

CHRs and Cancer Navigation: An Environmental Scan for CHR programs and Tribal clinics in Arizona

The Partnership for Native American Cancer Prevention

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I. Executive Summary

In the 2024-2029 funding cycle, the Partnership for Native American Cancer Prevention's (NACP) Outreach and Engagement Core (OEC) aims to increase cancer navigation capacity in Arizona's tribal communities, with a focus on Community Health Representatives (CHRs). CHR is the distinct term applied to Community Health Workers (CHWs) working in tribal communities. NACP, a collaboration between the University of Arizona Cancer Center (UACC) and Northern Arizona University (NAU), aims to reduce the cancer burden within the Native American population through research and community engagement. The National Cancer Institute has supported the NACP for more than 20 years.

In preparation for increasing cancer navigation capacity, the OEC conducted an environmental scan of cancer navigation among CHRs in the United States. To enhance the health of Arizona's Native American population, OEC plans to increase cancer patient navigation capacity through training and mentorship of community partners across the cancer care continuum. Environmental scans can help program planners by identifying risks or challenges and providing evidence about possible directions for an organization or program.⁵ This environmental scan presents a detailed synthesis of CHR roles, funding, training, and impact with an emphasis on cancer navigation using literature reviews, personal communications, and policy analyses.

a. CHRs: Health & Community Advocates

Community Health Workers (CHWs)/Community Health Representatives (CHRs) and Patient Navigators (PNs) hold distinct roles (see Table 1). This document explores how to integrate CHRs into cancer care navigation effectively by drawing from CHW and PN literature.

Table 1. Definitions		
Community Health Workers	Patient Navigators	Community Health Representatives
CHWs are also commonly referred to as <i>Promotores de Salud</i> , community health representatives (CHRs), community health advisors, and lay health educators. CHWs are non-licensed professionals whose duties serve community health by promoting health, preventing illness, and delivering health services. ⁹	A patient navigator is a trained individual employed by an organization to provide personalized assistance to patients in identifying practitioners, providers, and centers for their cancer care needs and support. ¹¹	CHRs serve Tribal communities as frontline public health workers who apply a unique understanding of the experience, language, and culture of the population served. ² CHR programs direct community-based health care professionals to integrate the unique support of Tribal life with the practices of health promotion and disease prevention. ¹⁰

Cancer navigation is a process that provides “individualized assistance to cancer patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience.”¹⁴ Cancer navigators assist patients in overcoming barriers to cancer screening and treatment, offer peer counseling, provide linkages to financial and community resources, and provide culturally competent patient education, particularly among the underserved.¹⁴

b. Cancer Navigation: A 35-year History

Dr. H. Freeman first developed the concept of patient navigation in 1990.¹¹ Freeman introduced the term “patient navigator,” referring to individuals whose role was to address the barriers in breast cancer diagnosis and treatment among medically underserved women in Harlem, New York.¹¹ In recent years, the patient navigation role has expanded to various aspects of healthcare.¹¹ The 2005 Patient Navigation Outreach and Chronic Disease Prevention Act (H.R.1812-109th Congress 2005–2006) supported research on the effectiveness of patient navigation programs by authorizing grants to improve health care outcomes by providing patient navigator services.²⁴ In addition, a 2012 mandate by the American College of Surgeons’ Commission on Cancer, required all health care facilities accredited by the Commission to have a patient navigation program and establish processes to identify and remove barriers to care for patients, addressing existing health disparities in cancer care.²⁴ Cancer navigators support patients throughout the cancer care continuum, from prevention to survivorship.

c. The CHR Workforce in the US and in Arizona

CHRs provide essential services to tribal communities across the United States. Nationally, the CHR workforce consists of roughly 1,700 CHRs, representing 264 Tribes.⁴ As of 2021, 95% of the 249 Tribal CHR programs are tribally governed.⁴ While CHRs are present in many regions, this scan focuses specifically on their presence in tribal nations throughout Arizona, which is home to 22 federally recognized tribes. As of 2021, 19 of the 22 tribes operate CHR programs and employ roughly 250 CHRs.⁴ CHRs’ prevalence throughout the state demonstrates the adaptability of CHR programs and their capacity to respond to the distinct needs of tribal populations in various locations and living conditions. Arizona has the 3rd largest Native American population of any state, comprising 5–6% of Arizona’s total population.¹⁰ This cultural richness offers opportunities for collaborative, multicultural health strategies, but also presents challenges due to persistent health disparities and limited resources. Social determinants of health, including discrimination, limited resources and health care access, and reduced availability of culturally appropriate healthcare services, drive these challenges.

In Arizona, a dedicated state office of CHWs does not exist, but the Arizona Department of Health Services (ADHS) has a CHW program housed within the Office of Chronic Disease and Population Health in the Bureau of Chronic Disease and Health Promotion. The statewide CHW professional organization, Arizona Community Health Workers Association (AzCHOW) helps organize, support, and build recognition for CHWs.¹⁸ The CHW workforce is made up largely of *promotoras/as de salud* working within the U.S.-Mexico border region and community health representatives (CHRs) serving Tribal and other Native American communities. They worked collaboratively to establish CHW Voluntary Certification to elevate their status and establish their credibility as a professional workforce.¹⁰ The CHW Voluntary Certification process allows CHW/CHRs to become certified through ADHS by meeting specific requirements and uploading supporting documents through an online portal. CHW/CHRs can apply for voluntary certification if they meet the following criteria: being 18 years of age or older, having a high school or equivalent diploma, providing documentation of training and/or paid or volunteer experience, and completing the initial CHW certification application.¹⁷ This certification can help enhance financial sustainability through Medicaid reimbursement, improve community integration, and provide more opportunities for CHWs. Six states in the United States have passed CHW certification laws: Massachusetts, New Mexico, Maryland, Ohio, Oregon, and Texas.¹⁰ Except for Texas, all states have voluntary certification, which provides a pathway for further professionalization of the CHW workforce by establishing a standard definition and set of core competencies. On May 16, 2018, Arizona's 23rd Governor Douglas Ducey signed the CHW Voluntary Certification HB2324 legislation into law. This law outlined the scope of work and core competencies of CHWs in Arizona. It also represented the unification of the two significant CHW workforces in the state: *promotoras* and CHRs.¹⁰ ADHS finalized the rule for voluntary certification in November 2022.

