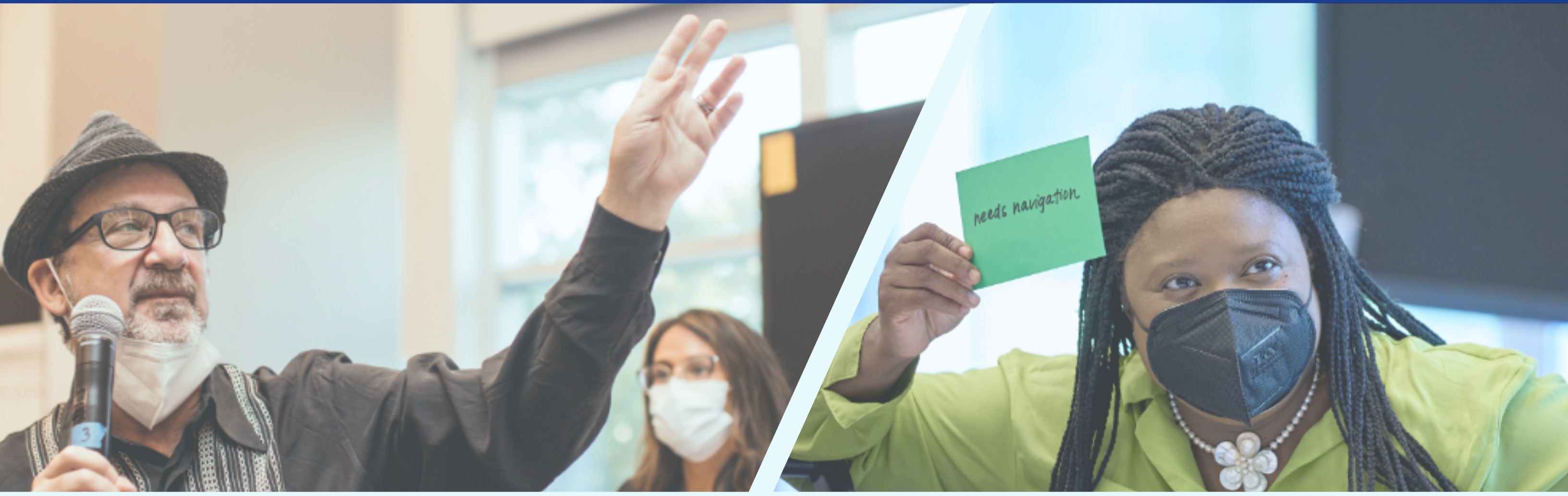
December 2022

Health Needs Navigation: Connecting Patients, Research and Policy to Solve Our Most Pressing Healthcare, Financial and Social Challenges



NPAF National Patient
Advocate Foundation

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Patient Advocate Foundation (PAF) is a national non-profit 501(c)(3) charity with decades of experience providing needs navigation to patients and families. Since 1996, PAF has provided direct, personalized assistance by telephone to more than 1.7 million patients and caregivers across all 50 states to help them access and afford care or other health-related needs.

Patient Insight Institute, an initiative of PAF launched in October 2021, was created to foster patient engagement in research. The Institute's person-centered approach to improving healthcare is centered on the voices of those who have been historically under-represented in research and policy.

National Patient Advocate Foundation's (NPAF) mission is to improve how we all experience healthcare through grassroots advocacy, education and partnerships. As the advocacy affiliate of PAF, NPAF is currently focused on positioning needs navigation as a standard of care reliably available in all care settings.

Acknowledgements

NPAF is proud to present this white paper, *Health Needs Navigation: Connecting Patients, Research and Policy to Solve Our Most Pressing Healthcare, Financial and Social Challenges.* The following individuals contributed content, experience and expertise:

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Foreword

Our Health *Needs* Navigation.

But *why now?*

It's because health system fissures made apparent during the COVID-19 pandemic have sparked a renewed sense of urgency in finding solutions to address healthcare access, affordability and inequities that both patients and caregivers experience. The healthcare system remains primarily oriented only to the clinical aspects of care. What happens in the community is still considered "out of scope."

We know the day-to-day realities such as getting to and from care, affording medications and other bills, as well as managing other life challenges is much more complicated when sick and are driven in part by social determinants of health. The good news is that health systems are internalizing this problem through screening for social needs which will soon be associated with quality measures and quality improvement initiatives. The bad news is that this type of support does not currently reach the people who need it most.

Now is the time to meet the health system's inertia with a proactive, patient-driven push for proven interventions.

Person-centered support addressing unmet social needs is the work Patient Advocate Foundation was founded on decades ago. Now having served more than 1.7 million patients and families, financial and social needs navigation services have continually been honed as an effective, evidence-informed health equity intervention responsive to health-related social risks.

