Expanding Access to Patient Navigation Services is Critical

Improved Navigation Supports Can Strengthen HIV Prevention and Care Outcomes

Making it easier for people to engage in HIV treatment and prevention services is a critical first step to sustaining good health outcomes. Patient navigation can play a key role in increased engagement in care.

Patient navigation has been proven to improve engagement in care and retention, improve health outcomes, and be cost effective,[1,2,3] and the evidence base for patient navigation in HIV care is growing.[4,5] Patient navigation is a term for a range of services offered by various types of health care workers to facilitate consistent, effective engagement with services and can be critical to a variety of care settings where HIV diagnosis can occur, including in CBOs, sexual health clinics, syringe service programs (SSPs), and emergency departments.

The U.S. health system is complex, numerous barriers can impede access to healthcare services, and many people engage with the health system with limited health literacy. People impacted by HIV are often managing other life and health-related challenges that may cause them to deprioritize their engagement in HIV treatment and prevention services or drop out of theses services altogether. Fears about health status, prior negative health care experiences, discrimination, disrespect, stigma, and trauma can create signifcant barriers to seeking healthcare.[6]

Further analysis and policy clarification are needed to define patient navigation, define community health workers (CHWs) and what specific roles they can play as navigators, and ensure that adequate mechanisms exist to reimburse for patient navigation services.

SUPPORTING CONTINUED ENGAGEMENT IN CARE MAXIMIZES POSITIVE CLINICAL OUTCOMES

Focused policy actions are needed to assist people living with HIV or who may benefit from HIV prevention to navigate complex health systems and receive the services they need to remain engaged in care:

1) Patient Navigators

Adapt the training, titles, and roles of patient navigators to meet the needs of people impacted by HIV, and provide specialized training in HIV prevention and care.

2) Community Health Workers (CHWs) as Patient Navigators

Establish tailored policies for CHW navigators that includes recruitment, professional development, career advancement, and ongoing support to address trauma and prevent burnout.

Develop standards for CHW navigators to ensure fair compensation including benefits, paid leave and other core professional employment benefits.

Embed CHWs in patient navigation in community-based organizations (CBOs) and health care settings.

3) Paying for Patient Navigation Across Health Care Programs

Leverage reimbursement options that may be available to clinics, community-based organizations or other health care providers for patient navigation services via Medicare, Medicaid, and private insurance (including marketplace health plans).

PATIENT NAVIGATION LESSONS FROM CANCER CARE

There are lessons learned from the use of patient navigation in cancer care that could be useful in HIV treatment and prevention. In cancer care, patient navigation services are considered a crucial aspect of treatment and care.

Patient navigation in cancer care has been show to:

1) Improve rates of cancer screening[1]
2) Reduce time to diagnosis[1]
3) Reduce time from diagnosis to initiation of treatment[1]
4) Reduce emergency department visits[2] and hospital admissions[1,2]
5) Increase adherence to appointments[1]
6) Improve decision making and treatment knowledge of cancer survivors[1]
7) Improve patient satisfaction with care[1]
8) Improve cancer survivor quality of life[1]
9) Reduce burden on oncology providers potentially reducing burnout, errors, and turnover[2]
10) Reduce costs to Medicare and healthcare use[3]
11) Improve quality of life among low income and racial and ethnic minorities[4]

There are potential benefits of expanding patient navigation services in HIV treatment and prevention across all entry points of the continuum, including testing and screening, engagement and retention in care, as well as improving quality of life and managing psychosocial wellbeing and other health concerns. Patient navigation in HIV may also decrease burden on providers and reduce costs to Medicaid, Medicare, Ryan White, and other funding sources.

1 Chan RJ et al., *Patient navigation across the cancer care continuum: an overview of systematic reviews and emerging literature*, CA Cancer J Clin, 2023;73(6):565–589.

2 Kline RM et al., *Patient navigation in cancer: the business case to support clinical needs*. J Oncol Navig Surviv. 2019:15(11):585- 591.

