notably, the Financial Advocacy Network, an initiative convened by the Association of Community Cancer Centers, has developed "Financial Advocacy Services Guidelines"¹⁸ that are being updated in 2022 with advisory input from NPAF. This process will further efforts to formalize characteristics, roles, and responsibilities of financial advocacy teams in the context of oncology practice. N/PAF has identified supplemental development and dissemination of evidence-backed quality needs navigation practice standards applicable for all diagnoses and care settings as a timely opportunity to convene and lead stakeholders in this collaborative activity.

Needs navigation reduces financial distress that produces better quality of life and outcomes for people while saving money for individuals and health systems. Building understanding and awareness about the value of these services, as well as developing the evidence base and accountability standards that drive quality services delivery, are fundamental next steps in creating and advancing a robust policy platform grounded in health equity principles. NPAF's navigation policy principles reflect our commitment to the core belief that all populations should benefit from reliable access to affordable care that includes financial and social needs navigation services as a standard of practice to mitigate patient and family exposure to financial distress.

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

Medicaid and CHIP are public safety net programs that provide health coverage to over 77 million low-income adults, disabled individuals, very low-income seniors as well as the infants and children who comprise approximately half (35 million) of the program beneficiaries.¹⁹ Medicaid covers one in five people in the U.S. and accounts for more than half of all spending for long-term services and supports for the elderly population and

¹⁵ de Souza JA, Yap BJ, Wroblewski K et al. Measuring Financial Toxicity as a Clinically Relevant Patient-Reported Outcome: The Validation of the COmprehensive Score for financial Toxicity (COST). *Cancer*. 2017 Feb 1;123(3):476-484.

¹⁶ NACHC. Protocol for Responding to and Assessing Patients' Assets, Risks and Experiences. Available at: <http://www.nachc.org/research-and-data/prapare/about-the-prapare-assessment-tool/>

¹⁷ The Health Leads Screening Toolkit. Available at: <https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/>

¹⁸ Association of Community Cancer Centers. Financial Advocacy Guidelines. Available at: <https://www.accc-cancer.org/home/learn/financial-advocacy/guidelines>

¹⁹ Medicaid.gov. September 2020. Medicaid and CHIP Enrollment Data Highlights. Available at:

<https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>

others with complex chronic conditions.²⁰ States are required to provide comprehensive benefits to Medicaid enrollees that span the entire continuum of care from birth and pediatric services to inpatient, outpatient, skilled nursing facilities and home health services for older populations.²¹

The Patient Protection and Affordable Care Act (ACA) strengthened the nation's largest health care safety net by expanding Medicaid coverage to adults under age 65 and to working families that earn up to 138 percent of the federal poverty level. Nevertheless, a June 2012 Supreme Court ruling allowed states to opt out, leaving a patchwork of states that have pursued expansion of Medicaid eligibility. As of January 2021, thirty-nine states and Washington, D.C. have adopted Medicaid expansion.²² Analysis from the Commonwealth Fund has linked Medicaid expansion to racial equity improvements in health insurance coverage and access to care,²³ signaling that this policy strategy represents a promising step for improving access in these populations among the twelve states that have yet to expand Medicaid coverage.

As Medicaid enrollment and health care costs trended upwards following ACA enactment, efforts to control spending and improve care delivery have prevailed through an influx of Section 1115 waivers that exempt states from certain federal Medicaid requirements. Most waivers appear to help patients and families by expanding coverage eligibility to certain individuals and better managing benefits such as behavioral health or managed long-term services and supports. Others focused solely on containing costs have concerning elements that effectively diminish access to coverage and benefits.²⁴

Block grant proposals that restrict funding and impose stricter utilization management rules, such as closed formularies, represent a tradeoff between reducing costs and access to care. Policy experts have warned that proposals to alter Medicaid's financing structure to a block grant results in fewer eligible beneficiaries and much thinner coverage.²⁵ Work requirement waivers raise practical and administrative barriers to accessing coverage and have a substantial impact on patients and families, many of whom report significant challenges maintaining employment as a direct result of their treatments or caregiving responsibilities. In fact, the Arkansas work requirement proposal led to 18,000 people losing

²⁰ Kaiser Family Foundation. 10 Things to Know about Medicaid: Setting the Facts Straight. Updated March 6, 2019. Available at: <https://www.kff.org/medicaid/fact-sheet/medicaid-pocket-primer/>

²¹ Medicaid.gov. Mandatory and Optional Medicaid Benefits. Accessed Jan 14, 2020. Available at: <https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits/index.html>

²² Kaiser Family Foundation. Status of State Action on the Medicaid Expansion Decision. Updated Nov 2, 2020. Available at: <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>

²³ Jesse C. Baumgartner et al., How the Affordable Care Act Has Narrowed Racial and Ethnic Disparities in Access to Health Care (Commonwealth Fund, Jan. 2020). Available at: <https://www.commonwealthfund.org/publications/2020/jan/how-ACA-narrowed-racial-ethnic-disparities-access>

²⁴ Kaiser Family Foundation. Approved and Pending Section 1115 Medicaid Waivers as of Jan 26, 2021. Available at: <https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/>

²⁵ Health Affairs Blog. Looking Inside Tennessee's Block Grant Proposal. Oct 4, 2019. Available at: <https://www.healthaffairs.org/doi/10.1377/hblog20191002.734156/full/>

their Medicaid coverage with a small decline in the employment rate triggering legal action that halted its implementation.²⁶

Fortunately for the children and families who rely on CHIP, Congress remains committed to funding and protecting the program in the long term.²⁷ Medicaid and CHIP have transformed over the decades since their inception to be critical safety net programs that ensure our nation's most vulnerable populations have access to quality health care. As policymakers continue to consider program reforms, NPAF will press for approaches that preserve and expand benefits and coverage for the millions of adults, children and families in need.

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

Government entitlement programs provide the public safety net protecting low-income individuals and families from the hardships and disparate outcomes of poverty. These programs include Medicaid and CHIP, Community Health Centers, the Supplemental Nutrition Assistance Program (SNAP), Low-Income Home Energy Assistance Program (LIHEAP) and family income support programs such as the Temporary Assistance for Needy Families (TANF), Supplemental Security Income (SSI), Social Security Disability, and others.

The safety net also includes a variety of private charitable assistance programs offered through local churches, food banks and free clinics as well as national programs like Meals on Wheels, NeedyMeds and PAF's services. Together, these public and private programs help address major gaps in assistance with health care, financial or food, energy and housing security. Safety net programs provide essential support for low-income patients and families, insured and uninsured individuals, working families caring for a seriously ill family member, people with disabilities, the elderly, pregnant women, those in need of mental health or addiction services and veterans.