With collaborative engagement of patients, caregivers, researchers, providers, payers, plans and policymakers, we are poised to lead coordinated, patient-driven research, policy and advocacy efforts that ultimately position financial and social needs navigation as a standard of care. We welcome individuals and organizations to join us in taking action to make needs navigation programs available and accessible to every patient and family in need – in every care setting they're needed.

Alan J. Balch, PhD
CEO, Patient Advocate Foundation and
National Patient Advocate Foundation

Background

Financial Distress is a Persisting Problem

A fate worse than death.

That is the prevailing view among those living with complex or chronic health conditions who report they fear the financial cost of care and the burden that would place on their families more than they fear dying from their illness.[1] In its most acute form, financial distress forces families to make impossible choices between paying for household expenses or life-saving prescriptions and medical care.

Unfortunately, many of us are just one diagnosis away from experiencing financial devastation. Findings from Kaiser Family Foundation's June 2022 Health Care Debt Survey revealed that 57 percent of adults in the United States have experienced owing money for medical or dental bills at some point in the last five years. People without insurance, those with lower incomes, parents, black and Hispanic adults, and women were more likely to have health care debt.

Financial distress disproportionately affects people with limited resources, which amplifies disparities rooted in systemic racism and discrimination towards low-income populations, communities of color, and those living in rural or medical professional shortage areas. These groups reflect a "silent majority" of hard-to-reach families often overlooked by researchers and health systems chronicling and treating the effects of chronic or complex conditions. Long-term financial consequences such as receiving a lower credit rating, taking on credit card debt or using up savings have been documented in a 2022 Commonwealth Fund publication among approximately forty percent of adults who had problems paying medical bills.

The Centers for Medicare and Medicaid Services (CMS) acknowledges that effectively addressing health-related social needs such as food, utilities, housing and transportation insecurities can help ameliorate damaging health effects. Still, screening for social needs with accompanying services referrals for patient support is not yet integrated consistently in clinical practice.

In 2021, almost half (45%) of PAF survey respondents reported their financial situation deteriorated during the COVID-19 pandemic due to lost jobs and disrupted insurance coverage or a reduction in their income. The economic aftermath of the pandemic will continue to drive up demand for effective, appropriate needs navigation to safety net supports like Social Security Income, Social Security Disability Insurance, unemployment insurance, assistance through the Temporary Assistance for Needy Families (TANF)

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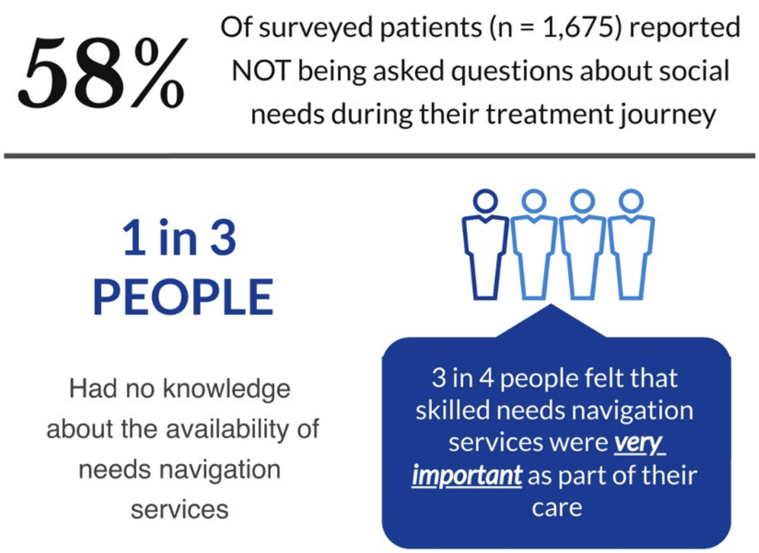
[1] In a 2019 survey of 2,800 people that Patient Advocate Foundation (PAF) serves, 63 percent flagged financial distress amplified by their illness as their most pressing concern and ranked that distress above fear of dying or suffering side effects of treatment.

program, the Supplemental Nutrition Assistance Program (SNAP) and other vital programs.



*Preliminary Data, Spring 2022 Survey (Patient Advocate Foundation)

A RECENT PATIENT ADVOCATE FOUNDATION (PAF) SURVEY FOUND THAT 58% OF PATIENTS REPORTED NEVER BEING ASKED QUESTIONS ABOUT THEIR SOCIAL NEEDS OR CONCERNS. THIS FITS WITH CURRENT HEALTH SYSTEM LANDSCAPE FINDINGS — FOR PATIENTS WHO SCREEN POSITIVE WITH UNMET SOCIAL NEEDS, FEW HEALTH CARE SETTINGS ARE EQUIPPED TO RESPOND WITH SUPPORTIVE INTERVENTIONS LIKE SKILLED NAVIGATION TO SAFETY NET PROGRAMS AND RESOURCES. YET A MAJORITY OF PEOPLE WANT THIS HELP.

