

July 6, 2021

Shalanda Young  
Acting Director, Office of Management and Budget  
725 17th St NW, Washington, DC 20503

**Re: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government**

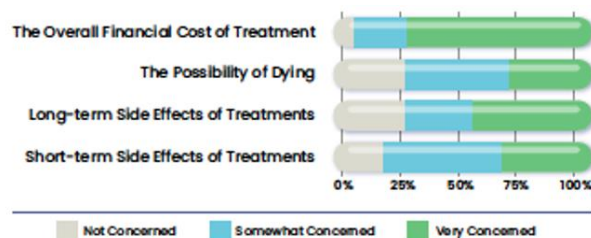
Dear Acting Director Shalanda Young,

National Patient Advocate Foundation (NPAF) is pleased to submit feedback to the Office of Management and Budget's Request for Information on advancing equity and supporting limited resourced and underserved populations through government. We appreciate the Administration's leadership to reduce the disparities entrenched in our laws, regulations, and public policies.

NPAF advocates for inclusive policies and practices that elevate patient and caregiver voices and put their perspectives at the heart of healthcare. Health equity forms the core of our person-centered agenda, which prioritizes health, financial and social stability as essential aspects of quality care. Our direct patient services counterpart, Patient Advocate Foundation (PAF), has delivered skilled navigation services specifically supporting social and financial well-being for thousands of patients and families over its 25 years. PAF works to identify and address individuals' unmet needs and overcome health system shortfalls that fail to account for the total costs of care that are common sources of distress and disparate outcomes among people coping with complex chronic conditions. Social needs gaps often involve material hardships such as food, utilities, housing, and transportation insecurities that are exacerbated by unaddressed social determinants of health within individuals' communities.

***Our comments address Area 2 on barrier and burden reduction:*** Approaches and methods for assessing and remedying barriers, burden, and inequities in public service delivery and access.

PAF has decades of dedicated experience helping hundreds of thousands of individuals across the country in overcoming barriers to accessing health care and needed safety net services. We have played an active role in addressing health inequities by helping people overcome financial distress resulting from total costs of care, both medical and nonmedical expenses, that can quickly overwhelm even the best planned household budget.



Responses to PAF's 2019 survey of more than 2,800 patients revealed **financial distress as the top concern** with many indicating that their family's financial viability is a critically important goal of care. In fact, 63% of patients in the survey ranked financial distress as a fate worse than death.

**Promoting Equitable Access to Vital Safety Net Supports.** Financial distress is particularly prevalent among populations with low socio-economic characteristics, communities of color and those living in rural regions or medical professional shortage areas. For limited resourced populations, unexpected health expenses compound the health and financial challenges that individuals and families may already be experiencing. At a macro level, the effects of financial distress exacerbate underlying health and economic disparities for these populations at large and can result in care inefficiencies and episodic health care engagement that limit access to quality healthcare for the broader population.

The COVID-19 pandemic has increased the need for reliable access to safety net programs for income loss including unemployment insurance, Social Security Income and the Supplemental Nutrition Assistance Program (SNAP), among other vital supports. People confronting complex chronic health conditions stand to benefit the most from these and other government safety net programs, yet they are often unaware about program availability, how to access them or eligibility criteria. Limited resourced individuals may also contend with social stigma in seeking these safety net supports and encounter other impediments caused by confusing, arduous, and overwhelming program compliance requirements.<sup>i</sup>

*NPAF urges consideration of health equity strategies that propagate predictable and understandable needs navigation services as essential gateways and guidance for at-risk populations to learn about available safety net programs and the steps for enrolling in them.* These needs navigation services must be reliably available in all care settings and introduced before patients' financial and social circumstances become dire to support the improved outcomes these programs are intended to achieve.

**Normalize screening that identifies peoples' financial and social needs.** Screening and services referral in clinical and community health settings to identify and address peoples' financial and social concerns and impending social determinants of health are scattered at best and not currently standardized to foster accountability for equity in quality care delivery. Most U.S. hospitals and physician practices do not have processes in place to discern or document patient and caregiver material hardships (food, utilities, housing insecurity), transportation barriers, and interpersonal violence challenges that would benefit from targeted intervention and safety net program supports.<sup>ii</sup> In contrast, care settings that provide these needs-based screenings and services referral navigating to specific financial and social supports have shown return on investment that includes increased treatment adherence, improved outcomes, and reduced overall costs for both patients and health systems.<sup>iii, iv</sup>

**Needs navigation as a tactical and practical service solution.** NPAF urges consideration of needs navigation as a proven approach for achieving the Administration's aims in addressing inequities in policy and practice. As detailed in the appended resource, needs navigation meets people where they are by helping determine their top financial and social concerns and providing a playbook with guidance for finding responsive safety net supports and services. This personalized approach helps people navigate complexities inherent in the health system by linking individuals and families to appropriate government and community resources. Making high quality, skilled needs navigation services equitably available in all care settings is a central aspect of improving health and financial stability for most

patients and families, especially those living in underserved communities and medical professional shortage areas. Expanding needs navigation availability is also essential to curtail disparities overall.