PAF case managers consistently report that safety net programs addressing non-medical costs are vital to help relieve the financial burdens of complex chronic conditions. Each year almost one-third (30 percent) of patients receiving PAF assistance encounter debt crises that impair their ability to afford transportation expenses, housing, utilities, or nutritional needs.²⁸ In PAF's 2019 survey of over 2,800 patients receiving its assistance, 43% reported that day-to-day living expenses including rent, mortgage and utilities were the most important financial burdens requiring relief, followed by health insurance premiums (39%) and hospital bills (33%).²⁹

²⁶ Sommers BD et al. Medicaid Work Requirements – Results from the First Year in Arkansas. *N Engl J Med* 2019; 381:1073-1082 <https://static.politico.com/8d/24/6ef0e361444bb034aabc884b2606/sommers-arworks.pdf>

²⁷ Georgetown University Health Policy Institute. Center for Children and Families. 2018 Available at: <https://ccf.georgetown.edu/2018/09/19/clearing-up-confusion-about-the-impact-of-the-chip-funding-rescission-in-labor-hhs-education-appropriations-conference-agreement/>

²⁸ Patient Advocate Foundation. Internal Case Management Data. 2018.

²⁹ Patient Advocate Foundation. Retrospective Survey. February 2019.

Using Center of Budget and Policy Priorities data that correct for underreporting, safety net supports and services such as SNAP, TANF, SSI and tax credits lifted nearly 37 million people (including 7 million children) above the poverty line in 2018.³⁰ Federal policies governing safety net programs have vacillated based on the political landscape and in some instances include concerning proposals that threaten to drastically cut funding for certain nutrition, housing and non-defense discretionary programs. Enacting funding cuts would increase poverty, decrease the number of insured individuals, and widen income and racial disparities.³¹

The Office of Management and Budget in the prior Administration had considered technical changes to the federal poverty threshold by adopting a lower inflation adjustment measure that would further lower the poverty line. It is widely documented that the official poverty line is already too low and does not accurately represent income required to meet basic family needs.³² Lowering the poverty line triggers harmful downstream effects that disrupt individual's eligibility for health, nutrition, and other safety net programs at the same time rising health care costs have increased pressure on scarce safety net resources. Many charities already struggle to keep pace with demand as public programs become increasingly vulnerable in the face of decreased funding.³³

Pursuing policies that bolster the network of safety net services and supports nationally and in communities will be an essential aspect of addressing SDOH challenges and social needs that contribute to inequities experienced among limited-resourced populations.³⁴ Reimagining a federal poverty level that accurately reflects people's dire needs is critical to avoid underestimating the number of people who live in poverty. Coupled with maintaining adequate access to safety net services and supports, these are vital strategies to mitigate health inequities.

Vigilant monitoring of the poverty level and safety net landscape and vigorous advocacy will identify and neutralize threats to these essential supports.

³⁰ Center of Budget and Policy Priorities. Chart Book: Economic Security and Health Insurance Programs Reduce Poverty and Provide Access to Needed Care. Updated Dec 11, 2019. Available at: <https://www.cbpp.org/sites/default/files/atoms/files/9-2-15pov.pdf>

³¹ Center on Budget and Policy Priorities. Cuts to Low-Income Assistance Programs in President Trump's 2020 Budget Are Wide Ranging. May 15, 2019. Available at: <https://www.cbpp.org/research/federal-budget/cuts-to-low-income-assistance-programs-in-president-trumps-2020-budget-are>

³² National Research Council 1995. Measuring Poverty: A New Approach. Washington, DC: The National Academies Press.

³³ Center for Medicare and Medicaid Services. Speech: Remarks by Administrator Seema Verma at the National Association of Medicaid Directors (NAMD) 2017 Fall Conference. Nov, 11, 2017. Retrieved from: https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2017-Fact-Sheet-items/2017-11-07.html#_ftn3

³⁴ Shekarchi A, Gantz L, Schickedanz. Social Determinant of Health Screening in a Safety Net Pediatric Primary Care Clinic. Pediatrics May 2018, 142 (1 Meeting Abstract) 748; DOI:10.1542/peds.142.1_MeetingAbstract.748

4. Obtaining and Using Health Insurance Coverage

All patients and families must have access to health care that meets their needs and protects them from financial distress. Having adequate health insurance coverage that is affordable and available for all patient populations is a key strategy for achieving equitable access to care, and NPAF promotes policies that enhance and expand insurance coverage and quality care under the ACA marketplace, Medicare, Medicaid and other public, commercial and employer-sponsored plans.

ACA enactment expanded health coverage to approximately 20 million people in its early years.³⁵ It spurred a decline in uninsured rates across all U.S. racial and ethnic groups and significantly closed gaps in health coverage between black, Hispanic and white populations in states that expanded Medicaid.³⁶ Previously uninsured middle-income people could obtain private coverage through the newly created Marketplace (ACA exchanges) that regulated plan offerings and pricing and imposed important patient protections³⁷

While people may have drastically different health care experiences depending on their type of plan, they are largely protected from discrimination, inadequate coverage, and unfair pricing. Additionally, individual and small group private insurance plans must cover a basic set of essential health benefits in the following service categories: emergency services, hospitalizations, outpatient care, rehabilitation services, maternity and newborn care, mental health and substance use disorder treatment, prescription drugs, laboratory services, preventive services and chronic disease and pediatric care.³⁸

Despite the ACA's success, affordability challenges persist for people who do not qualify for financial assistance or cannot afford Marketplace coverage even with assistance. Moreover, millions of people remain uninsured.

Policymakers are considering a range of proposals aimed at expanding coverage, including through a public option, universal coverage or a single-payer "Medicare for All" approach.³⁹ Expanding coverage through a single-payer system raises important questions about the private sector's role, payment approach and financing. Some stakeholders have cautioned that a single payer system has potential to prioritize care standardization over care personalization, despite the desired outcome of significantly expanding access to care. Details of these various proposals and nuances about their implications for limited

³⁵ Urban Institute. Who Gained Health Insurance Coverage Under the ACA, and Where Do They Live? December 2016. Available at: <https://www.urban.org/sites/default/files/publication/86761/2001041-who-gained-health-insurance-coverage-under-the-aca-and-where-do-they-live.pdf>

³⁶ Ajay Chaudry, Adlan Jackson, and Sherry A. Glied, Did the Affordable Care Act Reduce Racial and Ethnic Disparities in Health Insurance Coverage? Commonwealth Fund, Aug. 2019.

³⁷ Congressional Research Service. Private Health Insurance Market Reforms in the Patient Protection and Affordable Care Act (ACA). February 2016. Available at: <https://fas.org/sgp/crs/misc/R42069.pdf>

³⁸ The Center for Consumer Information & Insurance Oversight. Information on Essential Health Benefits Benchmark Plans. Available at: <https://www.cms.gov/ccio/resources/data-resources/ehb.html>

³⁹ Johnson M et al. Medicare For All: An Analysis of Key Policy Issues. Jan 2020. HEALTH AFFAIRS 39, NO. 1 (2020): 133–141. Available at: <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2019.01040>

resourced populations and promoting health equity will be scrutinized by NPAF and many stakeholders as options evolve during ongoing policy discourse.