People coping with complex and chronic health conditions stand to benefit the most from public and private safety net programs, yet are not made aware about program availability, how to apply, or eligibility criteria in a systematic way. Similarly, employer-based benefits tied to a patient's ability to maintain work like disability, family medical leave and services covered by insurance may be underutilized. People may also contend with social stigma in seeking these safety net supports and encounter other impediments caused by confusing, arduous, and overwhelming program eligibility and administrative requirements or long wait times for approval.

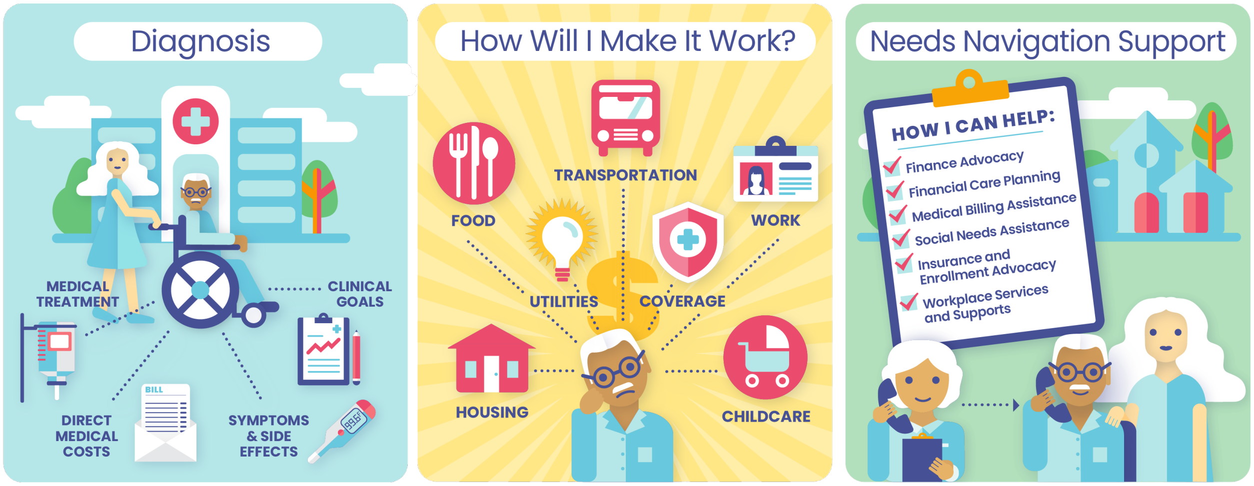
The pandemic also brought to light longstanding gaps in the social safety net that can impede access to care, affordability, and decision-making for people already experiencing financial distress. For example, The Brookings Institution described in its *June 2020 Up-Front blog* that individuals eligible for expanded unemployment insurance (UI) pursuant to federal COVID-19 relief efforts faced significant barriers to secure their benefits due to inadequate staffing, outdated computer systems, and insufficient data at UI offices to promptly process applications.

Volunteers engaged with the National Patient Advocate Foundation, (NPAF) the advocacy affiliate of PAF who are deeply connected in their communities affirm that these gaps and challenges interfere with peoples' lives and livelihoods, causing many to put their health and healthcare on the back burner.

Fortunately, needs navigation program access can be expanded and integrated with the health system to *provide real-time relief and proven practical help* for limited-resourced patients and families struggling with medical debt, household material hardships and other distressing financial and social concerns. This white paper details the coordinated strategic initiatives and collective action necessary to achieve this objective.

Our aims and activities are relevant for patients across multiple clinical areas, all of whom often experience disparate mortality rates within communities of color. NPAF has intentionally applied a denominator that encompasses limited-resourced patient populations with *any type of complex or chronic conditions who screen positive for social needs*. This inclusive approach is essential to achieving equitable needs navigation access for these patients and is also strategically advantageous for engaging policymakers in our healthcare transformation agenda. Policymakers gravitate towards legislative pathways that can assist a broad range of beneficiaries rather than parsing provisions by disease or diagnoses.

Continuity of Care from Clinic to Community



Patient Navigation
personalized focus on supporting disease-directed treatment in clinical settings

Social Risk Screening
identify unmet financial and social support needs

Needs Navigation
personalized focus on financial health and finding safety net supports while coping with disease

Needs Navigation is a Practical and Proven Health Equity Solution

Needs Navigation – as currently defined – is a dynamic intervention provided by people skilled in person-centered communication and resources coordination who serve as a primary contact in helping find relief for patients and families experiencing distressing financial and social burdens because of their medical conditions.