3 Rocque GB et al., *Patient Care Connect Group. Resource use and Medicare costs during lay navigation for geriatric patients with cancer*, JAMA Oncol, 2017;3(6):817-825.

4 Patel MI et al., *Effect of a community health worker-led intervention among low-income and minoritized patients with cancer: a randomized clinical trial*, J Clin Oncol, 2024;42(5):518-528.

1. WHAT IS THE ROLE OF PATIENT NAVIGATORS?

The National Cancer Institute defines a patient navigator as a person who helps guide a patient through the health care system.[7] This includes assistance going through screening, diagnosis, treatment, and follow-up of a medical condition such as HIV. However, screening navigation services are often not covered by payers, including Medicare, Medicaid, and private insurance. A patient navigator may help a patient communicate with their health care providers so they get the information they need to make decisions about their care. Patient navigation also may be used to support engagement in prevention services by sustaining engagement with HIV testing and treatment of sexually transmitted infections (STIs), linking people to ancillary services, and supporting PrEP adherence and persistence.[8]

Patient navigation can provide education, advocacy, and can create a bridge between clinical services and social services that can overcome barriers to engagement in care. Patient navigation may include a range of other supports to address health-related social needs, by helping patients set up appointments for doctor visits and medical tests and get financial, legal, and social support. They also may work with insurance companies, employers, case managers, lawyers, and others who may influence a person's health care needs. Many types of professionals on a care team can serve as patient navigators, including social workers, nurses, physician assistants, physicians, and case managers.

POLICY ACTION

Adapt the training, titles, and roles of patient navigators to meet the needs of people impacted by HIV, including specialized training in HIV prevention and care.

There are many names and titles under which patient navigation is carried out (case manager, peer navigator, patient navigator, PrEP navigator, social worker, medical assistant, disease intervention specialist, etc.). Therefore, there is a need to define the skills required for patient navigation within HIV treatment and prevention services. Staff providing patient navigation need to have the tools to provide culturally responsive and linguistically appropriate care, maintain patient privacy, and ensure compliance with internal policy and recognized standards. Trainings may be developed to provide various members of the health care team with HIV prevention and care navigation skills. For example, case managers or social workers already may be providing patient navigation services, yet those services are not formally recognized and/or being reimbursed for. Or, harm reductionists or recovery coaches from a substance

use disorder (SUD) program can benefit from HIV patient navigation skill training to work in an HIV clinic with patients living with HIV and SUD. HIV patient navigation skills, whether for treatment or prevention, must be available to more people, patients and care teams alike. Outlining these skills can support training for patient navigation across professions as well as enable reimbursement for patient navigation services.

2. COMMUNITY HEALTH WORKERS (CHWs) AS PATIENT NAVIGATORS

The American Public Health Association (APHA) defines a CHW as a frontline public health worker who is a trusted member of and/or has a close understanding of the community served. This trusting relationship enables the worker to serve as an intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.[9] CHWs are used across the health care system, but each field or institution may use slightly different terms and may define the roles and responsibilities differently.

People with lived experience similar to their clients have special ability to establish safe and trusting relationships with patients. This can be especially important for people impacted by HIV who face significant stigma and discrimination from health care providers.[10] CHWs with lived experience, often known as peers, bring their own knowledge to their work as patient navigators. One of the benefits of peers is that they can spend more time with individual clients than other more clinically trained team members. In clinical settings, CHWs can help clinics facilitate patient engagement in care and have the potential to be most effective in environments that reinforce client comfort and trust. CHWs, however, also have specific needs that must be met to effectively support and retain them in these roles.

POLICY ACTION

Establish professional policies for CHW navigators with lived experience performing HIV patient navigation that includes recruitment and training, professional development, career advancement, and ongoing support to address trauma and prevent burnout.