Even after coverage is obtained, access to quality care is still contingent on patients making the best use of their insurance coverage. PAF routinely helps patients navigate their insurance plan's benefit design, file appeals for denied claims, and understand how insurance coverage affects their financial responsibility for care. Providing proactive needs navigation services benefits patients by preparing them for making plan choices, contending with coverage challenges and costs of care they may incur based on their specific plan's policies.

Health insurance plans' widespread practice of utilization management involves internal evaluation of medical necessity, appropriateness and efficient use of health care services, procedures, and facilities under the provisions of the patient's health insurance plan. Prior authorization and step therapy are two common utilization management tools used in covering typically costly care. Prior authorization refers to pre-approval by the health plan for certain medications, imaging or services before they are covered.⁴⁰ Step therapy requires patients to try medicines on an insurer's preferred drug list before the insurer will cover the cost of another potentially more expensive medicine. Prior authorization and step therapy are routinely used by payers for coverage of medical care and prescription drugs⁴¹, yet patients are often unaware of these requirements at the time treatment plans and prescribing decisions are made with their physician.

In certain cases, prior authorization, step therapy, and other benefit design features can contribute to standardizing quality care. But requirements that lack transparency and flexibility create administrative burdens for prescribers and tremendous access problems for patients which can lead to delayed treatment, poor medication adherence and higher total costs.⁴² As a result, patients are deterred and delayed in their medication access, diagnostic tests or other therapies recommended by their physician to treat their condition. Plan requirements for non-medical switching to another treatment based on cost similarly put patients' health and well-being at risk. Although patients can appeal a coverage denial under these and other circumstances, the final decision usually rests with the health plan or insurance commissioner and takes valuable time, know-how and persistence to pursue the process.

Payers and prescribers are increasingly using technology to streamline claim transmission through electronic prior authorization (ePA) systems.⁴³ These efforts, when more broadly applied, should simplify plan processes for patients and improve access to care.

⁴⁰ Optum Rx®. Utilization Management Strategies. 2015. Available at: [https://cdn-](https://cdn-aem.optum.com/content/dam/optum3/optum/en/resources/fact-sheets/utilization-management-strategies-optumrx.pdf)

[aem.optum.com/content/dam/optum3/optum/en/resources/fact-sheets/utilization-management-strategies-optumrx.pdf](https://cdn-aem.optum.com/content/dam/optum3/optum/en/resources/fact-sheets/utilization-management-strategies-optumrx.pdf)

⁴¹ Chambers JD et al. Specialty Drug Coverage Varies Across Commercial Health Plans in the US. *Health Affairs*. July 2018. 37(7):1041–1047. Available at: <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2017.1553>

⁴² Seabury SA et al. Formulary Restrictions on Atypical Antipsychotics: Impact on Costs for Patients with Schizophrenia and Bipolar Disorder in Medicaid. *American Journal of Managed Care*. 2014;20(2), p. e52-e60.

⁴³ EMD Serono Specialty Digest TM Managed Care Strategies for Specialty Pharmaceuticals. 14th Edition. 2018.

Prescribed treatments, medications, diagnostic tests, or other therapies should be the result of personalized shared decision making between patients and their physicians based on what best meets the patient's needs and circumstances. While utilization management may be useful strategy within a plan's benefit design to reduce health care costs, it's imperative to apply these policies so they improve quality care rather than impede it.

NPAF's advocacy efforts continually reinforce opportunities for expanding coverage, its adequacy and affordability, and consumer understanding about using insurance and assistance effectively while addressing restrictive policies that impair access to care. For limited resourced populations, needs navigation is a vital solution to help people understand their eligibility for coverage, enrollment options and financial assistance availability to secure benefits, access needed care and understand their financial responsibility for that care.

5. Expanding Access to Care Through Telehealth Services

Telehealth effectively connects patients with their healthcare providers when in-person interactions are not clinically necessary, convenient, feasible or safe. Telehealth use and availability expanded significantly in response to the COVID-19 pandemic, with multiple policy changes accelerating adoption of telehealth for providing safe virtual care in 2020.

To contain community spread and protect patients and clinicians, the Centers for Medicare and Medicaid Services (CMS) issued temporary waivers allowing all beneficiaries to receive telehealth services in any location, including their homes. CMS also temporarily doubled the number of clinical and supportive services that Medicare beneficiaries could receive via telehealth, and waived cost-sharing for such visits during the public health emergency.⁴⁴ CMS issued a final rule specifying discrete telehealth services that could continue to be covered permanently, and a study has been commissioned to determine additional expansion opportunities.⁴⁵

Between one-quarter and one-third of Medicare beneficiaries across demographics had a telehealth service within the first three months of the policy change, including one-third using audio-only telephone visits. States have also followed suit by allowing new services to be delivered, broadening the types of clinicians that may deliver services and expanding the Medicaid populations that can use telehealth.⁴⁶ Likewise, private insurers have made similar policy changes that resulted in exponential growth of telehealth claims (up 4,347%) between 2019 and 2020.⁴⁷

⁴⁴ Medicare Telemedicine Health Care Provider Fact Sheet. <https://www.cms.gov/newsroom/fact-sheets/medicare-telemedicine-health-care-provider-fact-sheet>

⁴⁵CMS press release. <https://www.cms.gov/newsroom/press-releases/trump-administration-finalizes-permanent-expansion-medicare-telehealth-services-and-improved-payment>

⁴⁶ KFF. [State Efforts to Expand Medicaid Coverage & Access to Telehealth in Response to COVID-19](#). June 22, 2020. Accessed Jan 8, 2021.

⁴⁷ Telehealth Growth During COVID-19. AHIP. July 2020 <https://www.ahip.org/wp-content/uploads/Telehealth-Infographic-2020.pdf>

Patients and clinicians alike are embracing virtual care. Telehealth alleviates transportation and work disruptions and facilitates access to care for homebound or functionally impaired individuals among other benefits. Preliminary results from PAF's December 2020 survey of patients and caregivers affirmed key telehealth benefits tied to convenience, avoiding transportation costs, and improving access to experts that would not normally be available. Patients have long reported high satisfaction with their telehealth experiences and evidence suggests that care quality and clinical outcomes are comparable or superior to traditional visits.^{48,49} One study found that telehealth improved patients' quality of life and made their medical care more satisfying in the weeks following surgery, likely due to easing the challenges of getting in-person follow up care.⁵⁰

Despite early reluctance for some clinicians starting to implement telehealth in their practices, uptake in adoption was fueled by the dire circumstances during the pandemic.⁵¹ Coverage and reimbursement parameters still are not uniform across all payers, raising ongoing questions about appropriate billing practices for these services.⁵² The palliative care field has used telehealth particularly effectively during the pandemic to bridge communication between isolated inpatients and their families.⁵³

Many clinicians are optimistic about the surge of telehealth availability for helping homebound, frail, or underserved populations; but also recognize the dilemma around internet access challenges. The increased activity has spurred discussions about developing standards, education and training for clinicians on how to host virtual conversations most effectively.⁵⁴ These quality accountability activities should extend to all telehealth service types, support clinician training for delivering a high-quality experience and involve patients in determining the specific elements that constitute a high-quality virtual visit and outcome.