This personalized approach helps people navigate complexities embedded in the health care system that *affect their daily lives outside the hospital or clinic* – the "how will I make it work" worries about making ends meet and carrying on with daily life in the context of coping with their health conditions as depicted in the yellow middle box above. Needs navigation provides skilled help for patients and caregivers to identify their most distressing financial and social concerns and serve as their hands-on advocate in finding responsive safety net supports, assistance, and other public and private resources at local, state, and federal levels.

Needs navigation's focus on financial and social well-being in the setting of patients' living circumstances at home or wherever they reside complements the services provided by patient navigators and nurse navigators who are focused on helping patients and families find their way to and through health system complexities during disease-directed medical care and transitions taking place in various clinical settings (e.g., diagnosis, treatment and follow up depicted in the blue first box above). Both types of skilled navigation services should be delivered in tandem as complementary interventions responsive to positive needs screenings to support whole person-oriented care that fosters improved outcomes.

PAF has developed specialized expertise over its 25 years providing financial and social needs navigation services by phone to predominantly limited-resourced patients nationwide. Forty-five percent of PAF patients represent communities of color and 47 percent report a household annual income of less than $24,000. Based on patient and caregiver input about what people need to address their most pressing concerns, PAF postulates six domains (Table 1) pertinent to needs navigation that individually and collectively reinforce person-centered care and continuity from the clinic to the community.

Patient Impact

Waltrina | heart valve patient served by Patient Advocate Foundation

"The blessing of the financial help allows me to travel to the cardiac rehabilitation (55 miles away) that is supervised by my own cardiologist. This leaves my care and records in one system and gives me peace of mind and continuity of care. Additionally, I can no longer drive and must rely on others for transportation to all my appointments. Being able to cover the travel costs gives me a sense of control. It also reduces my feeling that I am burdening others and causing excess expenses to the them. Thank you for the program and the financial help."

Table 1. Six Domains of High-Quality Needs Navigation	
Financial Advocacy	Identify available resources at the local, state, and federal level that help alleviate financial distress once medical bills have already piled up.
Financial Care Planning	Builds financial literacy, teaches practical tips for anticipating costs and options to help handle them, as well as link to resources and supports that help preserve financial solvency.
Medical Billing Assistance	Clarify insurance documents (e.g., explanation of benefits) to help understand coverage and costs so they can plan for and access their specific treatments and services.
Social Needs Assistance	Help overcome household, income, and transportation challenges by identifying appropriate private or public safety net programs (e.g., social security disability income) and community resources that can help.
Insurance and Enrollment	Builds health insurance literacy that promotes enrolling in suitable plans and optimizing coverage to meet those most pressing needs.
Workplace Services and Supports	Assistance coordinating benefits with employers during an illness or to return to work after treatment to ensure continued financial stability.

NPAF pilot-tested these six domains and descriptions for each with an exploratory focus group of eight patients and caregivers in June 2022. The objective was to ascertain whether the language resonated with the personal experiences and perspectives of those who may have received or would have liked to receive needs navigation services. These patient-driven domains and descriptions will be further refined through a robust patient- and caregiver-engaged process that will also integrate insights from the broader navigation field.

Environmental Scan

Common Ground Across Navigation Providers and Care Settings

PAF's patient-reported program evaluation data demonstrate the benefits of needs navigation grounded in what patients and caregivers say is important to them. Among those receiving needs navigation support, ***seventy-seven percent*** of PAF survey respondents reported reduced distress and ***forty-six percent*** improved confidence in their communication with providers and/or insurers. Moreover:

- **95%** increased understanding of their health insurance plan details
- **100%** improved understanding about costs associated with their treatment and care
- **100%** increased awareness of local community resources that can help them

In NPAF's June 2022 focus group, patients and caregiver volunteers shared in their own words how navigation services have helped them or what would be helpful to them when facing a few blinded scenarios. A resounding theme capturing *what they most valued was having a committed and skilled individual who served as a consistent and continuous point of contact* ***committed to them.*** Respondents disregarded the person's title or type – the point of contact could be a community health worker, case manager, social worker, navigator, advocate or other position. What mattered most was their opportunity to forge a trusting relationship with someone skilled in listening to them, and who they could count on to be "their person" in understanding and responding to their top financial and social stability concerns.

Patient Impact

Deborah | breast cancer patient served by Patient Advocate Foundation

"My case manager has been a blessing to me. She shared valuable information that helped me get approved for some programs. She is very knowledgeable and patient. She took time with me as though I was the only person needing help. Thank you again for everything you did for me."

