Improving Cancer Prevention and Control: How State Health Agencies Can Support Patient Navigators and Community Health Workers
Acknowledgements

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Introduction

Although there are significant medical and technological advancements afforded by the American healthcare system, the fractured infrastructure can make it difficult for patients to access and manage their care. This may be particularly challenging for the millions of individuals coping with cancer and other chronic diseases, who are managing multiple medications, medical treatments, referrals, and payments. These challenges are exacerbated for medically underserved and some minority populations who already suffer from poor health outcomes.1

Patient navigators (PNs) and community health workers (CHWs) play important roles in addressing these challenges by educating people about cancer prevention and screening, connecting patients to healthcare providers, providing linkages to financial and community resources, and navigating patients through the healthcare system. PN and CHW efforts have led to increases in cancer screening rates ranging from 11 percent to 17 percent and increases in rates of adherence to diagnostic follow-up care ranging from 21 percent to 29 percent.2

Recent national-level efforts have been made to recognize and better integrate PNs and CHWs as legitimate service providers into the landscape of healthcare in America. The Patient Protection and Affordable Care Act (hereafter referred to as the Affordable Care Act) identifies PNs and CHWs as integral components of the nation’s health system. The Affordable Care Act includes authorizations for grant programs specific to PNs and CHWs, and CHWs were included in programs designed to foster innovation and expansion within the healthcare workforce.

Additionally, the National Prevention Strategy, a plan launched in 2011 by the Prevention and Health Promotion Council to promote the role of health in various sectors, recognizes the important role of patient navigation in promoting clinical preventive services by “assisting patients in overcoming barriers [to care].”4 PNs are mentioned throughout the National Prevention Strategy as vital to expanding access to preventive services. The National Prevention Strategy also includes a call to “support community health workers, patient navigators, patient support groups, and health coaches.”4 This recognition at the national level highlights the importance of PNs and CHWs and the opportunities that exist to expand their roles in effective healthcare delivery.

Despite the impact of PNs and CHWs in improving health outcomes and increased recognition of this impact at the national level, there are several major obstacles to sustainably integrating PN and CHW programs into the healthcare system. Obstacles include a lack of adequate workforce development, long-term financing mechanisms, and occupational associations to support their work.5,6,7,8

This issue brief will focus on how state health agencies and ASTHO members (referred to as state health officials or SHOs) can further bolster the sustainability of PN and CHW programs to support health reform and improve health outcomes for all populations.

State health officials serve a vital role in helping public health systems overcome these obstacles through high-level support of financial partnerships, coalition building, training and certification models, reimbursement and policy development, and recognition of the effectiveness of PNs and CHWs in improving health outcomes by integration in state programs.
**Background**

**PATIENT NAVIGATORS**

In 1990, Harold P. Freeman established patient navigation to address the challenges low-income, minority populations experienced with access to timely cancer screenings, treatment, and care. As a result of the successful program he pioneered, additional cancer PN programs have been funded through the American Cancer Society, the U.S. Health Resources and Services Administration, and the Centers for Medicare and Medicaid Services. As these and other demonstration projects continued to reveal favorable outcomes, interest in PN activities increased, bringing in private and public funding to support their growth. PN programs have been found to improve timeliness of cancer screening, follow-up care, and cancer treatment, particularly for those with breast, cervical, and colon cancers. Most recently, the Commission on Cancer (CoC) of the American College of Surgeons approved a requirement that all CoC-accredited cancer facilities employ PNs by 2015.

Several organizations working closely with PNs have established a joint definition of the role of PNs in cancer settings. The Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers have built on the C-Change definition of PN in cancer settings to delineate the work as “individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience.” The National Cancer Institute defines patient navigation as “assistance offered to healthcare consumers (patients, survivors, families, caregivers) to help them access and then chart a course through the healthcare system and overcome any barriers to quality care.” Agencies and institutions operationalize PN programs differently, most notably regarding whether they use a lay or professional (usually a social worker or a nurse) model.