d. Medicaid Reimbursement for CHR Services

CHWs may receive reimbursements for services under Medicaid if they first obtain voluntary certification through ADHS and are employed by an eligible Arizona Health Care Cost Containment System (Arizona's Medicaid system) registered provider. The Arizona Health Care Cost Containment System (AHCCCS) is working towards advancing Medicaid reimbursement for CHR services.²³ For services to be eligible for Medicaid reimbursement, the CHW/CHR shall complete certification obtained through ADHS as specified in A.A.C R9-16-802.²³ Effective April 1, 2023, ADHS may provide AHCCCS covered member education and preventative services, as outlined in AMPM 310-W, section B, to eligible members.²³ The Contractor must ensure providers maintain proof of certification for CHW/CHRs.²³ An eligible physician or other licensed practitioner must recommend and deem the claim medically necessary for it to be accepted.²³

e. Potential Alignment Between the Roles of CHR and Cancer Navigators

Cancer navigators may offer similar help with practical issues such as transportation, health insurance, financial concerns, access to medications, and care coordination, like CHRs.²⁵ Cancer navigators play a vital role in addressing the numerous barriers that patients often encounter throughout their cancer care journey. Since cancer navigator responsibilities closely align with the scope of work for CHRs, they may be effectively integrated into navigation roles across the continuum of cancer care.² Addressing workforce development, structural integration, and sustainable financing is essential to successful integration of CHRs into more specialized roles, such as cancer navigation.⁵ As cancer rates and disparities persist in Native American communities, integrating CHRs into cancer navigation programs can allow an opportunity to improve health outcomes. However, doing so effectively requires addressing capacity limitations in current service models. To meet the need for cancer navigation across the full continuum of care key strategies include:

- comprehensive navigation that supports patients at each stage of the cancer journey, including primary care;⁴
- multidisciplinary care coordination;⁴
- standardized training and certification for CHRs specific to cancer navigation;
- clear role definitions and ethical guidelines by job role;⁴
- and improved access for CHRs to clinical teams and patient data.⁴

Training, certification, full-time employment opportunities, and professional support are all important aspects to support a comprehensive CHR program. In addition, access to electronic health records (EHRs), standardized training, diversifying funding models, and supportive policies at state and federal levels can help sustain CHR funding.³ As the healthcare landscape evolves, tribal leadership, community partnerships, and policy advocacy are essential in creating systems that recognize and sustain CHRs' contributions.²

The purpose of this environmental scan is to determine how Community Health Representatives (CHRs) are currently involved in cancer navigation, evaluate their integration into health systems, and offer recommendations for strengthening the support systems to enhance CHRs' ability to participate in cancer navigation.¹ Understanding how CHRs can support cancer navigation will be helpful for programs that promote cancer prevention and screening, improve the quality of life for cancer survivors, and reduce disparities in cancer prevention and control. Overall, the findings show that CHRs can have a role in cancer prevention and control programs, including their planning and evaluation.

II. Introduction and Purpose

Cancer remains a major public health concern, placing a significant burden on individuals, families, and healthcare systems worldwide. The landscape of cancer prevention, diagnosis, and treatment continues to evolve rapidly, driven by advances in research, technology, and public health efforts. Despite progress in cancer care, the disease continues to be a leading cause of death globally.¹⁴ Cancer affects people across all demographic groups, and understanding the prevalence, risk factors, and system-level responses is critical for guiding effective interventions and policy. Minoritized populations, rural communities, and those with low socioeconomic status, including those who are under-insured, bear a disproportionately high burden of cancer in the United States.¹⁴ These disparities persist across the cancer continuum, from prevention to screening, treatment, and long-term survivorship.¹⁴ Due to historical mistreatment, poor or nonexistent health insurance coverage, financial difficulties, low health literacy and education, and lack of transportation in Native American communities, there are barriers to cancer prevention, screening, and care.

In the 1960s, American Indian/Alaskan Native (AI/AN) communities in the United States identified the need and advocated for community health professionals that would improve cross-cultural communication between American Indian communities and non-American Indian health care providers.¹⁰ This advocacy led to the emergence of a federally funded CHR program.¹⁰ In 1968, the Indian Health Service (IHS) funded the CHR program through P.L 100-713, which was the first federally funded CHW workforce.⁴ In 1969, Congress appropriated funds for the CHR Program as a component of health care services of American Indian people.¹⁰ The CHR Program is funded by Congress every year and is administered by the federal Indian Health Service (IHS).¹⁰ The Arizona Advisory Council on Indian Health Care (AACIHC) also serves as a resource for Tribal governments and the State of Arizona in meeting the unique health care needs of the Arizona American Indian population.¹⁰

Community Health Representatives act as bridges between tribal communities and healthcare systems, playing a crucial role in disease prevention, screening, treatment navigation, and survivorship support. AI/AN communities face systemic barriers that make it more difficult to access quality healthcare and achieve positive health outcomes. These challenges include language barriers, limited availability of culturally and linguistically appropriate care, geographic isolation, and mistrust of healthcare institutions due to historical mistreatment.¹⁹ For Native American communities, centuries of colonization and displacement have contributed to deep-rooted health disparities and reduced access to preventive care. CHRs provide vital support in navigating these obstacles by offering culturally grounded care, advocating patient needs, and connecting individuals to services in a respectful and trusted

manner. Their presence helps to build bridges between community members and the healthcare system, leading to more equitable and effective health outcomes.