Using PAF's program as a starting point, NPAF conducted an online environmental scan to identify the 1) types of existing services, organizations, or programs that address financial and social needs, 2) professionals who provide them, and 3) care settings where services take place. Keywords included "financial toxicity", "navigation", and "financial advocacy" among others. Findings were categorized by entity type such as health system/clinic/hospital, community-based program, national non-profit, innovation model, etc.

While likely not a comprehensive list, the search yielded 19 unique results capturing a variety of entities across the health care system nationwide that are taking at least some steps to identify and/or address patients' unmet financial and social needs. This patchwork of programs appearing in different care settings with piecemeal staffing situations also varies in level and type of support available, ranging from comprehensive, high-touch assistance that is individualized (like PAF) to providing only resource referrals or financial assistance eligibility information. Moving forward, NPAF will work with collaborators in developing a state-by-state "access report card" further evaluating the current landscape, recognizing with these early findings that needs navigation services are not equitably or reliably available for all patients and limited-resourced populations who would benefit.

We also identified a range of positions either directly involved in providing needs navigation and/or providing referrals to needs navigation for patients who screen positive for social risk. These are the groups we want to collectively engage with patients and caregivers to develop policy proposals for advancing access to needs navigation programs in all care settings.

Drawing these various groups from the field together for discussion in our August 2022 Unifying the Field webinar, several themes were evident:

1) An interconnected field of professionals works in a complementary fashion to provide a wide scope of “needs navigation” financial and social services.

2) More common characteristics that unite the field exist than differences.

3) Referrals among these different categories of professionals are common and encouraged to ensure patient social needs are met in addition to their clinical needs.

4) Different categories of professionals and programs use unique approaches in delivering needs navigation services to accommodate specific needs of their communities and patient populations.

5) The field would benefit from co-creation of common needs navigation definitions and descriptions that are patient-informed to boost knowledge, awareness and understanding that can ultimately help build public demand.

6) Development of program-level needs navigation core competencies and standards must engage patients and caregivers as “experts by experience”

together with the full complement of provider partners to foster person-centered program accountability.

7) Program evaluation approaches should be flexible in accounting for variation across provider roles and settings where needs navigation is delivered and accommodating the specific characteristics of diverse populations and communities being served.

Finally, we conducted a supplemental scan to ascertain existence of any established core competencies and standards of practice relevant to needs navigation topics and domains. We found that the following five entities published documents providing an overview of assessment, services, and promising practices to help meet patients' financial and social needs:

a. The Financial Advocacy Network (FAN), an initiative convened by the Association of Community Cancer Centers (ACCC), developed the "Financial Advocacy Services Guidelines" in 2018 providing recommendations on characteristics, roles and responsibilities of financial advocacy teams in cancer center settings. These FAN guidelines are now being updated with completion anticipated in 2023.

b. Community Health Worker Core Consensus Project (C3 Project) published in 2018 with primary aims to expand cohesion in the field and contribute to the visibility and greater understanding of the full potential of CHWs to improve health, community development, and access to systems of care. (See Full Report)

c. Oncology Navigation Standards of Professional Practice released in March 2022 by the Professional Oncology Navigation Task Force of the Academy of Oncology Nurse and Patient Navigators (AONN+), these standards were created to provide clinical oncology nurse navigators, social work navigators, and patient navigators with clear information regarding best practices in the provision of professional care.

d. Standards for Social Work Practice in Health Care Settings published by the National Association of Social Workers (NASW), these standards provide benchmarks describing the services social workers should provide, employers should support, and consumers should expect.

e. Case Management Standards of Practice and Scope of Services published by the American Case Management Association in 2020 (ACMA), this document describes the scope of services that are provided by case management professionals across various settings and includes processes and services that patients and their support systems can expect to receive. In addition, the Case Management Society of America (CMSA) has standards that are available only to members and not publicly available.

Responsive social risk support for patients and caregivers with complex and chronic conditions requires an expansive professional field skilled in and accountable for effectively and consistently describing and delivering needs navigation services and their benefits. As such, PAF's patient-driven needs navigation initiative will solicit and integrate insights among the various entities and service providers identified in our environmental scans.

Evidence Generation

Patient Engagement in Needs Navigation Research

New quality measures initiatives are pressing for health system action on equity. This means that social determinants of health (SDOH) screening is building momentum to help identify communities with increased social risk and individuals with unmet needs. Most healthcare settings, however, still do not have processes in place to screen for or address patient and caregiver financial and social risks or material hardships (food, utilities, housing insecurity), transportation barriers, insurance adequacy, SDOH and other challenges that would benefit from targeted needs navigation intervention and safety net program support.