**COMMUNITY HEALTH WORKERS**

The concept of the CHW has been in existence since the mid-1960s, when community-based advocates worked to find solutions to address poverty and ongoing problems in low-income communities. CHWs have since been thoroughly integrated into health outreach. The American Public Health Association defines a CHW as “a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the CHW to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy.”

While CHW efforts typically focus on prevention and primary care, about 27 percent of CHWs work in cancer care. Because of the various contexts in which CHWs may work, the title community health worker broadly encompasses other associated titles such as outreach worker/educator, promotora de salud, community health representative, community health advisor, peer health educator/advisor/counselor, patient navigator, and lay health advisor.
Efforts to use the skills and promote the profession of CHWs in public health have included a 2002 Institute of Medicine report recommending use of CHWs in health system interventions to promote high quality care for all patients and the formation of a CHW special interest group within the American Public Health Association. Recent developments through the Affordable Care Act and the National Prevention Strategy are paving the way for additional incorporation of CHWs into the healthcare workforce.

RELATIONSHIP BETWEEN PNs AND CHWs IN CANCER PREVENTION AND CONTROL

PNs and CHWs share a fundamentally similar role: linking individuals, communities, and the healthcare system with the goal of improving health outcomes. It is frequently noted that the myriad roles of PNs and CHWs tend to overlap with each other as well as with other models of patient assistance, including social workers, case managers, and nurses. In the role of navigator, the PN or CHW is generally a member of a healthcare delivery team and guides individuals and families through a complex healthcare system, linking them with the appropriate services, information, and resources and helping them interact with their providers. As an outreach-enrolling-informing agent, the PN or CHW engages individuals who are eligible for benefits, services, or programs and assists in enrollment and application for services. PNs and CHWs also can be community organizers or liaisons who educate the community on health behaviors and practices, including cancer screening, and provide links to community resources.

Local CHW programs in Maryland report that 85 percent of women eligible for annual breast and cervical cancer re-screening were seen within 15 months for that rescreen, helping improve early stage cancer diagnosis.

Recommendations and Case Studies

Several issues stem from the absence of standardized workforce development, including the establishment of core competencies, standardized training, and certification; long-term financing mechanisms; and organized occupational associations. These issues have made long-term sustainability of PN and CHW programs difficult to attain. In light of national efforts to improve the health system and increase access to healthcare for all populations, it is important for state health officials to engage in efforts to support PN and CHW capacity-building and sustainability.

Recommendation 1: Workforce Development

Goal: Support standardized training and certification of PNs and CHWs.

As PNs and CHWs gain traction in public health, reimbursement policies coupled with standardized training may facilitate their use in various healthcare settings such as hospitals, provider networks, and Federally Qualified Health Centers (safety-net facilities that provide primary-care services in underserved urban and rural communities). Investing in programs that advance state-based training and certification of PNs and CHWs will move the work of these individuals forward and create a consistent baseline of knowledge and skills. SHOs working with academia and state and national partners can draw on established training programs such as those in Colorado to replicate the standards of practice for PNs and CHWs.
COLORADO

Colorado recognizes and affirms the importance of academic partnership in successfully establishing certificate training programs for PNs and CHWs, both in Colorado and across the country. The Colorado Patient Navigator Training Program, in place since 2006, has been partially funded through the state health agency’s tobacco tax, the Colorado School of Public Health’s Center for Public Health Practice, training contracts, and participant tuition. The state’s four-day PN training course is intended to benefit licensed professionals as well as lay navigators, addressing care coordination, reducing barriers to care, providing patient resources and support, and more. Colorado also maintains a robust Patient Navigator Training website (www.patientnavigatortraining.org), featuring “Ask a Navigator,” an interactive site allowing PNs to dialogue with other PNs on various topics and issues.