Barriers to care contribute to cancer being the second leading cause of mortality among Native Americans.¹⁹ In Arizona, only the Navajo Nation and the Hopi Tribe have Center for Disease Control and Prevention funding through the National Breast and Cervical Cancer Early Detection Program to provide breast and cervical cancer screening and diagnostic services.¹ Many Native Nations in Arizona have no cancer specific education, prevention tools, support programs, or trained navigators to promote screening. Many patients must travel over 150 miles one way to receive cancer treatment, creating significant barriers to timely and effective care.¹ When transitioning from primary care at a 638 facility* to a distant specialty care center or to oncology services, the involvement of CHRs in navigation becomes essential. CHRs can play a critical role in coordinating care and supporting patients as they seek treatment in urban centers.⁷ There is a pressing need for CHRs as connectors to care given rising cancer incidence rates, lower reported screening rates, and reduced survival outcomes among Native Americans.

a. Methods – Environmental Scan

This environmental scan was conducted to understand the current landscape of CHR involvement in cancer navigation, assess their integration in health systems, and provide recommendations for improving support structures that enhance the potential for CHRs to be involved in cancer navigation. An environmental scan gathers data using a variety of techniques, including surveys, in-depth interviews, focus groups, literature reviews, and the examination of internal documents, policy analyses, and private correspondence. An environmental scan's findings might be particularly helpful in assisting a program or organization in defining its goals and tactics. This environmental scan uses a literature review, informed by discussions with stakeholders throughout the United States and in Arizona.

Programs that support cancer prevention and screening, enhance the quality of life for cancer survivors, and lessen inequities in cancer prevention and control will benefit from an understanding of how CHRs can support cancer navigation. Overall, the results of this environmental scan show how CHRs can be used to inform the design and assessment of cancer prevention and control initiatives in both public health and oncology care systems.

* 638 facilities are health centers operated by Tribes or Tribal organizations under the Indian Self-Determination and Education Assistance Act.

III. Professional Roles of CHRs

a. CHR Roles and Function

Community Health Representatives address the needs of their community through health promotion, education, and outreach. CHRs play an essential role in Native American communities, and the healthcare delivery system. As most CHRs serve Tribal communities, they serve as frontline public health workers who apply a “unique understanding of the experience, language, and culture of the population served.”² CHR programs integrate cultural values with the practices of health promotion and disease prevention.¹⁰ Their effectiveness stems from the trust they build through shared traditions and lived experiences with community members.

In a 2017 study, researchers created a report that indicated four main thematic findings important to the development and sustainability of a well-functioning CHR-client relationship on the Navajo Nation. These four findings highlighted that 1) trust plays a vital role in the CHR-client relationship, 2) trust is built upon the shared culture and traditions, 3) losing a community member brings the CHR-client relationship together through tradition, and 4) CHRs’ ability to connect with clients lies in their unique understanding of, and respect for, the culture and social dynamics.¹ Although this report is specifically from the Navajo Nation, it mirrors the importance of CHRs’ client relationships.

CHR can have a variety of roles, which differ for each community. CHRs can offer psychosocial support, promote healthy behaviors, and/or assist with elder care. Half of CHR Programs identified environmental health, community development, and emergency patient care as additional CHR roles.⁴ 100% of CHR Programs identified the following national CHW core competencies in their CHR staff: (1) providing culturally appropriate health education and information, (2) conducting outreach, (3) providing direct service, (4) offering care coordination, case management and systems navigation, and (5) participating in evaluation and research.⁴ These competencies equip CHRs to advocate for the medical and social needs of their communities.⁴ CHRs typically serve a dual role: managing a high-risk caseload of 50 to 150 individuals and providing broader community-wide health promotion and disease prevention services to populations that can range from 1,000 to 2,500 residents.¹ These assignments are rooted in the local context of each tribal community, ensuring culturally aligned and place-based care is grounded in trust, relationship-building, and respect for tribal sovereignty.⁵ Furthermore, more than half of all programs reported having a full collaboration with senior service programs operating in their communities, with full collaboration with medical transport services operated by the Tribe and IHS.⁵

b. Geographical Areas Served

Community Health Representatives (CHRs) provide essential services to tribal communities across the United States. As of 2023, The Indian Health Service CHR Program has more than 1,600 CHRs representing over 250 tribes in all 12 IHS Areas throughout the U.S. While CHRs are present in many regions, this scan focuses specifically on their presence in tribal nations throughout Arizona, which is home to 22 federally recognized tribes, of which 19 operate CHR programs. This demonstrates the adaptability of CHR programs and their capacity to respond to the distinct needs of tribal populations in various locations and living conditions, whether urban, rural, or remote. The diversity of CHR programs across Arizona is significant. Tribal reservations make up over a quarter of Arizona's land base.¹⁰ The Navajo Nation makes up the largest share of the American Indian alone population (14.6%).¹⁵ The Navajo Nation, covering parts of Arizona, New Mexico, and Utah, is particularly well known for its CHR program, which serves a diverse rural population.⁷ According to the 2010 US Census, among the 174,667 individuals living on the Navajo reservation, 41% live below the federal poverty line, 32% live in homes without electricity, 38% lack running water, and 31% lack complete plumbing.⁷ Importantly, CHR programs operate in a wide variety of settings to meet people where they are.