Even where some form of needs navigation may currently be available, navigation program awareness, access, and accountability for providing quality services is inconsistent and the navigation services and professionals providing them are siloed, preventing care continuity and efficiencies across healthcare settings and patient populations.

Most research publications on "navigation" document results and return on investment relating to oncology patient navigation in the context of clinical care (i.e., finding their way to and through diagnosis, cancer treatment and survivorship). Over a decade of patient navigation studies exist demonstrating that these programs address cancer care disparities. Cancer centers and other settings that provide, or refer patients to, patient navigation services have shown a return on investment that includes increased treatment adherence[2], improved outcomes, and reduced overall costs for both patients and health systems.[3]

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[2] Ell K et al. Cancer treatment adherence among low-income women with breast or gynecologic cancer: a randomized controlled trial of patient navigation. Cancer. 2009 Oct 1;115(19):4606-15.

[3] Yezefski T et al. Impact of trained oncology financial navigators on patient out-of-pocket spending. Am J Manag Care. 2018 Mar;24(5 Suppl):S74-S79. PMID: 29620814. Available at: https://pubmed.ncbi.nlm.nih.gov/29620814/

Financial and social needs navigation is a newer area for investigation requiring research investment for evidence generation. Advancing the strategic agenda for needs navigation will require its own body of studies and peer reviewed publications to demonstrate its specific return on investment and system efficiencies that can foster policy change required for scaling these services. For example, innovative studies must be developed to generate evidence demonstrating that needs navigation delivers:

- Positive patient outcomes
- Reduction in duplicative health system services
- Avoidance of costly treatment delay while promoting treatment adherence
- Saved costs – for people, health systems/plans and government

Study findings must also be packaged in a way that can inform the development of legislative policy proposals to increase access to needs navigation services. To be "actionable" in the eyes of state and federal policy makers, the research must support, to the satisfaction of budget analysts, the assertion that needs navigation produces quantifiable outcomes relative to health and/or fiscal savings.

The Accountable Health Communities model (AHC), an ongoing demonstration developed by the Center for Medicare and Medicaid Innovation (CMMI), is a promising indication that policymakers are interested in pursuing delivery system reform that includes assessing financial and social needs. The AHC Model is testing whether systematically identifying and addressing the health-related social needs of Medicare and Medicaid beneficiaries through screening, referral, and navigation services will impact health care costs and reduce health care utilization.

PAF's Patient Insight Institute (PII) was launched in October 2021 to foster patient engagement in actionable research and lead collaborative evidence-based practices informed by the whole patient experience. The Institute will conduct projects to demonstrate that needs navigation interventions can transform care and lead to a more responsible use of federal resources.

These evidence-based practices will be illuminated by patient experiences in access to healthcare, the impact of cost of care on treatment choices and care goals, and the effects on low income/communities of color patients resulting from barriers to care. This patient centered approach prioritizes the interconnectedness between patient perspectives, health services research and policy development to ensure that widespread solutions reach under-represented patient populations and communities.

New research conducted by PII partner, Social Interventions Research & Evaluation Network (SIREN) found that 1) we know relatively little about the prevalence of social screening across the U.S. health care settings, little research has explored the perspectives of racially, ethnically, and linguistically diverse populations, and 3) very little research exists exploring screening sustainability.[4] As such, federal efforts to scale needs navigation – both screening and interventions – must be informed by strong evidence about the feasibility in busy practice settings.

The Institute's leadership will partner with research, healthcare, and policy allies in developing and disseminating evidence-based research projects that integrate diverse patient and caregiver perspectives – our "Experts by Experience" – in the development and design of needs navigation research projects whose goal is to be relevant to state and federal policy makers as well as health systems and practitioners.

Policy Pathways

Systematizing Access to High-Impact Needs Navigation

Informed by the evidence-based research spearheaded by PII, NPAF will launch a patient-driven coalition effort to leverage federal entitlements focused on increasing reliable access to needs navigation for all patients in all care settings. This multi-year effort involves patients, caregivers, health systems, payers, providers, researchers, and policymakers as key allies to achieve collective policy goals. Critical to this effort is engagement with the Senate Finance committee and companion House committees (i.e., Ways and Means, Energy and Commerce). These committees have jurisdiction over all federal entitlement programs including Medicare, Medicaid, the Children's Health Insurance Program, and welfare programs.

Federal entitlement programs comprise the bulk of funding that the federal government spends on health care. Entitlement programs are generally not subject to the annual appropriations process. Once the eligibility criteria are met, funding for services is guaranteed. Amendments to entitlement programs generally become permanent features of the statute, codified in the Social Security Act.