People impacted by HIV often have adverse experiences in health systems and face more barriers to consistent and effective engagement than others.[11] People who have learned how to navigate health and social services systems for themselves can bring special skills and perspective which can be especially effective. However, many people with lived experiences—including CHWs—may lack more traditional educational or work credentials, thus job postings and expectations need to be tailored to these individuals. For example, employers should tailor job postings to core competencies that have been acquired through professional and/or lived experience rather than credentialing. CHWs with lived experience may be challenged in operating within a professional work environment. This may call for different supervision than for other clinical staff and dedicated development of the skills necessarily to operate in a professional workplace. CHWs with lived experience may face stigma, and for those in HIV care settings, being labeled a peer is especially stigmatizing. Living with HIV comes with trauma and for some, assisting clients can be re-traumatizing, reminding them of their own experiences. Therefore, special attention is needed to pro-actively take steps to build resilience, mitigate stigma (by not identifying CHWs with HIV as peers), prevent burnout and take steps to protect their own mental health. These programmatic considerations should be viewed as an investment in the retention of critical members of a care team. All team members, whether they have lived experience or not, should have the tools and resources necessary to maintain their own health.

POLICY ACTION

Develop standards for patient navigation roles to ensure adequate compensation including benefits, paid leave, and other employment benefits.

CHWs are often in entry level positions and receive some of the lower salaries within care teams. To foster sustainable CHW patient navigator roles, it is important to fairly compensate individuals for the roles they fulfill. In addition to adequate wages, CHWs serving as patient navigators need access to standard employment benefits such as health coverage, retirement savings, paid leave, and defined opportunities for career advancement.

POLICY ACTION

Embed CHWs as patient navigators in community-based organizations (CBOs) and health care settings.

Placing CHWs in community-based organizations (CBOs) and health care settings may build capacity and competency. Local and state health departments may provide funding for their placement and some payers reimburse for patient navigation services. For instance, Medicare coverage of patient navigation services requires patient navigators attest to a series of core competencies. Embedding CHWs also may enable organizations to meet state and federal training requirements. One way to promote the use of CHWs as patient navigators is for health departments to

recruit, hire, and supervise CHWs, but deploy them to CBOs and health care settings such as clinics and emergency departments. These CHWs may require training and certification, depending on the state. Their integration can foster stronger collaboration between the health department and organizations and may foster retention. The District of Columbia is one example of a health department that has embraced this approach for HIV care. Out of 47 funded HIV CBOs in the DC metropolitan area, more than half of them have received health department funded CHWs, many of whom serve as patient navigators.[12]

3. PAYING FOR PATIENT NAVIGATION ACROSS HEALTH CARE PROGRAMS

Sustainable financing is a critical consideration in establishing patient navigations programs. Health departments that have established pilot programs for patient navigators often rely on funds for which there are competing resource needs. As such, there is a need to increase funding available for patient navigation as well as to ensure funding is available in various health care and community-based settings. The Ryan White HIV/AIDS Program (RWHAP) has many demands for its resources and funding for patient navigation is limited, therefore there is a need to identify alternative funding sources for these services such as Medicaid, Medicare, and other payers.

Funding for patient navigation also may be available through federal, state, and local health departments through grants and other mechanisms. For example, in Florida, an emergency department at an academic health center utilizes federal funding for behavioral health through the Department of Children and Families (DCF) as a contracted provider for the local regions DCF managing entity.[13] This Florida emergency department also utilizes county level funds through local government and department of health to cover patient navigation services.[14] Health departments and clinics should proactively explore various state and local-level grant and funding resources that could be utilized for patient navigation.

POLICY ACTION

Leverage reimbursement options that may be available to clinics, community-based organizations or other health care providers for patient navigation services via Medicare, Medicaid, and private insurance (including marketplace health plans).

To successfully expand access to patient navigation services, new and reliable sources of funding are needed. There are several current opportunities that merit attention in Medicare and Medicaid.