c. CHR Education and Training Requirements

Educational prerequisites vary, but most CHR programs prefer candidates to have at least a high school diploma or GED, with some requiring college coursework or associate degrees. Experience is highly valued, with 92% of programs requiring or preferring CHRs to have six months to four years of experience in health care, direct patient care, or previous CHR employment.⁴ About 58% of programs prefer CHRs to speak the tribal language, and 75% require familiarity with local community resources and health systems.⁴

Training requirements for CHRs also vary by program. Approximately 75% of CHR programs require or prefer Certified Nursing Assistant (CNA) or Certified Medical Assistant (CMA) certification, while 58% require or prefer CPR, First Aid, and Basic Life Support (BLS) certifications upon hire or within the first year.⁴ In an Arizona survey, 76% of CHRs reported completing basic CHR certification provided by the Indian Health Service (IHS) CHR National Program.⁴ This online training consists of 18 modules covering three training tracks: Core Skills, Chronic Illnesses, and Healthy Living.¹⁶ Advanced training opportunities include modules on motivational interviewing, case management, mental health, maternal and child health, and chronic disease prevention.⁴ Approximately 63% of CHRs reported having completed an advanced CHR training in health promotion and disease prevention while 53% of CHRs reported

completing modules in case management or mental health, with slightly less than half of CHRs receiving advanced training in maternal and child health.⁴

Furthermore, Arizona established a voluntary CHW certification process, supported by tribal and state agencies, to professionalize and unify the workforce. In 2018, House Bill 2324 established the CHW voluntary certification, and on September 7th, 2022, Gov. Doug Ducey's Regulatory Review Council (GRRC) unanimously approved the rules for the voluntary certification process.¹⁷ The Arizona Community Health Worker Association (AzCHOW) launched the voluntary certification effort in 2017 in collaboration with ADHS and the Arizona Prevention Research Center.¹⁷ Now, CHWs can apply for voluntary certification if they meet the following criteria: 18 years of age or older, high school diploma or equivalent diploma, documentation of training and/or paid or volunteer experience, and completion of initial CHW certification application.¹⁷

d. CHR Funding

In Arizona, CHR programs are mainly funded through federal grants, tribal contracts, and Medicaid reimbursement. The Arizona Health Care Cost Containment System (AHCCCS, Arizona's Medicaid system) is working towards advancing Medicaid reimbursement for CHR services.²³ For services to be eligible for Medicaid reimbursement, the CHW/CHR must complete certification obtained through the Arizona Department of Health Services as specified in A.A.C R9-16-802.²³ Effective April 1, 2023, they may provide AHCCCS-covered member education and preventative services, as outlined in AMPM (AHCCCS Medical Policy Manual) 310-W, section B, to eligible members.²³ The Contractor must ensure providers maintain proof of certification for CHW/CHR.²³ The claim will only be accepted as it is medically necessary, and it must be recommended by an eligible physician or other licensed health practitioner acting within the scope of authorized practice under State law.²³ It is important to highlight that CHWs and CHRs are not individually registered as practitioners with AHCCCS, which can lead to challenges with formal recognition and reimbursement.

IV. Synopsis of Cancer/Patient Navigation Literature

a. Scope of Practice

Patient navigation is an important health service delivery tool to promote timely movement of an individual patient across the complex healthcare continuum.¹¹ The concept of patient navigation was first developed by Dr. Harold Freeman in 1990.¹¹ Freeman introduced the term "patient navigator," referring to individuals whose role was to address the barriers in breast cancer diagnosis and treatment among poor, uninsured, and underserved women in Harlem, New York.¹¹ In recent years, the patient

navigation role has expanded to various aspects of healthcare.¹¹ Patient navigation (PN) interventions have been demonstrated to reduce health disparities by addressing the social determinants of health.¹⁴ PNs primarily operate at the individual level, focusing on each patient's unique needs and helping connect them with appropriate healthcare services and providers.¹⁴ Their key role is to guide patients through the often complex healthcare system and help them overcome barriers to accessing care.²⁴ Since 2015, the American College of Surgeon's Commission on Cancer has required PN services as a component of accreditation for cancer programs.¹⁴

Cancer navigation is a subset of patient navigation that specifically focuses on the cancer care continuum. Cancer navigation is a process that provides “individualized assistance to cancer patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience.”¹⁴ Cancer navigators assist patients in overcoming barriers to cancer screening and treatment, offer peer counseling, provide linkages to financial and community resources, and provide culturally competent patient education, particularly among the underserved.¹⁴ Cancer navigators offer help with practical issues such as transportation, health insurance, financial concerns, access to medications, and care coordination.²⁵ Similar to CHRs, they also address patients' medical challenges by helping manage treatment side effects, improving self-care abilities, and arranging for mobility aids like wheelchairs or walkers, as well as making appropriate referrals.²⁵ In addition, navigators support social and emotional well-being by recognizing signs of anxiety or depression, explaining diagnoses and treatments, connecting individuals to support groups, and addressing spiritual or existential concerns.²⁵

Navigators play an essential role in cancer care delivery. Most navigators engage with clients both in person and via telephone.¹² A review of National Comprehensive Cancer Control Program (NCCCP) action plans found that 82% included CHW or PN-related activities.¹² Among those, 47% targeted breast cancer, 45% cervical cancer, and 40% colorectal cancer.¹⁴ The majority of these interventions occurred during the screening (60%) and survivorship (55%) phases of care.¹⁴ CHW/PN responsibilities included patient education, outreach, barrier identification, resource dissemination, and advocacy, while fewer were involved in psychosocial support or discussions around clinical trials.¹⁴ These responsibilities closely align with the scope of work performed by CHRs, suggesting that CHRs can be effectively integrated into navigation roles across the continuum of cancer care. Challenges for CHR integration may include having access to clinical data; in models of clinic-based interventions, PN/CHWs have access to electronic health records (EHRs) and documented client interactions and activities directly within the EHR¹².