Telehealth is widely viewed as a key strategy for increasing access to care for limited resourced populations, yet it is far from certain that these services can measurably mitigate racial and socioeconomic disparities. One study concluded that despite live video communication tripling between 2013-2016, underserved populations such as Medicaid, low-income and rural populations did not use live video as widely as other study populations.⁵⁵ Another study found that African American patients and other ethnic minorities were significantly less likely than white patients to have activated their online portal to access

⁴⁸ Polinski JM et al. Patients' Satisfaction with and Preference for Telehealth Visits. *J Gen Intern Med* 31(3):269-75

⁴⁹ Uscher-Pines L, Mehrotra A. Analysis of Teladoc use seems to indicate expanded access to care for patients. *Health Aff.* 2014;33:258-64.

⁵⁰ Mousa AY, Broce M, Monnett S, et al. Results of Telehealth Electronic Monitoring for Post Discharge Complications and Surgical Site Infections following Arterial Revascularization with Groin Incision; *Annals of Vascular Surgery*. 57: 160-169 (2019). DOI:<https://doi.org/10.1016/j.avsg.2018.09.023>

⁵¹ Moving On From Telehealth-By-Desperation: What Will Make Telehealth Stick. August 14, 2020. <https://www.healthaffairs.org/doi/10.1377/hblog20200810.737666/full/>

⁵² KFF. [Opportunities and Barriers for Telemedicine in the U.S. During the COVID-19 Emergency and Beyond](#). May 11, 2020.

⁵³ Telemedicine: Virtual Connection in an Age of Social Distancing. CAPC Blog. July 13, 2020. <https://www.capc.org/blog/telemedicine-virtual-connection-age-social-distancing/>

⁵⁴ The Role of Telemedicine in the Future of Hospice and Palliative Medicine. AAHPM. <http://aahpm.org/quarterly/winter-20-feature>

⁵⁵ Are State Telehealth Policies Associated With The Use Of Telehealth Services Among Underserved Populations? December 2018. <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2018.05101>

telehealth.⁵⁶ While growing evidence supports the effectiveness of telehealth overall, considerable research questions remain to determine how application of these services can work for different populations under various circumstances and help tackle health disparities and challenges in medical shortage areas.

Understanding telehealth usage and population characteristics will help policymakers design better approaches for boosting access to telehealth that targets the populations most in need. Three overlapping “digital divide” barriers have been well documented and disproportionately affect older people of color and those with low socioeconomic status. These include limitations or absence of: (1) technology availability, (2) reliable internet coverage and (3) digital literacy.⁵⁷ In fact, a large body of comparative clinical effectiveness telehealth research studies is underway fueled by Patient Centered Outcomes Research Institute (PCORI) support to determine which health care options work best for various patient populations based on their needs and preferences. Current PCORI-funded telehealth research is focused on racial and ethnic minorities, low socioeconomic status populations, women, older adults, children, rural populations, people with multiple chronic conditions and those with low health literacy.⁵⁸

Further research is also needed to identify and address specific social determinants and other telehealth barriers experienced by underserved and marginalized populations, including limitations in broadband internet access and ability to engage with telehealth technology. Cross-sector research should also focus on developing understandable and practical curricula and resources for patients and families to feel comfortable and practitioners to feel competent in using telehealth platforms.

Concurrently, the development of person-centered telehealth practice standards and quality measures is beginning to garner attention and gain momentum. The National Quality Forum has produced a measurement framework that serves as a foundation to assess the quality of care provided through telehealth.⁵⁹ As these quality improvement initiatives continue, it will be important to position patient and family perspectives as integral in these efforts so that accountability and payment reforms promoting telehealth services are person-centered and match what matters to people.

Telehealth’s momentum creates opportunities for expanding person-centered coverage policy and payment practices to include financial and social needs navigation services so they can be available for all patients needing them. Modernizing current programs and policies by integrating financial and social needs services optimizes opportunities to mitigate SDOH by ensuring a person’s basic living needs are met and helping them avoid financial distress. PAF case managers have decades of experience delivering personalized financial and social needs

⁵⁶ Racial and Socioeconomic Disparities in Access to Telehealth. October 2020.

<https://agsjournals.onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.16904>

⁵⁷ Ensuring The Growth Of Telehealth During COVID-19 Does Not Exacerbate Disparities In Care. Health Affairs Blog.

<https://www.healthaffairs.org/doi/10.1377/hblog20200505.591306/full/>

⁵⁸ PCORI Research Spotlight on Telehealth. <https://www.pcori.org/sites/default/files/PCORI-Research-Spotlight-Telehealth.pdf>

⁵⁹ National Quality Forum. Creating a Framework to Support Measure Development for Telehealth. Final Report. August 31, 2017.

navigation via telephone, and PAF's data demonstrate the value of these services for patients, families and health systems.

PAF's decades of data also confirm that using audio-only telehealth is a cost-effective and highly engaging approach for conducting conversations about social needs and financial concerns that also embed timely referral to community-based resources and other required safety net supports. Pursuing policies that familiarize, standardize and scale these financial and social needs services through national telehealth and other policy initiatives will accelerate achievement of efforts to reliably meet all peoples' needs and mitigate health disparities.

In expanding telehealth's reach and reliability, it will be important to explore and understand the conditions, circumstances, and characteristics among patient populations and clinical fields that are most suitable and sustainable for adopting and using telehealth in practice.⁶⁰

6. Integrating Personalized and Value-Based Care

Advancing precision medicine was deemed a national priority under the 21st Century Cures Act of 2016, which authorized National Institutes of Health (NIH) funding directed to research in genetic, lifestyle and environmental variations of disease.⁶¹ Precision medicines can help drive more personalized care tailored to a patient's genetic profile or immune system, including delivery of molecularly targeted therapies that use diagnostic and other tests to identify a patient's genomic variations that may reveal predispositions to a disease or likely therapeutic response. These targeted techniques provide information about which therapies may improve outcomes with fewer clinical adverse effects.⁶²

These clinical advances have the potential to also reduce costly acute services utilization such as emergency department visits and inpatient hospitalizations. Despite the national investment in developing precision medicines and related genomic testing, insurance plans often apply coverage restrictions that diminish patient access or increase out-of-pocket costs.