**Enhancing existing government programs can help pave the way.** Congress has provided promising options to address people’s social needs, including Express Lane Eligibility (ELE) that is now used in 14 states and the U.S. Virgin Islands. Many of these states have reported decreased administrative burdens coupled with cost savings attributable to using the ELE approach.<sup>v</sup> Building on this encouraging evidence, NPAF urges consideration of actions that would expand and intensify the reach, scope, and evaluation of these outcomes together with other approaches that boost equitable access to essential programs and safety net supports.

Policy makers are well positioned to consider adding needs navigation enhancements to address persisting health and social inequities through targeted refinements in programs such as SNAP, the Temporary Assistance for Needy Families (TANF), and Medicaid’s Targeted Case Management. NPAF supports modifications to the purpose and allowable use of funds in these and other federal safety net programs which could facilitate improved social needs outcomes and mitigate disparities.

Federal efforts to standardize and scale needs navigation can be a solution to help link all eligible people to appropriate government programs across all agencies and care settings. The federal government can also look to some state examples such as Michigan’s State Innovation Model and Rhode Island’s Accountable Health Communities model that integrate health-related social needs screening and referrals.<sup>vi, vii</sup> These initiatives will be important to monitor, particularly in examining their impact on reducing racial, ethnic, and other disparities in limited resourced populations.

**Area 5 on stakeholder and community engagement:** Approaches and methods for accessible and meaningful agency engagement with underserved communities.

NPAF recommends that agency outreach and engagement activities reflect person-centered values by involving diverse patient and caregiver perspectives extensively and meaningfully in all aspects of program development, enhancement, and evaluation. Proactively seeking and securing input from populations who are typically overlooked and therefore under-represented in research findings is an essential attribute of justice, equity, diversity, and inclusion initiatives.

NPAF is well situated to lift such efforts through collaborative engagement opportunities with our national network of patient and caregiver grassroots volunteer advocates who are well established in their communities for health equity outreach and influence. Our volunteers are uniquely galvanized to inform state level execution to address these critical areas. Borrowing from PAF’s needs navigation case manager services platform, agencies can also embed communication skills development courses<sup>viii</sup> that include cultural competency and humility training and other effective supportive tactics to effectively communicate, understand, and assist racial and ethnic minority populations in articulating their top concerns and priority needs so interventions can be tailored to reach them effectively.

Additionally, program websites, application forms and other collateral are often jargon-laden and difficult to understand, particularly for people with limited health and financial literacy or health system

exposure. Again, agencies and their materials would benefit from creating standard procedures for involving patient and caregiver representation to provide early, real-world input, ongoing feedback, and consumer-driven expertise about plain language use for program or outreach materials. Based on our extensive grassroots capacity, NPAF is well poised to assist in “user friendly” procedures.

Finally, outreach activities should enable people to participate in various ways that are accessible to them whether that be via telephone, the internet, or in-person. Additional barriers emerge for those seeking out and trying to obtain resources due to lack of internet access or due to limited broadband and technology experience (e.g., people living in rural areas and seniors.) Given that the digital divide disproportionately affects older people of color and those with low socioeconomic status<sup>ix</sup>, it will be important for the Administration to utilize flexible and accessible outreach methods to capture input from traditionally underserved and underrepresented populations. PAF has extensive experience and expertise in these engagement activities, and we are prepared to work collaboratively with relevant agencies to support inclusive outreach efforts.

In conclusion, NPAF appreciates the Administration’s focus on health equity and will be pleased to work with Administration offices and staff to optimize existing government programs, so they effectively connect eligible individuals to appropriate services and supports. Providing needs navigation services directly to patients and caregivers is a hallmark of PAF’s two and a half decades of organizational experience, expertise, and history. We are happy to share lessons learned and welcome the opportunity to meet directly with Administration staff to discuss our input in these comments. Please contact Nicole Braccio at [Nicole.Braccio@npaf.org](mailto:Nicole.Braccio@npaf.org) or 202-301-9552 if we can provide further details.