i. Types of Cancer Navigators

There are several types of cancer navigators, each with unique responsibilities based on their training and focus areas. Clinical navigators are trained healthcare professionals who rely on their clinical knowledge to guide patients through the medical aspects of care.²⁷ Oncology nurse navigators, who are registered nurses with cancer care expertise, collaborate with care teams, monitor patient progress, manage side effects, and help individuals understand their treatment plans.²⁷ Oncology social work navigators, on the other hand, are social workers trained in both oncology and mental health. They focus on identifying and addressing patients' emotional and social needs, offering counseling or referring patients to appropriate services.²⁷ Cancer site-specific navigators provide tailored support for individuals with a particular type of cancer, offering specialized knowledge and resources. Financial navigators assist patients in understanding their insurance benefits, managing out-of-pocket costs, setting up payment plans, and finding financial assistance to make treatment more affordable.²⁷ Other navigator roles include clinical trial navigators who help patients understand and participate in clinical research, address concerns, and arrange practical support like transportation or insurance coordination.²⁷ Pediatric, adolescent, and young adult navigators address the unique needs of younger cancer patients and their families, while cancer screening navigators focus on increasing participation in screenings for cancers such as breast, lung, or colorectal.²⁷ They also ensure individuals who need follow-up care to receive appropriate testing and support.

ii. Different Levels of Patient Navigation

Community Health Representatives (CHRs) serve in multifaceted roles that closely mirror the structured progression found in patient navigation. A nationwide group of patient navigation experts have proposed a framework for understanding different levels of proficiency of patient navigators.⁸ This framework not only helps define job roles but also supports administrators in creating training pathways and standard aligned job descriptions. This model is an example of different levels of proficiency that patient navigators can work towards to increase their skills and create clear career paths. Importantly, it can be used in CHR programs to offer CHRs a vision for career growth, skill advancement, and scope of practice. Further, the authors note, "It is important to note that some of [job] experiences can fulfill education requirements and/or qualify candidates for intermediate level positions, which enriches the hiring process and the workforce".⁸

Entry-level patient navigators typically begin their roles with minimal experience in patient navigation. At this stage, they are introduced to essential tools and practices for addressing patient barriers but often require supervision and mentorship.⁸ Core attributes include maintaining confidentiality and privacy when engaging with patients and staff, organizing culturally and linguistically appropriate health resources, and

respecting patient modesty and privacy, particularly in sensitive cultural or clinical contexts.⁸

Patient navigators who have three to four years of experience or equivalent qualifications often move into intermediate positions. At this stage, they have a solid understanding of patient care systems and can function more independently. They can identify barriers to care, connect clients with appropriate resources, and demonstrate cultural sensitivity in diverse patient encounters.⁸ Their core attributes include applying patient confidentiality standards across care systems and community partners, engaging respectfully with cultural and spiritual practices, such as ceremonies or traditional healing, and proposing patient centered solutions that respect privacy and support holistic well-being.⁸

Advanced-level navigators, with five or more years of experience or equivalent, take on leadership responsibilities. These individuals draw from accumulated knowledge and experience to guide care coordination, mentor new navigators, and contribute to policy development.⁸ They are skilled at synthesizing data and implementing culturally competent strategies in a range of settings. Their core attributes include leading improvements in privacy practices and data protection across systems, serving as champions of cultural humility by recognizing biases and promoting cross cultural learning, and advocating for structural changes that respect diverse beliefs and improve access to care.⁸

This framework serves as a resource for administrators to create job descriptions that align with a specific level of expertise, and it is a resource for navigators to see how one may advance over time to various stages of responsibilities. By transitioning from entry level to advanced level positions, the navigator can gain knowledge and expertise that allows them to remain "patient-centric" in any situation or stage of the cancer care continuum while removing obstacles and facilitating prompt access to care.⁸ As their role develops, navigators can lead initiatives to identify gaps in community resources, work with other service providers, and train other navigators and team members. The framework may also be used to conceptualize CHRs' scope of practice within cancer care.

b. Navigation Education and Training Requirements

In the United States, standardized training efforts are being developed to ensure consistency across patient navigator programs. Ongoing professional development is essential to keep navigators' skills and knowledge aligned with the needs of the communities and patients they serve. While the exact number of navigators is unknown, as of 2019, around 8,200 individuals involved in navigation are members of the Academy of Oncology Nurse & Patient Navigators (AONN).²⁶ Organizations such as the Oncology Nursing Society (ONS), AONN, the American Cancer Society, and the

National Navigation Roundtable are leading initiatives to formalize the navigator role in cancer care and support its development through research-based practices and sustainable funding models.²⁶ A certification program for both oncology nurse navigators and oncology patient navigators is currently being tested. Once implemented, it may help better define the workforce and support the continued expansion of the field.²⁶

c. National Navigation Funding

In addition to potential state-level Medicaid reimbursement for navigation services, a significant development occurred in 2024 when the Centers for Medicare & Medicaid Services (CMS) included reimbursement for professional, non-clinical patient navigation services under the Physician Fee Schedule.²⁷ This applies to patients with a “Principal Illness,” including cancer and other serious health conditions. For the first time, patient navigation services have a formal federal reimbursement pathway, helping to support the workforce in a sustainable way.²⁷ Certification or formal training in these areas is part of the qualifications required for reimbursement, reinforcing the professionalization and long-term growth of cancer navigation services.²⁷ The CDC's National Comprehensive Cancer Control Program (NCCCP) is another major funding stream that supports PN/CHW-related work.¹⁴ A recent content analysis of NCCCP action plans revealed that many awardees incorporate patient navigation and CHW interventions as central strategies in cancer control efforts.¹⁴