Major life-saving advances in targeted treatments continue to progress through clinical trials. Barriers remain, however, resulting in delays in recruiting, conducting, and completing trials which can diminish research efforts and increase overall study costs. In addition, many patients eligible for trial enrollment may experience obstacles to participation, such as

⁶⁰ NASHP. State Use of Patient-Centered Outcomes Research in Telehealth Policymaking. December 7, 2020.

<https://www.nashp.org/state-use-of-patient-centered-outcomes-research-in-telehealth-policymaking/#toggle-id-1>

⁶¹ U.S. House of Representatives Committee on Energy and Commerce. The 21st Century Cures Act. Fact Sheet. November 2016.

Retrieved on Jan 8, 2018. Available at: <https://archives-energycommerce.house.gov/sites/repUBLICans.energycommerce.house.gov/files/documents/114/analysis/20161128%20Cures%20FAct%20Sheet.pdf>

⁶² Personalized Medicine Coalition. The Age of Personalized Medicine. Fact Sheet. Retrieved Jan 8, 2018. Available at:

http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/pmc_age_of_pmc_factsheet.pdf

transportation and financial issues, which preclude them from reaching clinical trial sites or even considering the possibility of participating.

Regulatory agencies and researchers have taken steps to improve access to innovative medicines through clinical trials and expanded access programs with the Food and Drug Administration.⁶³ Non-regulatory efforts to expand accessibility aim to decentralize clinical research through use of in-home technology and community-based data collection at satellite locations. Enhancements in outreach and community engagement are essential to improve diversity in clinical trials participation, where limited-resourced communities remain severely underrepresented in critical research studies.⁶⁴

Implementation of the Medicare and CHIP Reauthorization Act of 2015 (MACRA) value-based payment program continues its path to overtake traditional fee for service arrangements by rewarding practitioners and practices who can demonstrate improved outcomes at lower cost. These shifts are helping reshape health system approaches by encouraging integration of patient and caregiver input through patient-reported outcomes and other measures built around peoples' priorities, preferences, and stated goals for care.

As precision medicine continues to evolve and more therapies are assessed in clinical trials that include person-centered measures for quality accountability, NPAF will strive to align these innovation efforts with strategies promoting health equity, diversity and inclusion so that research results are ultimately representative, applicable and accessible for all populations.

7. Total Costs of Care and Transparency

NPAF prioritizes policies that curb total costs of care from all sources and minimize financial distress and household material hardships that disproportionately affect limited-resourced populations.

Patients consider costs of care and the impacts on their financial well-being as the basis of every health care decision they make. High total costs of care often force families to choose between the burdens of paying for treatments and meeting basic living expenses. Patients consider out-of-pocket (OOP) costs to be the amount they must pay for medical care outside of what their insurance covers, including monthly premiums for insurance, annual deductibles, and cost-sharing through coinsurance and/or copayment at the point of service.

OOP cost obligations often lack understandable information that helps consumers calculate, consider and compare costs and benefits when choosing among insurance plans or selecting a treatment with their care team. Patients also incur costs far beyond what their plan's

⁶³ Food and Drug Administration. Expanded Access to Investigational Drugs for Treatment Use – Q&A. Guidance for Industry. June 2016, Updated October 2017. Available at: <https://www.fda.gov/downloads/drugs/guidances/ucm351261.pdf>

⁶⁴ Oh SS et al. Diversity in Clinical and Biomedical Research: A Promise Yet to Be Fulfilled. *PLoS Med.* Dec 2015. 12(12): e1001918

benefit design outlines, such as transportation and lost wages associated with frequent medical appointments that can pose an equal or greater financial burden than customary OOP expenses.

The health care system has historically operated under one-sided and asymmetric information exchange between patients, providers, and plans that puts the burden on patients to make decisions without complete information far enough in advance. Information about health care costs is rarely intuitive for consumers to absorb, and the specialized lexicon used is unfamiliar without years of exposure to the various terms, what they mean, and how they affect care. These barriers collectively interfere with access and affordability, particularly for low income populations and limited resourced communities.

Total costs of health care for managing complex chronic conditions typically exceed what many families in the United States can afford. Even with health insurance, patients and families are exposed to significant cost sharing in annual deductibles, monthly premiums, copayments and coinsurance for covered services. Caregiving is also major contribution that is not credited or accounted for in any way to offset OOP burdens.

High OOP expenses can influence a patient's ability to afford basic living expenses and prevent or delay patients from seeing their doctor and receiving prescribed treatment. Simultaneously, total national health care expenditures have soared over the past several decades⁶⁵ which spurred cost-containment measures across the health care industry. System efforts at cost-reduction, unfortunately, can jeopardize access to care and drive higher costs for patients. For instance, industry journalists report that unchecked hospital and provider mergers, which have been touted to save costs, raise overall health care costs with patients bearing the brunt through higher OOP costs and premiums.⁶⁶ In addition, some payers have implemented accumulator adjustment programs that no longer apply manufacturer copay coupons to patient deductibles or OOP maximums, thereby increasing the overall amount patients must spend to reach their deductible.⁶⁷

Since payer discussions are confidential, questions arise whether payment negotiations translate to lower patient cost-sharing at their provider's office or pharmacy counter. Similarly, there are discount programs (e.g., 340B) and other negotiations commonly used to lower prices between stakeholders in the system. The benefits of these programs rarely reach patients even though some of the policies that create such savings were specifically intended to curtail their costs.

Policymakers are examining solutions to address both societal and individual burdens across all sources of cost including hospital care, prescription drugs and insurance coverage. While bipartisan transparency policies have emerged aimed at equipping patients with

⁶⁵ Peterson-KFF. Health System Tracker. How has U.S. spending on healthcare changed over time? Posted Dec 23, 2020.

⁶⁶ HealthcareDive. BRIEF Hospital M&A spurs rising healthcare costs, MedPAC finds. November 7, 2019. Available at: <https://www.healthcaredive.com/news/hospital-ma-spurs-rising-healthcare-costs-medpac-finds/566858/>

⁶⁷ New Accumulator Adjustment Programs Threaten Chronically Ill Patients. Health Affairs Blog. August 31, 2018. Available at: <https://www.healthaffairs.org/doi/10.1377/hblog20180824.55133/full/>

accurate cost information to guide health care decisions, more must be done to shift cost disclosures upstream to the time when patients make decisions about their treatment. Meaningful cost conversations that help identify patients' concerns and financial/social needs must occur at the time treatment is being discussed to ensure individuals are aware of their options, financial responsibility, and consequences affecting their livelihood and well-being.