Respectfully submitted,



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EVP Policy and Programs

<sup>i</sup> The Brookings Institution. The social safety net: The gaps that COVID-19 spotlights. June 23, 2020. Accessed June 22, 2021. Available at: <https://www.brookings.edu/blog/up-front/2020/06/23/the-social-safety-net-the-gaps-that-covid-19-spotlights/>

<sup>ii</sup> Frazee TK et al. Prevalence of Screening for Food Insecurity, Housing Instability, Utility Needs, Transportation Needs, and Interpersonal Violence by US Physician Practices and Hospitals. *JAMA Network Open*. 2019;2(9):e1911514

<sup>iii</sup> 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

<sup>iv</sup> Ell K, Vourlekis 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.

<sup>v</sup> Office of Inspector General. State Use Of Express Lane Eligibility For Medicaid And Chip Enrollment. October 2016. Available at: <https://oig.hhs.gov/oei/reports/oei-06-15-00410.pdf>

<sup>vi</sup> Michigan Department of Health and Human Services. Community Health Innovation Regions. Available at: [https://www.michigan.gov/mdhhs/0,5885,7-339-71551\\_64491\\_86050---,00.html](https://www.michigan.gov/mdhhs/0,5885,7-339-71551_64491_86050---,00.html)

<sup>vii</sup> The Executive Office of Health and Human Services, State of Rhode Island. Accountable Entities. Available at: <https://eohhs.ri.gov/initiatives/accountable-entities>

<sup>viii</sup> <https://www.vitaltalk.org/>

<sup>ix</sup> 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/>

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## APPENDIX I

## Needs Navigation: A Practical and Proven Solution to Address Patients' Unmet Needs

### THE PROBLEM: Financial Distress is a Reality for Many Patients and Their Families

According to recent [Centers for Disease Control and Prevention data](#), chronic illnesses like cancer, heart disease and diabetes are the leading cause of death and disability and are also the leading drivers of the nation's **\$3.8 trillion** in annual health care costs. These conditions disrupt quality of life and financial stability for millions of people every year.

Uninsured, underinsured and low-income patients are particularly predisposed to financial distress and resulting harms on health outcomes, including health disparities. Many must choose between buying groceries or filling their prescriptions, seeing their doctor or paying for rent, mortgage or utilities. Most people also scale back their spending on everyday essentials.

**The hard reality is that nearly all people living in the U.S. today are just one serious diagnosis away from experiencing financial devastation.** This is true even when individuals have insurance coverage. Total costs of care include medical and nonmedical expenditures that can quickly overwhelm even the best planned household budget. For limited resourced and underserved populations, these unexpected expenses further compound health inequities and the economic challenges that individuals and families are already experiencing.

**63%** of patients surveyed by Patient Advocate Foundation (PAF) rank financial distress as a fate worse than death.

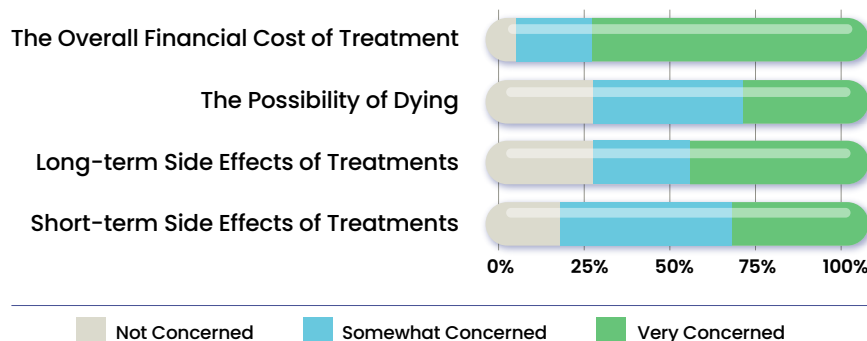


► Financial distress often manifests as a major side effect of illness. Patients and caregivers experience lost wages because of unpaid absences from work. Unpaid caregivers also take on child and adult care additional financial responsibilities.

► Financial distress is particularly prevalent among populations with low socio-economic characteristics, communities of color and those living in rural regions or medical shortage areas.