V. Examples/Models & Recommendations

The following section outlines how CHWs, CHRs, and Community (non-licensed) Navigators have engaged in cancer programming, outlines recommendations for financial sustainability, CHR training, program evaluation, and institutional capacity building.

a. CHRs in Cancer Navigation

Community Health Representatives (CHRs) serve as trusted patient advocates and navigators within Native American communities, offering a culturally grounded bridge between patients and the healthcare system. Their roles can extend beyond basic health education, and can include supporting those living with cancer, raising awareness about cancer, engaging in cancer care advocacy, and connecting patients to available resources. In cancer care specifically, CHRs can address disparities by educating patients, facilitating adherence to screening and diagnostic services, and linking individuals to financial, social, and community resources.¹² Their trusted presence and community-based approach enable them to reduce barriers to care, enhance public health responses, and support the physical and emotional well-being of

Native populations. As part of multidisciplinary care teams, CHRs can help develop patient care plans and ensure continuity, completion, and acceptability of services.⁵

Navigation can focus on five intervention points in cancer care: prevention, screening, diagnostic testing, treatment, and survivorship.²² While some navigation programs operate only during the prevention and screening phases, comprehensive models span the entire cancer continuum, offering sustained support through post-treatment survivorship. For CHRs, adopting multi-phase navigation models may offer opportunities for CHRs to engage with specialty care and significantly improve outcomes for underserved populations. To maximize CHR impact in cancer care, programs should integrate CHRs into all phases of the cancer continuum, from education to survivorship. For instance, CHRs might be involved in screening education that focuses on early detection, understanding available tests, and recognizing the benefits of timely diagnosis, and they can expand reach through partnership with community organizations. During treatment, patients often need help understanding diagnoses, coaching in asking questions of their health care team, and identifying financial resources to manage costs. CHRs can contribute by supporting patients' self-advocacy, coordinating transportation, connecting patients with mental health resources, and assisting with applications for programs, like Medicaid. CHRs are also well-positioned to offer family and caregiver support, connecting them with resources as well.

CHRs' comprehensive approaches are especially valuable in cancer care, where they can help patients navigate logistical and emotional challenges. However, training and capacity-building initiatives must prepare CHRs for both clinical coordination and culturally sensitive outreach. Further, structural challenges such as staffing stability, transportation barriers, and communication gaps should be addressed through policy, funding, and interagency collaboration to strengthen the reach and effectiveness of CHR-led cancer navigation.

i. Examples from Patient Navigation for Cancer Screening

CHWs have been engaged in breast cancer screening education and navigation. In providing information about general breast health and screening, they use Motivational Interviewing, door-to-door conversations, and home visits to educate people about breast cancer. CHWs tasks include: screening recruitment, scheduling initial appointments with primary care providers or radiology services for mammograms, following up with screening results, and scheduling treatment appointments if a woman was diagnosed with breast cancer.⁹ These tasks highlight the multifaceted role CHWs play in breast cancer control, demonstrating their impact across education, screening support, and navigation to ensure timely access to diagnosis and treatment, which CHRs can incorporate.

Colorectal cancer (CRC) is the second leading cause of death from cancer among American Indian and Alaska Native (AI/AN) men and third among AI/AN women.³ U.S. Preventative Services Task Force recommends stool-based tests and direct visualization tests for CRC screening.³ However, with barriers to care, it can be difficult to provide direct visualization screening tests. Barriers to care include geographic isolation, lack of regular healthcare provider, failure of providers to recommend screening, lack of clinical tracking and reminder systems, lack of transportation, embarrassment, privacy concerns, distrust in the health care system, and insufficient knowledge about CRC.³ The combination of mailed Fecal Immunochemical Testing (FIT) kits and phone follow-up have been shown to increase adherence to CRC screening.²⁸ However, many parts of tribal lands cannot mail FIT programs due to lack of U.S. Postal Service home delivery and cell phone coverage, contributing to barriers that CHRs may help address.²⁸

Study #1: Clinic-Based Colorectal Cancer Screening Increases FIT Completion

In one Arizona study, patient navigators were tasked with increasing FIT completion. The navigators were trained in CRC biology, epidemiology, risk factors, diagnosis, and treatment. The training also covered Native American CRC disparities, behavioral and psychosocial aspects of screening, and motivational interviewing techniques.²⁸ Hands-on training was given on data entry with mock patient material and screening results.²⁸ One-on-one training was conducted by team leaders on how to integrate AI-adapted evidence-based messages into the navigation process.²⁸ The navigators interacted with a total of 678 patients. Of the 678 patients, 150 (22%) did not engage in screening.²⁸ Of 467 patients provided a FIT kit, 43% applied stool and returned the kits for assessment,²⁸ and 252 patients (37% of those engaged by a navigator) completed screening by FIT ($n = 199$) or colonoscopy ($n = 53$). Of the 199 patients who returned a FIT kit to the laboratory for development 18% tested positive and 82% negative.²⁸ These early results suggest the intervention was successful for improving CRC screening rates.