8. Surprise Medical Billing

When patients unknowingly or involuntarily seek medical care from a health care provider or facility that is out-of-network, they may receive an unexpected or "surprise" medical bill. The practice is known as "balance billing" because patients are left responsible for the difference between what the health plan covers and what the provider or facility charges. Surprise medical bills are prevalent in almost all areas of the country for enrollees in both employer and individual market health plans and across plan types.⁶⁸ The bills can range from hundreds to thousands of dollars, causing financial distress and medical debt. In a 2020 survey conducted by Kaiser Family Foundation, unexpected medical bills topped the public's list of concerns around their ability to afford health care and basic living costs.⁶⁹

Surprise medical bills often lead to confusion about coverage, cost, and benefit parameters. Patients mistakenly assume visiting an in-network hospital means that every doctor at the hospital would be in-network.⁷⁰ When patients are not provided adequate information about network status, they are unlikely to know their OOP responsibilities which can affect key health care decisions. Legislation to protect patients from surprise medical bills has proliferated in state legislatures. In December 2020, Congress passed the *No Surprises Act*, national legislation that protects patients so they are only responsible for paying the in-network cost sharing amount even where they unknowingly get care from an out-of-network provider.

Monitoring ongoing state efforts and implementation of the federal law beginning in January 2022 will include outreach to communicate about these critical protections in communities where patients and families remain at risk for balancing billing. NPAF has produced new resources to improve understanding about the *No Surprises Act* protections that grassroots volunteers are helping to disseminate.

⁶⁸ Adler, L., Fiedler M, Ginsburg, P, et. al. State Approaches to Mitigating Surprise Out-of-Network Billing. Feb 2019.

⁶⁹ Kaiser Family Foundation. Data Note: Public Worries About And Experience With Surprise Medical Bills. Feb 28, 2020. Available at: <https://www.kff.org/health-costs/poll-finding/data-note-public-worries-about-and-experience-with-surprise-medical-bills/>

⁷⁰ Consumers Union. *Getting Started on Surprise Medical Bills: An Advocate's Guide*. Nov 3, 2015. Retrieved Dec 1, 2015 from <http://consumersunion.org/research/getting-started-on-surprise-medical-bills-an-advocates-guide/>

9. Medical Debt and Credit Protections

Millions of people in the U.S. each year are at risk for losing their health, homes, credit standing and financial security because of the harms of medical debt. Unlike regular consumer debt, which is often incurred in a voluntary and predictable manner, having an unplanned medical condition or other medical emergency leaves families little time to anticipate and prepare for the unexpected costs of treatments or ability to maintain steady income.

Each year almost one-third (30 percent) of patients receiving PAF assistance experience debt crises that impair their ability to afford transportation, housing, utilities, or nutritional needs.⁷¹ Other studies also conclude that most patients struggle with saving money, racking up credit card debt, and paying for medical bills and living necessities like food, heat and housing.⁷²

Balance billing practices or billing errors can further exacerbate medical debt. Medical billing and reimbursement complexities have long been documented as a potential source of confusion or misunderstanding between patients, clinicians, hospitals and insurers.⁷³ Even in cases where a medical bill has been paid in full or otherwise resolved, the recorded debt may remain on credit reports and interfere with a patient's credit score for up to seven years.

The three major credit reporting agencies—Experian, Equifax and TransUnion—provide a 180-day waiting period before medical debt can be included on a consumer's credit report. This policy gives patients and families more time to resolve coverage or billing disputes so they are not unfairly penalized in circumstances where they withhold payments pending a resolution.

Health system changes must also protect patients and families from distressing financial hardship. Cost of care planning, risk assessment and financial support needs discussions should begin at diagnosis of complex chronic conditions with processes in place for navigation referrals to find safety net services and supports based on the results of the assessment.⁷⁴ By examining methods for increased coordination of care and specialized protections for those at risk for economic distress related to medical bills, policies can be crafted that help minimize these financial harms and improve patient and family well-being.

⁷¹ Patient Advocate Foundation. Internal Case Management Data. 2020.

⁷² West Health Institute, NORC at the University of Chicago. *American Views of Healthcare Costs, Coverage, and Policy*. March 2018. Retrieved from: <https://s8637.pcdn.co/wp-content/uploads/2018/03/WHI-Healthcare-Costs-Coverage-and-Policy-Issue-Brief.pdf>

⁷³ Consumer Financial Protection Bureau. Consumer credit reports: A study medical and non-medical collections. Dec 2014. Retrieved from: https://files.consumerfinance.gov/f/201412_cfpb_reports_consumer-credit-medical-and-non-medical-collections.pdf

⁷⁴ Pelletier, W. and Bona, K. (2015), Assessment of Financial Burden as a Standard of Care in Pediatric Oncology. *Pediatric Blood Cancer*, 62: S619–S631. doi:10.1002/pbc.25714

10. Skilled Communication, Shared Decision-Making and Patient Engagement

Patients and families require reliable and affordable access to high quality treatment and supportive services throughout the care continuum in the settings that they prefer. Today's disease-centric system environment is fragmented across multiple specialists and settings, creating pressures to navigate pathways-driven treatments that often overlook quality of life, functional outcomes, financial distress and other patient-reported priorities or individual characteristics that matter to them.

Knowing precisely what is important to patients and families is essential to align treatments with principles of person-centered care. Patients value relationships with their care team rooted in respect and compassionate communication to identify their priorities and concerns so they can feel heard and understood. Empathic communication skills foster patient-practitioner partnerships that affect adherence and decisions about treatment, and patients also want to know about direct and indirect costs.

Patients may be reluctant, particularly if not prompted by their provider, to ask questions, request clarification, express emotions, or state their opinions and preferences.⁷⁵ Research shows that professional skills development enhancing person-centered communication competencies yields positive results, with physicians using more empathy and asking more questions to understand and explore patient concerns, preferences and values that are the backbone of effective shared decision making.⁷⁶ While both patients and clinicians alike express a willingness to practice shared decision making, they often do not know how to begin such a process, and there is no current clinical practice standard or accountability measure in place for doing so.

Many of the existing decision-support tools used by clinicians to identify the most appropriate treatment within practice guidelines do not consistently incorporate patient-reported insights or outcomes. While professional guidelines have long provided information about what constitutes the most appropriate care for a given medical condition,⁷⁷ some clinical pathways are overly standardized and don't reflect the true range of factors known to be appropriate for personalizing care. This can undermine the shared decision-making process and clinical information systems efforts to track patients throughout the decision-making process.⁷⁸

Decision-support tools must be paired with conversations to effectively engage patients. Evidence-based communication skills development programs and resources already exist

⁷⁵ Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled "difficult" among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012;31(5):1030-103

⁷⁶ Back AL, and Arnold RM. *Journal of Palliative Medicine*. February 2014, 17(2): 141-144. <https://doi.org/10.1089/jpm.2013.0197>

⁷⁷ Peer-reviewed, published, and promulgated by the communities and societies trusted to establish the appropriate courses of treatment.