Table 2 outlines three policy pathways developed to align with jurisdictions of the Senate Finance committee and associated House committees. They are not mutually exclusive and can work in tandem alongside efforts to advance reimbursement, authorization efforts, and administrative actions (i.e., Health and Human Services, Centers for Medicare, and Medicaid Services).

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[4] De Marchis EH et al. State of the Science on Social Screening in Healthcare Settings. 2022. San Francisco, CA: Social Interventions Research and Evaluation Network. Available at: https://sirenetwork.ucsf.edu/tools-resources/resources/screen-report-state-science-social-screening-healthcare-settings

Table 2. Pathways to Improve Access to Navigation Services	
Enhancement	Explore current pending legislation and refine existing programs such as allowing broader use of certain block grant funds (e.g., Temporary Assistance for Needy Families and Social Services Block Grant) to improve access to navigation services.
Flexibility and Innovation	Advance policies that would allow states to spend federal dollars on services or populations not currently contemplated under existing law (e.g., state plan amendments, waivers, and demonstrations).
Expansion	Expand or direct the use of entitlement funds allocated to states to support needs navigation services (e.g., Medicaid's Targeted Case Management Program).

Enhancement

Existing programs such as Temporary Assistance for Needy Families (TANF)[5] and the Social Services Block Grant (SSBG)[6] are capped funding streams to states. Funding can be used to support a range of services for low-income families to promote self-sufficiency including case management. It has been many years since either program has been reauthorized. The TANF and SSBG target populations are under-resourced communities which frequently have issues stemming from social determinants of health. Needs navigation would improve financial outcomes for the target population and therefore promote self-sufficiency.

While there is no guarantee that legislative efforts would move forward, this pathway can be designed as a technical expansion with no additional cost.

Flexibility and Innovation

Many federal funding streams have conditions attached to receipt of such funds such as what money can be spent on (i.e., referrals not services in Targeted Case Management) and who can receive services (i.e., means testing under Medicaid). In the past, new ideas have been tested to allow states additional options for how

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[5] Title IV-A of the Social Security Act establishes the TANF Block Grant. The TANF program is designed to help needy families achieve self-sufficiency.

[6] Title XX of the Social Security Act establishes the SSBG. The purpose of SSBG is to support social services directed towards achieving economic self-sufficiency; preventing or remedying neglect, abuse, or the exploitation of children and adults; preventing or reducing inappropriate institutionalization; and securing referrals for institutional care, where appropriate.

and whom money is spent. Policies could allow spending of federal dollars on services, such as needs navigation, or populations not currently contemplated under existing law. For example, states could submit State Plan Amendments, Medicaid 1115 waivers, or Home and Community Based services 1915(c) waivers. The Centers for Medicare and Medicaid Innovation could initiate demonstration programs to test needs navigation services.

This pathway is time consuming and labor intensive for states, but presents an opportunity for innovation, setting precedent and collecting important evaluation data.

Expansion

The federal government authorizes taxpayer dollars to support policy priorities. For example, federal resources are spent to provide health care coverage to low-income populations. Funding is allocated to states through formulas, block grants or competitive grants. The use of that funding could be expanded, increased, or directed to support needs navigation services.

For example, Medicaid was created to provide health care services to low-income individuals. Since 1967, changes to Medicaid have been enacted to advance policy goals such as providing access to home and community-based services, vaccines for children, and breast and cervical cancer prevention and treatment. It is consistent with legislative precedent to amend Medicaid to expand access to needs navigation services, specifically Medicaid's Targeted Case Management Program.[7]

The expansion pathway can be politically challenging, costly, and requires a feasible vehicle for advancement. However, this pathway could guarantee access to needs navigation services and has a broader range of possible Congressional champions.

These policy pathways may apply to patients with a variety of complex chronic conditions and complement current efforts being explored to provide patient navigation reimbursement in oncology settings. NPAF and PAF have been committed participants in helping shape activities of the National Navigation Roundtable as well as the AONN+ oncology nursing navigation community. NPAF also serves as an advisor for the Association

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[7] Consists of services to assist eligible beneficiaries in obtaining medical and other services necessary for their treatment. Case management is not the direct provision of medical and related services, but rather is assistance to help beneficiaries receive care by identifying needed services, finding providers, and monitoring and evaluating the services delivered. Targeted case management (TCM) refers to case management that is restricted to specific beneficiary groups defined by disease or medical condition, or by geographic regions. Targeted populations, for example, may include individuals with HIV/AIDS, tuberculosis, chronic physical or mental illness, developmental disabilities, and children receiving foster care.

of Community Cancer Center's Financial Advocacy Network (FAN) and contributing person-centered input in ACCC's current project updating FAN's practice guidelines.