In 2023, the Centers for Medicare and Medicaid Services (CMS) released their final rule for the 2024 Medicare Physician Fee Schedule. The rule finalizes new reimbursement codes for patient navigation services, known as Principal Illness Navigation (PIN) under Medicare, focused on patients with serious illnesses expected to last at least 3 months, including cancer and HIV. Under the new rule, services provided by health care support staff under provider supervision, such as patient navigators, can now be reimbursed. CMS does not endorse any specific organization, certification process or credential, deferring to state-based credentialing requirements where they exist and requiring navigators to attest to a set of competencies when state-based credentialing is not in place. These codes may be used by any staff performing eligible services based in clinic or community health settings where there is expected to be follow up care.[15] Importantly, this means settings such as the emergency department are not eligible to render and bill for PIN services, despite people with HIV having higher emergency department visit rates compared to people who do not have HIV.[16] More than half of health care encounters in the U.S. occur in emergeny departments, with Medicaid and Medicare beneficiaries, racial and ethnic minorities, and women disproportionately represented.[17]

In Medicare, the recent changes to the physician fee schedule create reimbursement options that will not be used unless clinics and CBOs are aware of these reimbursement pathways and are trained to use them. Health departments should work with the local provider community to conduct trainings and raise awareness of the ways that Medicare can support improved access to patient navigation.

There are also options for reimbursement through Medicaid programs. As of July 1, 2022, Medi-Cal (CA Medicaid) covers patient navigation which includes “health navigation services to support access and connection to community resources” in individual or group settings.[18] Medicaid and Medicare cover patient navigation and CHW programs and recent policy changes in both programs have sought to expand access to these services. Additionally, California is also funding a Health Enrollment Navigators project, that will last until Jun 30, 2026. The program is intended to improve outreach and enrollment for hard-to-reach populations in Medi-Cal.[19] As of February 12, 2022, Louisiana Medicaid covers services provided to beneficiaries by qualified CHWs including health system navigation.[20] Health departments should work with Medicaid agencies to educate them on the importance of patient navigation for people with HIV and communities impacted by HIV and provide information on these various state models for expanding access to patient navigation.

EXPANDING INSURANCE COVERAGE CAN MAKE CHW AND PATIENT NAVIGATION SERVICES MORE SUSTAINABLE

The U.S. has a complex system of paying for HIV care and services. To expand the use of CHWs as patient navigators in a way that is sustainable, it is important to consider all potential funding sources, and maximize the opportunities for insurance programs to cover these costs:

Ryan White HIV/AIDS Program (RWHAP)

Ryan White HIV/AIDS Program (RWHAP) funding can beused to support CHW programs. Just as the RWHAP legislation requires the program to serve as the payor of last resort for individuals, meaning it cannot pay for a service if another source of funding is available, at the policy level, these flexible resources also should be conserved and only used when other payment sources are not available as a coverage source for people with HIV. Therefore, expanding the use of insurance to cover CHW services is an important way to improve HIV outcomes and conserve HIV resources. A critical role that the RWHAP has played is to examine the effectiveness of CHW programs in serving people with HIV and developing resources, trainings, and various materials to support health departments and RWHAP recipient clinics to adopt CHW programs.[1] The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) that administers the RWHAP has taken steps to identify effective approaches and strategies for using CHWs to improve HIV outcomes. From 2016-2019, they funded a project to use CHWs to improve linkage and retention in care. The project was conducted by Boston University who worked with ten RWHAP recipient clinics to provide training, technical assistance, and support to integrate CHWs into their multidisciplinary care teams and to strengthen their capacity to reach racial and ethnic minority communities and increase health equity. An evaluation of the project found that CHW interventions can improve HIV outcomes by increasing engagement and retention in care.[2]