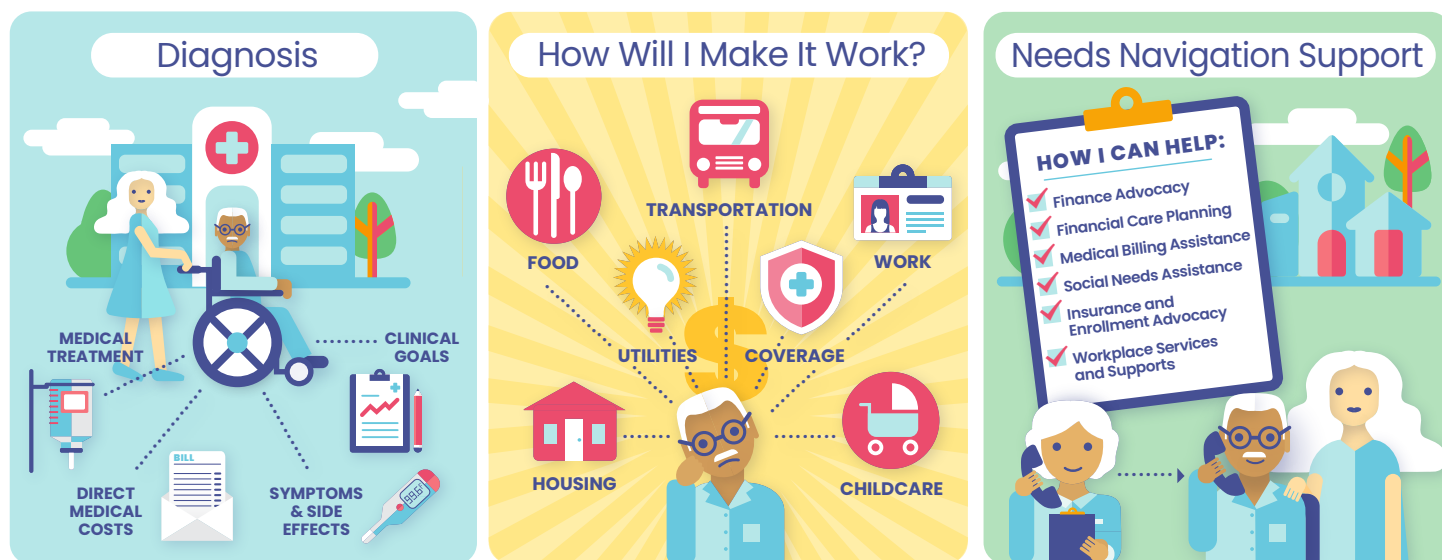
► The distressing effects exacerbate existing underlying health and economic disparities for these populations and result in care inefficiencies that limit access to quality healthcare for the broader population.

### TOP HEALTH CONCERNS IN LIMITED RESOURCED AND UNDERSERVED POPULATIONS



Responses to PAF's 2019 survey of more than 2,800 patients report **financial distress as a top concern**, with many stating that their family's **financial viability is a critically important goal of care**.

## THE SOLUTION: Needs Navigation is a Lifeline for Patients and their Families



Findings from a robust National Patient Advocate Foundation (NPAF) environmental scan in 2020 revealed six domains (depicted above) as key features of providing high quality needs navigation services.

## Promoting Health Equity and Better Outcomes by Addressing Social Needs

**Providing needs navigation services directly to patients and caregivers is a hallmark of PAF's two and a half decades of organizational experience, expertise and history.**

Making skilled needs navigation services equitably available in all care settings is a central aspect of improving health and financial stability for many patients and families, especially those living in underserved communities and medical shortage areas. Expanding needs navigation is also essential to curtail disparities overall.

While some health systems, clinics and centers provide limited social work support and/or financial counseling, personalized financial and social needs screening and services referrals are scattered at best, still inaccessible in some settings, and not currently standardized to support adequacy, consistency or core competencies in quality care delivery and accountability.

### Our Ultimate Aim

As PAF's advocacy affiliate dedicated to amplifying the voices of patients and caregivers and meeting their pressing needs, NPAF is taking action to integrate financial and social needs navigation as a scalable health system solution for improving health outcomes and turning the tide on persisting health disparities. To accomplish this, we will pursue collaborative partnerships in research, policy and advocacy to:



1. **Advance** the work of social determinants of health screening
2. **Standardize** needs navigation as a viable intervention
3. **Measure** the impact to patients, communities and programs
4. **Scale** these evidence-based approaches to increase quality and expand availability

**NPAF welcomes other organizations to join us in advancing this health equity agenda.**

Visit [www.npaf.org](http://www.npaf.org) and contact [Rebecca.kirch@npaf.org](mailto:Rebecca.kirch@npaf.org) to learn more about options and opportunities for adding your organization as a collaborative partner. Together we can achieve transformational change to benefit all patients and families.