Study #2: Colorectal Cancer Screening Program Challenged by CHRs' Scope of Work

In one study, participants were mailed Fecal Immunochemical Test (FIT) kit and received a telephone and/or home visit follow up with a CHR; 11.4% returned their FIT kit during the 4-week period before any CHR outreach began.³ After receiving a single round of CHR outreach, an additional 3.3% returned their FIT kit. Following a second round of CHR outreach, another 4.2% returned their FIT kit showing some promise for CHR intervention.³ However, nearly one in four members who failed to return their FIT did not receive any CHR outreach. The researchers attributed this outcome to staff turnover during the study period and conflicting CHR job responsibilities.³ These findings underscore both the potential for and the challenges of CHR involvement in

colorectal cancer screening, highlighting how CHR outreach can increase FIT kit returns, while also pointing to structural barriers and program limitations that must be addressed to improve follow-up care and screening outcomes in Native American communities.³

Study #3: Cancer Screening in Hispanic Populations with CHWs

Breast, Cervical, and Colorectal Cancer Education and Navigation: Results of a Community Health Worker Intervention (Mojica, 2016) explored the effectiveness of a CHW-led cancer education and navigation intervention targeting breast, cervical, and colorectal cancers, which collectively account for 24% of all U.S. cancers. Recognizing that early detection is critical for improving outcomes, the study implemented an education plus navigation model grounded in the Health Belief Model (HBM) to improve cancer knowledge and screening behaviors. The HBM is a psychological framework that explains how individual belief and values influence health behaviors.²¹ CHWs delivered culturally tailored educational sessions, as well as offering support with appointment scheduling, reminder calls, and follow-up.²¹ CHWs underwent intensive two-week training covering study protocols and cancer specific content, followed by annual booster sessions and regular team meetings. They also maintained weekly communication with project coordinators and participated in session audits to ensure compliance.²¹ Educational sessions were structured around the HBM construct. Each session used bilingual tabletop flip charts with culturally relevant visual content.²¹

Participants were able to ask questions at any time during the presentation, and time was allotted for sharing personal stories and experiences and discussing misconceptions. Sessions also included large, colorful, visual, and tactile posters and models outlining the anatomy of the breast, cervix, and colon.²¹ Women also received a flyer announcing upcoming locations of a local mobile mammography van and a schedule of breast health classes and clinical breast exams.²¹ Results demonstrated a significant impact: women who attended cervical or breast cancer sessions were significantly more likely to receive a Pap test or mammogram, respectively, than those who did not attend.²¹ However, attendance at colorectal cancer sessions did not significantly improve screening rates, suggesting that barriers for colorectal screening may require different strategies.²¹ Overall, the study supports the value of CHW-led, HBM-based interventions.

In addition to navigation to screening, there are examples of navigation through survivorship:

- The Patient Care Connect Program (PCCP) at the University of Alabama used trained navigators (non-clinicians with at least a bachelor's degree) to assist Medicare cancer patients across 12 sites in five southern states.²⁴ Navigators received multidisciplinary training, were integrated

into clinical care teams, and achieved high patient satisfaction. Eighty-three percent (83%) of patients reported being satisfied or very satisfied, and nearly 90% would recommend the program.²⁴

- The Livestrong Cancer Navigation Program in Austin, Texas, deployed patient navigators to conduct initial needs assessments, coordinate referrals, and provide ongoing support for cancer survivors.²⁴ This resulted in increased patient self-efficacy, reduced distress, and strong participant satisfaction in cancer navigation.²⁴

These models highlight the effectiveness of integrating navigators into cancer care to promote health equity, improve outcomes, and enhance patient experiences.

Cancer Care Continuum	Cancer Type	CHW/CHR/PN	Program Goal	Staff Training	Program Activities	Program Outcomes	Program Challenges
Study #1: Clinic-Based Colorectal Cancer Screening Increases FIT Completion							
Screening (focus on increasing FIT completion and CRC screening updates)	Colorectal	Patient Navigator (PN)	Increase colorectal cancer screening rates, specifically completion and return of FIT kits	Trained in CRC Biology, Epidemiology, Risk Factors, Diagnosis, and Treatment. Education on Native American CRC disparities, Behavioral and Psychosocial aspects of screening, Motivational interviewing techniques, Data entry, and Evidence-Based Navigation	678 patients with 467 patients' distribution of FIT kits. Patient engagement and follow-up encourage screening completion. The use of culturally adapted and evidence-based training messaging, Support for both FIT screening and colonoscopy completion	678 patients interacted with navigators, 22% (150 patients) did not engage in screening, 43% patients who received FIT kits returned them, 37% (252 patients) completed screening (FIT:199 patients or colonoscopy: 53 patients), FIT: 18% Positive Results, 82% Negative Results, Overall improvement in CRC screening rates suggested	22% of patients did not engage in screening, with less than half (43%) distributed FIT kits completed and returned. Indicating an ongoing barrier to screening engagement and completion rates.
Study #2: Colorectal Cancer Screening Program Challenged by CHR's Scope of Work							
Screening (FIT kit distribution, follow-up, and return)	Colorectal	Community Health Representatives (CHR)	Increase FIT kit return rates through CHR outreach and follow-up		Mailing FIT kits to participants, CHR Follow-up Outreach, Ongoing engagement to encourage FIT kit completion and return	11.4% returned FIT kits before any CHR outreach, +3.3% additional returns after first CHR outreach, +4.2% returns after second CHR outreach, Demonstrates incremental improvement in FIT returns with CHR involvement	Nearly 25% of participants who did not return FIT kits received no CHR outreach, Staff turnover impacted program delivery, Conflicting CHR job responsibilities limited outreach capacity, and Structural and organizational barriers affected follow-up and overall screening outcomes
Study #3: Cancer Screening in Hispanic Population with CHWs							
Screening and early detection (education, navigation, and screening uptake)	Breast, Cervical & Colorectal	Community Health Workers (CHWs)	Improve cancer knowledge and increase screening behaviors using a culturally tailored education and navigation model based on the Health Belief Model (HBM)	Intensive two-week initial training on study protocols and cancer-specific content, annual booster training sessions, regular team meetings, weekly communication with project coordinators, and participations in sessions audits to ensure fidelity and compliance	Patient navigation support (appointments scheduling, follow-up, reminder calls), Informational materials (flyers), Interactive discussions, bilingual tabletop flip charts, CHW-led culturally tailored education sessions	Increase in receiving Pap tests and mammograms among woman attending both cervical and breast cancer sessions, no significant improvements in colorectal cancer screening despite participation in CRC sessions, Evidence support effectiveness of CHW-led, HBM-based interventions for certain cancer screenings	Lack of significant improvement in colorectal cancer screening updates, suggests that CRC screening may require different or additional strategies beyond education and navigation, Highlights variability in effectiveness across cancer types