Medicaid

A 2024 50-state scan of state health policies by the Connecticut Health Foundation found that 24 states pay for CHW services through Medicaid and three more are implementing these services.[3] An earlier survey by KFF in July 2022, however, found that half of responding states (29 of 48) reported allowing Medicaid payments for services by CHWs.[4] States have several pathways for covering CHW programs through Medicaid. Within Medicaid State Plans (the formal agreement between the state and CMS for how they will operate their Medicaid program), states can cover CHWs through both the preventive services and the outpatient services benefits. Covering CHWs under the state plan generally requires them to be available when necessary to all Medicaid beneficiaries. Nine states covered CHWs this way in 2022 and four states indicated their intention to begin doing so in 2023. States also can cover CHWs through the ACA Home Health Option which enables states to develop programs for targeted populations of people with chronic conditions. Twenty-one states have health home programs. Only one state, Wisconsin, specifically focused on HIV, but several other states have programs for chronic conditions that could be inclusive of HIV.[5] As of July 2022, 40 states plus the District of Columbia contract with comprehensive risk-based managed care plans and some of these have contract requirements mandating that the plans offer CHW services. States also can use the Section 1115 waiver authority wherein states receive federal permission to be exempted from specific Medicaid rules to cover CHW services for some populations.

In recent years, the Biden Administration has taken steps to bolster Medicaid CHW programs. In 2022, with funds from the American Rescue Plan, the Administration provided $225 million to train over 13,000 CHWs and in 2023, with funds from the Consolidated Appropriations Act of 2023, authorized $50 million annually to build workforce capacity from state fiscal years FY 2023 through FY 2027.3

Medicare

Effective January 2024, the Centers for Medicare and Medicaid Services (CMS) updated the physician fee schedule (PFS) which is the set of rules that guide payment for Part B physician services in Medicare. The PFS now has two payment categories that enable the coverage of patient navigation services. These are principal illness navigation (PIN) services for persons with serious conditions such as HIV and provide for a physician visit followed by monthly navigation services which can be provided by CHWs.[6] Additionally, community health integration (CHI) services can be provided monthly by CHWs for services such as care coordination, health education, patient self-advocacy training, and social and emotional support.[7]

Private Insurance

Private health insurance can cover CHW services, but limited data are available of how widespread this is. Looking to the future, greater use of CHWs could be influenced by expanding the evidence-base in support of their effectiveness and cost-effectiveness. Further, future efforts to focus on ACA marketplace coverage of CHWs could identify policy incentives for their greater use.

1 TargetHIV, *Using Community Health Workers to Improve Linkage and Retention in Care*, https://targethiv.org/chw, (last visited November 26, 2024).

2 Drainoni, ML et al.., *Integrating community health workers into HIV care teams: Impact on HIV care outcomes*. Journal of HIV/AIDS & Social Services, 19(3), 204–219.

3 Connecticut Health Foundation, *50-state scan of Medicaid payment for community health workers* (January 31, 2024), https://www.cthealth.org/publication/50-state-scan-of-medicaid-payment-for-community-health-workers/.

4 Kaiser Family Foundation, *State Policies for Expanding Medicaid Coverage of Community Health Worker (CHW) Services* (January 23, 2023), https://www.kff.org/medicaid/issue-brief/state-policies-for-expanding-medicaid-coverage-of-community-health-worker-chw-services/.

5 Centers for Medicare and Medicaid Services, *Medicaid Health Homes: State Plan Amendment Overview (October 2024)*, https://www.medicaid.gov/resources-for-states/downloads/hh-spa-overview-oct-2024.pdf.

6 Medicare.gov, *Principal illness navigation services*, https://www.medicare.gov/coverage/principal-illness-navigation-services, (last visited November 26th, 2024).

7 Medicare.gov, *Community health integration services*, https://www.medicare.gov/coverage/community-health-integration-services, (last visited November 26, 2024).

THE TIME IS NOW

Providing support to assist individuals in navigating health and social services is a critical component of sustaining progress against HIV. Opportunities for funding and reimbursement are available and must be seized by providers. Health departments, emergency departments, CBOs, and clinics should work with supporting organizations and agencies to expand patient navigation.