⁷⁸ Legare, France, and Holly O. Witterman, "Shared Decision Making: Examining Key Elements and Barriers to Adoption into Routine Clinical Practice," *Health Affairs* 32, no. 2(2013): 276-84.)

and are available in multiple formats and platforms.⁷⁹ Prioritizing communication skills development and holding health systems and practitioners accountable for demonstrating core competencies in person-centered communication can provide a firm foundation for creating a standardized approach to shared decision-making and goal concordant care.

Patient and caregiver engagement in health services research is also critically important to improve the quality of care, how it is delivered, and evaluate progress. Patient-reported outcomes development and patient/caregiver engagement in advisory boards, research projects and community outreach initiatives will not only lead to better outcomes but will also help advance quality improvement initiatives. Patients require mentorship and resources so they feel comfortable and supported in providing insights and feedback throughout the care experience, play an active role in shaping health care decisions affecting treatment and become more aware about the opportunities to do so when they arise. These steps will ensure greater patient and caregiver engagement in the transformative health policy pipeline.

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

Evidence has established the importance of pairing palliative care, psychosocial/behavioral care support, and impairment-driven rehabilitation services with treatment early in the course of disease to improve physical and psychological function and alleviate pain, symptoms, and other preventable suffering.^{80,81,82} Patients, caregivers and frontline clinicians caring for them may lack understanding about how such services can be helpful in improving patient and family quality of life, especially in the context of complex chronic conditions. As a result, patients may experience significant symptom and emotional burden and functional impairments that are often undetected or untreated.

Palliative care serves as a practical and well-established person-centered model for identifying and meeting patient and family care needs and helping them avoid unwanted and expensive crisis care. Palliative care helps determine goals through skilled communication, treating distressing symptoms and coordinating care with patient and family involvement throughout.⁸³ These gains in quality also have been shown to reduce costs.⁸⁴

⁷⁹ National Academies of Sciences Engineering and Medicine. Integrating the Patient and Caregiver Voice into Serious Illness Care: Proceedings of a Workshop. Washington, DC, 2017. <https://doi.org/10.17226/24802>

⁸⁰ Early Specialty Palliative Care — Translating Data in Oncology into Practice. Parikh RB, Kirch RA, Smith TJ, Temel JS. *New England Journal of Medicine*. 2013

⁸¹ Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps. Kirch R, Reaman G, Feudtner C, et al. *CA: A Cancer Journal for Clinicians* 2016

⁸² Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services. Silver J, Raj V, Fu J, Wisotzky E, Robinson Smith S, Kirch R. *Supportive Care in Cancer* 2015

⁸³ Lukas L, Foltz C, Paxton H. Hospital outcomes for a home-based palliative medicine consulting service. *J Palliat Med*. 2013;16(2):179-184.

⁸⁴ Penrod JD, Deb P, Dellenbaugh C, et al. Hospital-based palliative care consultation: effects on hospital cost. *J Palliat Med*. 2010;13(8):973-979.

Pain management is an integral part of palliative care for many patients with complex conditions. Palliative care systematically screens and assesses for pain and other symptoms, tailoring pharmacological and other interventions to patients' individual circumstances, and carefully monitoring and adjusting treatment regimens as needed over the course of their condition.⁸⁵ Psychosocial support is another important, yet widely underutilized person-centered approach to address mental and emotional health needs. It has been found to reduce distress for patients, families, and caregivers by providing coping resources after diagnosis, screening for and addressing behavioral changes, and maintaining well-being in a culturally relevant context.⁸⁶

Despite the supportive evidence, gaps persist in professional, public, health plan and policymaker understanding about the need to provide these person-centered interventions. Most large hospitals now have palliative care programs, yet availability in community settings where most patients receive their care is highly variable and remains difficult for many to access.^{87,88} Psychosocial care availability also varies across care settings, is underfunded, and is emphasized and studied almost exclusively in the context of cancer, even though this type of comprehensive support is appropriate for all conditions.^{89,90}

Some barriers to accessing integrative pain management include lack of information for patients and health care professionals about effective pain management approaches, particularly regarding opioid use and other non-pharmacological therapies.⁹¹ Balanced policy approaches that prioritize evidence-based screening and risk assessments, and do not interfere with patient access to integrative pain therapies should be incorporated into practice.^{92,93} To preserve the functional status and quality of life for many individuals suffering as a result of their serious illness, increased funding; education and research for palliative care; pain management; psychosocial support and rehabilitation services are needed to integrate these approaches in all care settings.

The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP) provide evidence-driven guidance for health systems, payers, policymakers and clinicians to prioritize delivery of person-centered and family-focused quality care. Evidence-based

⁸⁵ Morrison LJ, and Morrison RS. Palliative care and pain management. *Med Clin N Am*. 2006; 90(5):983-1004. doi: 10.1016/j.mcna.2006.05.016. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/16962853>

⁸⁶ National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp>

⁸⁷ America's Care of Serious Illness, 2019 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals. Retrieved from: <https://reportcard.ccapc.org>

⁸⁸ National Academy for State Health Policy (NASHP) "Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs (December 2018) available at <https://www.johnahartford.org/events/view/report-advancing-palliative-care-for-adults-with-serious-illness-a-national/>

⁸⁹ Scialla MA et al. Delivery of care consistent with the psychosocial standards in pediatric cancer: Current practices in the United States. *Ped Blood & Cancer*. 2017;65(3) Available at: <https://onlinelibrary.wiley.com/doi/abs/10.1002/pbc.26869>

⁹⁰ Chan KY, Chan ML. Enhanced psychosocial support as important component of neuro-palliative service. *Ann Palliat Med* 2018;7(3):355-358. Available at: <http://apm.amegroups.com/article/view/16394/20137>

⁹¹ National Academies Press. *Pain Management and the Opioid Epidemic: Balancing Societal and Individual Benefits and Risks of Prescription Opioid Use* (2017). Retrieved Jan 16, 2018 from <https://www.nap.edu/read/24781/chapter/1>

⁹² National Academy of Medicine. *Marshaling Clinician Leadership to Counter the Opioid Epidemic: A Special Publication of the National Academy of Medicine* (2017). Retrieved from <https://nam.edu/wp-content/uploads/2017/09/Key-Messages-Opioid-SP.pdf>

⁹³ Twillman B, Kirch R, Gilson A. Efforts to control prescription drug abuse: Why clinicians should be concerned and take action as essential advocates for rational policy (July 14, 2014). Available at: <https://acsjournals.onlinelibrary.wiley.com/doi/full/10.3322/caac.21243>

standards for psychosocial support in pediatric cancer also exist and are integrated within the NCP guidelines.^{94 95} Value-based payment reforms, associated quality measures development, health system investment in core competency skills training applicable to all clinicians, and ensuring accountability for adhering to these practice guidelines will help support national strategies for integrating these services in all settings.⁹⁶ These essential steps will help enhance shared decision-making and improve the patient and family lived experience – key markers for delivering high-quality care.