b. Payment Models and Financing

The integration of CHRs into cancer navigation programs requires sustainable funding mechanisms that align with tribal health systems and broader healthcare reform efforts. The Arizona Advisory Council on Indian Health Care (AACIHC) ensures that tribal governments, tribal organizations, and urban Indian health programs in Arizona have a voice in shaping healthcare policies that affect Native American communities. Several policy developments have created new opportunities to finance CHR services. In January 2014, the Centers for Medicare & Medicaid Services (CMS) implemented rule CMS-2334-F, allowing for reimbursement of preventive services provided by non-licensed individuals, such as CHWs and CHRs, when recommended by a licensed healthcare provider.¹² This rule presents a significant opportunity to expand CHR roles in preventive care and chronic disease management under Medicaid. In addition, the Affordable Care Act (ACA) authorized states to establish Health Homes for Medicaid beneficiaries with chronic conditions, many of which now include CHWs in their care teams.¹² Some states have also amended their Medicaid State Plans to explicitly integrate CHWs into their service delivery models. Federal initiatives, like the State Innovation Models (SIM), have supported new care delivery approaches, with several states incorporating CHWs into their strategies. In the first round of SIM funding, nearly \$300 million was awarded to 25 states, with four of the six currently implementing SIM plans including CHWs in their strategies.¹² These models reflect growing recognition of team-based care.

Despite these policy advancements, funding cancer navigation programs remains a challenge. Running a navigation program involves various costs, including staff salaries, training, and administrative needs. The total cost depends on factors like the number of patients served, the navigator's qualifications, and the scope of their role.²⁴ While lay navigators typically earn less than licensed professionals, they often need supervision from clinicians.²⁴ While their tasks are mostly non-clinical, professional navigators can offer broader, more integrated services. The continued collaboration between tribal health leaders, state policymakers, and federal agencies is critical to advancing financing structures that support CHRs' integration into cancer care.

c. Education, Training, and Evaluation Strategies

To strengthen the effectiveness of CHR programs and integrate them into cancer navigation, it is essential to address workforce shortages and improve collaboration between CHRs and their programs. Implementing formal orientation programs for new healthcare staff can promote mutual respect and a clearer understanding of CHR roles within the broader health system. Additionally, expanding CHRs' access to electronic health records (EHRs) can enhance their ability to coordinate care, track patient

outcomes, and strengthen community-clinical linkages. Patients also report that CHR support leads to improved general health. The Community Outreach and Patient Empowerment (COPE) program on the Navajo Nation provides strong evidence of CHR effectiveness.⁷ COPE patients showed a 3.1% increase in primary care outpatient visits, a 6.1% increase in counseling and behavioral health services, and an 8.6% increase in pharmacy visits, with no meaningful change in inpatient or emergency services.⁷ A key driver of these outcomes was CHR access to electronic health records (EHRs), which enabled better care coordination. To improve health outcomes and equity, best practices should include the integration of CHRs into care teams through EHR access, culturally tailored training, and support for community-based care models. Greater inclusion of CHRs in cancer navigation can be used to assess cancer prevention.

d. Strengthening CHR Capacity and Cancer Navigation Integration

Barriers to full integration of CHRs within care teams remain a persistent issue. Key challenges include unclear roles and insufficient coordination with healthcare providers. While some CHRs report working as part of a care team and sharing physical workspaces with other providers, integration remains uneven.⁵ A workforce assessment, developed by the Arizona CHR Movement in 2018, revealed that a lack of awareness about CHR roles among Indian Health Service (IHS)/638 staff and insufficient communication between CHRs and clinical providers are among the most significant barriers to CHR integration.⁴ Based on the assessment findings, the Arizona CHR Movement issued several key policy, systems, and environmental recommendations to support CHR workforce development both locally and nationally:

1. **Mandatory Orientation:** Mandate orientation for all healthcare staff on CHR roles, competencies, and responsibilities to promote awareness and collaboration.⁴
2. **Evaluation Systems:** Engage with CHR programs in establishing an evaluation system to track workforce performance and impact.⁴
3. **Formal Integration Protocols:** Create formal procedures and protocols to integrate CHRs as active members of the healthcare team.⁴
4. **Medicaid Reimbursement:** Establish Medicaid reimbursement mechanisms through state and federal policies for CHR-provided services.⁴
5. **Data Sharing Systems:** Develop standardized systems for communication and data sharing between CHRs, public health departments, and clinical care teams to enhance care coordination.⁴
6. **Voluntary Certification:** Support CHRs in pursuing voluntary CHW certification through the state of Arizona to promote workforce mobility and recognition.⁴

Addressing these issues is crucial to successful integration of CHRs into more specialized roles, such as cancer navigation. As cancer rates and disparities persist in Native American communities, integrating CHRs into cancer navigation programs

presents a powerful opportunity to improve outcomes.⁶ However, doing so effectively requires addressing both capacity limitations and gaps in current service models. To meet the demands of cancer navigation across the full continuum of care, key strategies include: a comprehensive navigation design that supports patients at each cancer journey stage; multidisciplinary care coordination; standardized training and certification for CHRs specific to cancer navigation; clear role definitions and ethical guidelines.⁷ As the healthcare landscape evolves, tribal leadership, community partnerships, and policy advocacy will be essential in creating durable systems that recognize and sustain CHRs' contributions. Investing in this workforce means investing in culturally grounded, community-driven care that advances health equity across the cancer care continuum.

VI. References

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