The Colorado Community Health Worker Certificate Program was developed through a collaboration between the Community Voices program of Denver Health, an organization serving Denver’s medically underserved, and the Community College of Denver. This program is organized around three core activities: workplace/academic classes, vocational classes, and a cooperative educational experience. As the program provides CHW training and work readiness competencies, it equips individuals with competencies necessary for the role of CHW and provides them with a set of highly transferable skills to succeed in the public health workforce. While Colorado does not have state-level accreditation for CHWs or PNs, many clinics and agencies employing PNs or CHWs preferentially hire those with a certificate through Colorado’s training programs or send their employees to the training courses.6,24

KOSRAE

Kosrae is one of the four states of the Federated States of Micronesia, a U.S. Affiliated Pacific Island, located in the western Pacific. Kosrae has a small population and only one hospital. Consequently, the focus of patient navigation programs is different from that of U.S. PN programs. Rather than navigating patients through the healthcare system, navigators in Kosrae, called “survivorship support staff,” focus on creating a supportive environment for cancer survivors to ensure that they are compliant with treatment plans, return to see doctors as necessary, and receive the care they need. The survivorship support staff in Kosrae currently consists of only one individual, a nurse, trained in palliative care. In 2010, Kosrae hosted a palliative care training designed for the Pacific region, led by the University of Hawaii Pacific Center of Excellence for the Elimination of Health Disparities. The Center provided technical assistance to host the train-the-trainer course for Micronesian participants and developed a palliative care curriculum consisting of eight different modules. Each state representative who attended the training is responsible for training all other healthcare workers in their state on palliative care. Kosrae hopes to eventually increase the number of survivorship support staff in the state who can then train families in caring for their cancer survivor family members.25

Recommendation 2: Long-Term Financing

Goal: Support standard reimbursement for PN and CHW services.

Lack of uniformity in core competencies, training, certification, professional standards, and reimbursement has prevented the formation of a standard reimbursement protocol for PNs and CHWs. Additionally, the varying terminology and meaning of specific terms within and between each vocation often causes confusion about roles, potentially limiting the functions that PNs and CHWs contribute to the workforce. Without a reimbursement structure or a steady source of funding to adequately staff a program, properly evaluate it, and expand programmatic reach, PN and CHW programs cannot be successfully sustained long-term. SHOs working with Medicaid directors, private insurers, the Centers for Medicare and Medicaid Services, and state and
national partners—such as the American Cancer Society—can work together to build secure funding options.

FLORIDA
To pursue the development of CHWs in the state, the Florida Department of Health established and convened a taskforce which rapidly grew into the Florida Community Health Worker Coalition (www.floridachw.org). The Coalition consists of key stakeholders—including CHWs—familiar with Florida CHW efforts to plan awareness activities, implement strategies, and educate policymakers and the public on issues that endorse and advance CHWs as part of an integrated healthcare delivery system in the state. Five working groups—policy, practice, curriculum development, networking/sustainability, and research/grant writing—operate in tandem to generate awareness and move toward an established, reimbursable CHW profession in Florida. Partnering groups within the Coalition have proposed legislative language to institute a Community Health Worker Task Force in the state which, if established, would provide policy recommendations around the integration of CHWs in Florida’s health system. As each subgroup makes progress, the Coalition moves closer to establishing state policies recognizing the value of CHWs and, eventually, creating a high quality and sustainable profession that will help improve population health outcomes in the state of Florida.26

MINNESOTA
In Minnesota, the Minnesota Community Health Worker Alliance—a group comprised of state agencies, government officials, academic institutions, nonprofit organizations, healthcare providers, and CHWs—has worked to maintain steady funding streams or reimbursement protocols for CHWs.18 The Alliance first developed a statewide standardized curriculum for CHWs, and from there drew support for the development of state legislation that authorized hourly reimbursement for CHWs through Medicaid. This applies to CHWs who have received a certificate from the standardized curriculum program.18 Presently, the Alliance is working to ensure CHW reimbursement from Federally Qualified Health Centers as well as inclusion as a part of the patient centered medical home.

Recommendation 3: Occupational Associations

Goal: Create occupational networks to strengthen PN and CHW effectiveness in the workforce.