1 Bakshi S et al., *Improving care coordination and reducing ED utilization through patient Navigation*, American Journal of Managed Care, 2022 May 1;28(5).

2 Shade S et al, *Outcomes and costs of publicly funded patient navigation interventions to enhance HIV care continuum outcomes in the United States: A before-and-after study*, PLoS Medicine, 2021 May 13;18(5):e1003418.

3 Bernardo BM et al., *The efficacy and cost-effectiveness of patient navigation programs across the cancer continuum: a systematic review*, Cancer, 2019 Aug 15;125(16):2747-61.

4 Mizuno Y et al., *Is HIV patient navigation associated with HIV care continuum outcomes?* AIDS. 2018 Nov 13;32(17):2557-71.

5 Teggart K et al., *Effectiveness of system navigation programs linking primary care with community-based health and social services: a systematic review*, BMC Health Services Research, 2023 May 8;23(1):450.

6 Stuber et al., *Stigma, prejudice, discrimination and health*, Socialscience & medicine. 2008 Aug 1;67(3):351-7.

7 Cancer.gov, *Definition of a Patient Navigator*, https://www.cancer.gov/publications/dictionaries/cancer-terms/def/patientnavigator, (last accessed November 26, 2024).

8. Salabarría-Peña Y et al., *Informing the future of PrEP navigation: findings from a five-site cluster evaluation*, Evaluation and Program Planning, 2022 Feb 1;90:101999.

9 American Public Health Association, *Community Health Workers*, https://www.apha.org/apha-communities/member-sections/community-health-workers, (last accessed November 26th, 2024).

10 Geter A et al., *HIV-related stigma by healthcare providers inthe United States: a systematic review*, AIDS patient care and STDs. 2018 Oct1;32(10):418-24.

11 Chambers LA et al, Stigma, *HIV and health: a qualitative synthesis*, BMC Public Health, 2015 Dec;15:1-7.

12 Barnes C, (June 21, 2024) An Examination of Patient Navigation, Peers, and Model Programs, Oral Presentation, Georgetown University.

13 Henderson, H, personal communication, October 14, 2024.

14 ibid.

15 Department of Health and Human Services Centers for Medicare & Medicaid Services, 88 Fed. Reg. 78818 (Nov 16, 2023) (to be codified at 42 C.F.R pts. 405, 410, 411, 414, 415, 418, 422, 423, 424, 425, 455, 489, 491, 495, 498, and 600).

16 Siddiqi KA et al, *Estimating resource utilization for emergency department visits by patients' HIV seropositivity in the United States, 2009 to 2018*, The American Journal of Emergency Medicine, 2022 Mar 1;53:73-9.

17 Marcozzi D et al., *Trends in the Contribution of Emergency Departments to the Provision of Hospital-Associated Health Care in the USA*, International Journal of Health Services, 2018;48(2):267-288.

18 California Department of Health Care Services, *Community Health Workers*, https://www.dhcs.ca.gov/community-health-workers (last visited November 26, 2024).

19 California Department of Health Care Services, *Medi-Cal Health Enrollment Navigators Project for Clinics* https://www.dhcs.ca.gov/services/medi-cal/eligibility/Pages/NavigatorsProject.aspx (last visited, November 26, 2024).

20 Medicaid.gov, Louisiana State Plan Amendment, https://www.medicaid.gov/medicaid/spa/downloads/LA-22-0003.pdf (last visited November 26, 2024).

O'NEILL INSTITUTE
CENTER FOR HIV & INFECTIOUS DISEASE POLICY

DECEMBER 2024

Prepared by **Jeffrey S. Crowley** and **Kirk Grisham**.

This brief is a product of the **O'Neill Institute Center for HIV and Infectious Disease Policy** and was developed with support from, and in partnership with, ***Gilead Sciences, Inc.*** It is informed by a stakeholder consultation held in June 2024. The views expressed are solely those of the authors.

http://bit.ly/USHIVpolicyproject