The comprehensive strategic agenda crafted for needs navigation will leverage the learnings of the patient navigation community activities while also considering and testing opportunities for new policy pathways aligned with applicable federal entitlement programs under the Senate Finance Committee's jurisdiction for funding.

Next Steps

Activating a Consensus-Based Needs Navigation Coalition

Our goal is to build a collaborative health equity learning and action community collectively committed to expanding availability of quality needs navigation in all care settings for patients who screen positive for social risks/SDOH. Achieving this objective relies on discrete research, policy and advocacy steps orchestrated to **Socialize, Standardize and Scale** needs navigation as a responsive, effective health equity intervention.

SOCIALIZE

Understand the impact of SDOH and financial distress

Educate audiences on needs navigation and how it can address the problems of patients and caregivers

Connect this work as a solution that needs to be scaled

▶

STANDARDIZE

Define and describe needs navigation and services

Detail core completeness and develop consensus-based guidelines

Create accountability for quality services delivery

▶

SCALE

Systematize these services and scale to serve more patients with reliable access

Evaluate impact continuously

Socialize the problem and the solution. Our comprehensive needs navigation environmental scan explored a variety of terms used to define and describe the role, job titles of different types of staff involved in delivery, the various settings where programs or services exist, and the scope of services offered. In 2021, we also interviewed several senior Capitol Hill staff and key Administration officials about their understanding of patients' challenges and lived experiences concerning social needs, what they currently know about needs navigation, and to hear their thoughts about federal policies and pathways that might help improve understanding and access to navigation services. While important groundwork has been laid, more is needed to be done to fully educate Hill and

Administration staff on the need to expand access to social and financial needs navigation services.

Standardize the words we use. Our scan findings and staff interviews revealed that the myriad terms in use relating to "navigation" in healthcare contexts cause confusion across all audiences that interferes with efforts to advance the field's progress and expand access. To execute a successful socialization strategy, we will first have to bring the field together for term testing involving focus groups, polling research and other methods that will facilitate collaborative development of resonant, patient-informed definitions and descriptions that can be used consistently in our efforts (and the field's vernacular) to increase understanding and curtail confusion. This important work will also help us:

(a) Use patient and caregiver insights that inform messaging which supports the grassroots campaign and defines the services with consistent terminology that is succinct, clear and helps build buy-in and demand.

(b) Generate ideas for patient-reported outcomes research that will help in evaluating needs navigation programs on access/availability now, and eventually, on quality.

Broaden Access: Scaling Policy Goals. 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 Medicaid and other safety net supports and programs in multiple states. Through policy pathways exploration and proposal development, coalition cultivation and grassroots advocacy engagement, NPAF will pursue opportunities with partners to:

- Expand awareness and availability of needs navigation and investment in research essential to quality improvement and evaluation

- Dismantle harmful effects of restrictive policies that interfere with equitable access, affordability, and outcomes

- Preserve and expand access to vital entitlement programs for limited-resourced populations of patients and families whose lives depend on them

To advance this strategy, we are asking organizations to join our efforts to make needs navigation a standard of care equitably accessible in all care settings. Our Statement of Principles (page18) describes the policy principles that we believe will best integrate needs navigation within our healthcare system.

As a signatory, you will join us and advocate for policy proposals that will increase equitable access to *Needs Navigation* services guided by the following principles:

Statement of Principles

1. *Needs Navigation* services must be a standard of care embedded in the US healthcare system.
2. *Needs Navigation* services must be reliably available to all patients and caregivers in all care settings regardless of diagnosis, age, race, gender, geographic location, language barriers, income or other factors related to social determinants of health.
3. *Needs Navigation* includes financial advocacy, financial care planning, medical billing assistance, social needs assistance, insurance and enrollment advocacy, and guidance about workplace benefits, services and supports, as appropriate.
4. *Needs Navigation* should simplify the healthcare experience for patients and their families and improve access to quality care without introducing additional administrative burdens.
5. *Needs Navigation* must be provided by individuals trained to demonstrate core competencies that include skilled communication, health literacy and cultural sensitivity.
6. As a consistent standard of practice, all patients must be regularly assessed for their financial and social risks and appropriately referred to *Needs Navigation* services.
7. Limited-resourced communities require strategic investments and support to develop new and enhance existing community-based *Needs Navigation* programs responsive to the populations' unique needs.
8. Investments are needed to determine best practices and bring *Needs Navigation* services to scale.
9. *Needs Navigation* practice standards and outcome measures must involve patients and caregivers in their development.
10. Federal, state and local governments are key partners in ensuring that all patients have access to high quality *Needs Navigation* services.

To sign on the Statement of Principles, visit NPAF's website, NPAF.org.