Occupational networks can help provide the necessary support and resources for PN and CHW programs to thrive. As new research is documented, new challenges arise, and new technology becomes available, an occupational association can help foster communication, technical assistance, and the exchange of ideas. Various types of state, local, and regional associations to support the work of CHWs and PNs have been developed throughout the United States. One city-wide network in New Orleans and one regional network in Appalachia that support cancer navigators are highlighted in this brief.

NEW ORLEANS
The New Orleans Patient Navigation Network (PNN) is a collaborative effort to bring together navigators from public and private facilities who work in cancer care, including the Greater New Orleans Patient Navigator Program. The PNN receives information and technical assistance from the Louisiana Comprehensive Cancer Control Program and provides members with an opportunity to network with other cancer navigators, share resources and ideas, and support each other. Because PN is still a relatively new concept to many local physicians and their staff, one important way the PNN supports navigation services in greater New Orleans is by connecting navigators with physician champions. Such champions, who often wield great influence in the medical community, help spread awareness and open new doors for PNs.27
APPALACHIAN REGION

The Appalachian region faces unique challenges to cancer care availability and accessibility due to the geographic isolation of many communities. With funding from the CDC and the Appalachian Regional Commission, representatives from the Appalachian Community Cancer Network, University of Virginia, Eastern Tennessee State University, state cancer programs, and other leaders from the multistate region met to discuss ways to improve, expand, and extend cancer navigation programs across Appalachia. The group conducted a multi-stage project that included gathering programmatic information via key informant interviews and convening workshops with presentations where project findings were disseminated and an action plan for future direction of navigation programs was developed. Gaps in navigation program operations and care (across the cancer continuum) were discovered due to limitations of navigators, lack of understanding of services navigators can provide, and poor connectivity between navigators, healthcare providers, and health system administrators. To overcome these challenges, the project identified the need for a coalition or network of PNs to improve connectivity, support, and ongoing communication among navigators; provide increased training and education opportunities; and develop simplified evaluation tools. Future plans for the project include developing a network of PNs and creating a regional data format to share best practices, measure and benchmark services, and provide outcome measures to evaluate and assess the value of navigation.

Incorporating All Recommendations: A Comprehensive Approach

Massachusetts is finding ways to address the three recommendations laid out in this brief: workforce development, long-term financing, and occupational associations. As part of the 2006 Massachusetts health reform law, the CHW Advisory Council was formed and charged with studying the use, funding, and impacts of CHWs in the state along with producing a set of recommendations on creating a sustainable CHW program in Massachusetts. The Council, consisting of 40 members from organizations specifically mentioned in the health reform law as well as other stakeholders, rigorously researched the CHW workforce in Massachusetts, and produced a comprehensive report—including 34 recommendations regarding professional identity, workforce development, financing, and infrastructure development. The report produced by the Council has provided significant rationale for the Massachusetts Department of Public Health to enact many of the Council’s recommendations. The department plans to continue implementing the Council’s recommendations, as resources are available.
Conclusion

PNs and CHWs play important roles in supporting and guiding patients, individuals, and communities through the complexities of the healthcare system, linking both patients and their families with medical and community resources. As discussed, PN and CHW activities can increase rates of cancer screening and diagnostic follow-up, and lead to a reduction of Medicaid costs and increased healthcare savings. The Affordable Care Act and the National Prevention Strategy also highlight various ways PNs and CHWs may be further integrated into the health system to improve cancer outcomes. This issue brief offers examples and evidence of effective PN and CHW programs across the nation and identifies challenges with funding, reimbursement, and standardization. To support the growth and sustainability of such programs, priority attention should be given to workforce development, training, and long-term financing. State and territorial health leadership can support the development of PNs and CHWs in the healthcare system by forming collaborations and partnerships to establish core workforce competencies, long-term reimbursement protocols, and occupational associations that will enable PNs and CHWs to thrive in the healthcare system.

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