12. Caregivers Engagement and Support

Caregivers are unpaid individuals, often family members or friends, involved with assisting seriously or chronically ill patients with activities of daily living (i.e., feeding, bathing, toileting or walking) or even complex medical tasks (i.e., medication management, administering injections). While they serve a vital role in providing the quality care that patients need, our health care, long-term care and social systems are growing increasingly dependent on individuals who are not compensated or trained to carry out the complex caregiving tasks often expected of them. Currently more than 1 in 5 Americans (21.3 percent) across all demographics serve as unpaid caregivers totaling an estimated 53 million adults in the United States.⁹⁷

Caregivers are often referred to as the backbone of our nation’s long-term supports and services system; yet perhaps the biggest complaint that caregivers share is the inability to effectively carry out their caregiving roles and responsibilities because they are excluded from important conversations and decisions with the health care team and do not receive the necessary training to perform complex medical tasks at home. Further compounding the problems caregivers face, health care professionals often expect caregivers to coordinate care or manage treatments—leaving many caregivers to learn by trial and error.

In fulfilling their role, many caregivers experience distressing physical, emotional, and economic effects that strain their own health, well-being and financial security. Like patients suffering from a chronic or serious illness, caregivers may also take time off work, cut back on paid work hours or leave the workforce altogether to care for a loved one. As a result, they lose income and may receive reduced Social Security and other retirement benefits.⁹⁸ Individuals experiencing the highest financial strain tend to be lower income, non-White/non-Asian caregivers providing support for a relative or close friend who needs assistance with at least one activity of daily living⁹⁹. Recent data also suggest that the impact of caregiving on

⁹⁴ Kazak AE, Abrams AN, Banks J, et al. Psychosocial Assessment as a Standard of Care in Pediatric Cancer. *Pediatric blood & cancer*. 2015;62(S5):S426-S459.

⁹⁵ Wiener L et al. Standards for the Psychosocial Care of Children with Cancer and Their Families: An Introduction to the Special Issue. *Pediatr Blood Cancer*. 2015;62:S419-S424. Available at: https://docs.wixstatic.com/ugd/27074d_4456612ec4674f9f865b8c784509ff90.pdf

⁹⁶ Meier DE, Back AL, Berman A, et al. A National Strategy for Palliative Care. *Health Affairs (Project Hope)*. 2017;36(7):1265-1273.

⁹⁷ AARP and National Alliance for Caregiving. Caregiving in the U.S. May 2020. Available at: <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html?CMP=RDRCT-PPI-CAREGIVING-042920>

⁹⁸ National Academies of Sciences Engineering and Medicine. Families caring for an aging America. Washington, DC, doi: 10.17226/23606;2016.

⁹⁹ AARP. Family Caregiving and Out-of-Pocket Costs: 2016 Report. November 2016. Retrieved from: <https://doi.org/10.26419/res.00138.001>

one's health is much larger in communities with a majority black population, therefore, efforts to address racial and ethnic disparities should be prioritized.¹⁰⁰

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act enacted in 2018 spurred the development and maintenance of a coordinated national strategy to address many of the challenges confronting caregivers today. Ongoing efforts are underway to recognize caregivers as part of the unit of care and equip them with the information, training and resources they require to undertake their roles and responsibilities. Building upon the *RAISE Family Caregivers Act*, state officials suggest several actions that the federal government can take to improve family caregiving as part of a national strategy. State Medicaid programs can serve as a model for supporting family caregivers as many programs provide training, care coordination, and sometimes payment – but additional needs exist.¹⁰¹

Studies have demonstrated the positive impact of providing supports and services to caregivers.^{102,103} Consensus recommendations from the National Academies of Sciences Engineering and Medicine (NASEM) also call for further research investment to support the development and testing of national and community interventions that will help address the unmet needs of caregivers.¹⁰⁴ In June 2022, NASEM's Quality Care for People with Serious Illness Roundtable is hosting a workshop on caregiving to supplement these earlier recommendations by proffering the next generation of policy action steps, quality measurement opportunities and intervention ideas that embed caregiver input and engagement early to ensure that solutions are person centered and family focused.

Conclusion

Recent reporting in *Health Affairs Forefront* indicates that most consumers in the US rank health care affordability as a top concern that they want policy makers to address.¹⁰⁵ Confronted with continually rising health care costs, constituents are looking to policy makers for relief to address problems with health care access and affordability that cause physical and mental distress for families, curtail other critical family spending, and create disparate and poorer health outcomes for populations overall. RWJF polling results in 2021 affirm that patients' affordability concerns span income levels and insurance coverage status.¹⁰⁶ NPAF's

¹⁰⁰ BlueCross BlueShield. The Impact of Caregiving of Mental and Physical Health. (Insights from ARCHANGELS 2020 Survey.) Sept 9, 2020 Available at: https://www.bcbs.com/sites/default/files/file-attachments/health-of-america-report/HOA-Caregivers_3.pdf

¹⁰¹ NASHP. Medicaid Supports for Family Caregivers. October 29, 2020. Available at: <https://www.nashp.org/medicaid-supports-for-family-caregivers/#toggle-id-1>

¹⁰² Courtney Harold Van Houtven, et al. Development and Initial Validation of the Caregiver Perceptions About Communication with Clinical Team Members (CAPACITY) Measure. *Medical Care Research and Review*. Dec 21, 2017. Available at: <https://doi.org/10.1177/1077558717747985>

¹⁰³ Elizabeth B Fauth, et al. *External Validity of the New York University Caregiver Intervention: Key Caregiver Outcomes Across Multiple Demonstration Projects*. *Journal of Applied Gerontology*. June 23, 2017 Available at: <https://doi.org/10.1177/0733464817714564>

¹⁰⁴ National Academies of Sciences Engineering and Medicine. *Families caring for an aging America*. Washington, DC, doi: 10.17226/23606;2016.

¹⁰⁵ "States Hold Keys To Health Care Affordability, But Are They Using Them?", *Health Affairs Forefront*, February 8, 2022. DOI: 10.1377/forefront.20220204.765285

¹⁰⁶ Healthcare Affordability: Majority of Adults Support Significant Changes to the Health System. Bipartisan consensus exists on ideas to lower out-of-pocket costs. Robert Wood Johnson Foundation Survey June – July 2021. Available at:

person-centered policy principles directly align with these consumer-driven priorities to bolster health equity through enhancements in care access, affordability and quality, and our advocacy influence will be exerted strategically to achieve these goals.